

## The patient perspective of the diagnostic process for leprosy in Brazil. An exploratory study

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### *Summary*

*Objectives:* To explore the patient experience of being diagnosed with leprosy and the support provided during this process in selected populations in Brazil. To understand the information needs of patients during diagnosis. To identify characteristics of patients with different diagnostic experiences. To add to the evidence base used for improving the diagnostic process for leprosy patients.

*Design:* A self-constructed questionnaire delivered to 116 participants, at three leprosy health centres, across three states in Brazil.

*Results:* Most participants felt under-informed during diagnosis; 68.1% wanted more information about leprosy. Nearly one-quarter of patients reported feeling unable to ask questions at diagnosis. Almost half of patients reported being worried about treatment, yet 43.3% reported not having the chance to talk about their concerns. Younger participants were significantly more likely to report feeling unable to ask questions and talk about their worries. The majority of participants (59.5%) reported not being given any written information to take away with them. 36.5% reported not being given advice about how to reduce the chance of other family members becoming ill with leprosy. Older males were most likely to be given this advice despite females being in most contact with family members in most cultures.

*Conclusions:* It is recommended that patients are encouraged to ask questions and invited to talk about their concerns, particularly younger patients. It is recommended that a simple information leaflet be provided to all patients. These suggestions may require some financial input, more staff and longer consultations but should significantly improve the diagnostic process.

## Introduction

Despite significant progress in reducing the prevalence of leprosy over the past 50 years, the disease remains a major problem in several countries. Transmission of leprosy continues with 250,000 new cases detected each year.<sup>1</sup> The deformities and disabilities that can be caused by the disease result in patient suffering, stigma, and social and economic burden.<sup>2</sup> Brazil has the second highest prevalence of the disease worldwide with a point prevalence rate of 1.54 per 10,000 of the population in 2010.<sup>3</sup> It contains areas of high transmission, particularly in the north, north-east and central-west regions.<sup>4</sup> Brazil had nearly 35,000 new cases in 2010 and had the highest Grade 2 disability rate among new cases per 100,000 of the population in the world in 2009.<sup>5</sup>

Prompt diagnosis is important to reduce transmission, disease progression and disability.<sup>6</sup> Leprosy is the leading infectious cause of disability.<sup>6</sup> Delay in diagnosis increases risk of nerve damage and disability.<sup>2</sup> Obtaining information about the patient perspective of the diagnostic procedure should enable the diagnostic process itself to be improved. This should increase treatment compliance and improve the effectiveness of treatment.

Literature searches, without an English language filter, using the terms 'patient experience' and 'leprosy diagnosis' produced no relevant papers on this topic. Parallel literature was identified for patients receiving cancer diagnoses,<sup>7,8</sup> where communication and satisfying the information needs of patients were highlighted as key to the process. Aspects of communication identified in this literature may also be important in diagnosis of leprosy, but there has been no research to investigate this. The stigma and disability associated with leprosy can result in a stressful diagnosis process. It is therefore important that patients are adequately informed and supported during diagnosis. Research into this area could result in recommendations to improve the diagnostic process to best meet the needs of patients.

The manner of delivery of bad news impacts upon the doctor-patient relationship and future consultations.<sup>9</sup> Good communication is associated with increased compliance.<sup>9</sup> Leprosy treatment involves 6–24 months of medication.<sup>10</sup> During this time patients often endure side effects; a Brazilian study found that 45% of patients suffered side effects and that this often resulted in interruption or stoppage of treatment.<sup>11</sup> However, if completed, treatment cures the patient and removes infection risk within about a week of starting treatment.<sup>12</sup>

The patient perspective of leprosy diagnosis may highlight ways to improve the diagnostic process for patients, resulting in improved patient satisfaction and compliance. This study aims to provide a unique insight to support the development of the diagnostic process in Brazil.

### AIMS

#### Primary Aims

1. To explore the patient experience of being diagnosed with leprosy and the support provided during this process, in selected populations in Brazil.
2. To understand the information needs of patients during diagnosis.

#### Secondary Aims

3. To identify characteristics of patients with different diagnostic experiences.
4. To add to the evidence base used for improving the diagnostic process for leprosy patients.

## **Design**

Descriptive, retrospective questionnaire-based study.

## **Methods and Materials**

### MEASUREMENT TOOL - QUESTIONNAIRE

A self-constructed questionnaire to be translated into Brazilian Portuguese was designed to capture the patient's perspective of the diagnostic process for leprosy. There are no previous similar studies available and therefore no validated questionnaire to use. Questions were designed based on studies looking at how patients found receiving bad news from healthcare staff,<sup>8</sup> and information from supervisors. The questionnaire was constructed to include four sections of questions about the patient's experience of being tested for leprosy, being told that they had leprosy, receiving information about diagnosis and treatment, and the support patients received when diagnosed. The order of the sections was chronological to reflect the sequence of the diagnostic process making it easier for patients to remember. Pictures of diagnostic tests were included to aid recall. A demographic questionnaire was also designed and delivered to participants. The director of the Instituto Lauro de Souza Lima (ILSL) translated the questionnaires into Brazilian Portuguese and another member of staff at the Institute checked the translation. The questionnaire was piloted in the first week of the study on inpatients at ILSL.

The questionnaire uses a mixture of open and closed questions. Open questions were used so that the patient perspective could be explored in greater depth and using the patient's own words. Use of open questions was appropriate due to limited literature and understanding of the topic.

### LOCATION AND SAMPLE

A total of 116 participants were recruited from three sites, in three different states of Brazil, over a period of 7 weeks. Maximum feasibility sampling was used due to the exploratory aims of the study. Specialist leprosy centres were used because of the relatively low prevalence of leprosy. Fifty-two patients were recruited from a specialist dermatology and leprosy centre in Sao Paulo, the Instituto Lauro de Souza Lima. Twenty-six patients were recruited from the Centre for Hansen's Disease and Tuberculosis in Dourados in the state of Mato Grosso do Sul. Thirty-eight patients were recruited from the Centre for Hansen's Disease and Tuberculosis in Sinop in the state of Mato Grosso. Only two participants refused to take part. The sites are representative of a spread of leprosy detection rates within Brazil. In 2007, Mato Grosso reported the highest case-detection rate in Brazil with a rate of 100.27/100,000 inhabitants.<sup>13</sup> Mato Grosso do Sul reported a detection rate of 23.85/100,000 and Sao Paulo reported a low detection rate of 5.25/100,000.<sup>13</sup>

### QUESTIONNAIRE DELIVERY

It was explained to patients what participation in the study would involve, that their answers would remain confidential and anonymous and that participation was voluntary. Participants were given the option of writing answers to the questionnaire themselves or

**Table 1.** Study eligibility criteria

Participants must:	Participants must not be:
Be aged 15 and over – after consulting with the director of ILSL and member of the Brazilian Committee for Ethics in Research, it was deemed culturally appropriate for patients of this age to be included in the study. Have capacity to consent for themselves.	Unable or unwilling to consent.  Unsuitable to approach. This includes patients who are identified by staff as likely to be adversely affected as a result of participation. For example those who have suffered a recent bereavement.
Have been diagnosed with leprosy for more than one month. This was to ensure the diagnostic process was complete and to exclude patients who are likely to be vulnerable.	

an interpreter writing down their answers on their behalf. For participants who were unable to read or write, the questionnaire was verbally delivered and the interpreter wrote down their answers.

#### ELIGIBILITY CRITERIA

Staff were informed of eligibility criteria (Table 1) so that only those meeting the criteria were asked to participate.

#### RECRUITMENT

At ILSL, doctors seeing outpatients with leprosy referred those willing to complete the questionnaire to a private room where researchers explained, via the interpreter, what participation would involve. The interpreter verbally delivered the questionnaire to participants who were unable to read and write well. The researchers visited inpatients with leprosy with an interpreter who explained the project and what participation would involve. If the individual agreed to participate but was unable to read and write well, a time was arranged for the researchers and interpreter to return to verbally deliver the questionnaire. If the individual was able to read and write well, the pack of questionnaires was left with them to complete and was collected at a later time.

In Dourados and Sinop, staff at the centre telephoned patients with leprosy and arranged for them to come to the centre to complete the questionnaires.

#### OUTCOMES

Due to the exploratory nature of the study, the outcomes are as follows:

- The proportion of participants who had discretely defined diagnostic experiences.
- The proportion of participants expressing particular opinions and themes.
- Participant characteristics that are associated with different diagnostic experiences.

#### ETHICAL APPROVAL

Before leaving the UK, ethical approval was obtained from the BMedSc Population Sciences and Humanities Internal Ethics Review Committee at the University of Birmingham. In Brazil, ethical approval was obtained from the Brazilian Committee for Ethics in Research.

#### STATISTICAL ANALYSIS

Data were analysed using the Statistical Package for the Social Sciences (SPSS) version 21.0.

#### ANALYSIS OF PRIMARY AIMS

The primary aims are to explore the patient experience of being diagnosed with leprosy, the support provided, and to understand the information needs of patients during diagnosis. To address these aims, results from closed questions were reported as proportions with 95% confidence intervals. For questions requiring a free text response, answers were used to develop themes and the frequency of themes reported in answers were recorded and reported as percentages with confidence intervals.

#### ANALYSIS OF SECONDARY AIMS

The secondary aim was to identify characteristics of patients with different diagnostic experiences. Characteristics used in analysis were the WHO leprosy grade, age, gender, education level, income and age at diagnosis. Five questions were selected to be analysed. Selection was focused on question areas that would identify characteristics of participants who reported being worried and felt unable to talk, receiving written information and being advised on preventing transmission to family. These areas were felt to be of most potential use in advising improvements to the diagnostic process.

Participants were categorised as answering 'yes' or 'no' to questions. Univariate analysis was undertaken considering leprosy grade, age, gender, education level, income and age at diagnosis. Chi-squared tests, individual T-tests and Mann-Whitney U-tests were used as appropriate.

Binary logistic regression analysis was undertaken to identify which patient characteristics were most associated with particular patient experiences of diagnosis. Predictors were participant characteristics and outcomes were answering 'yes' or 'no' to a closed question. Participant characteristics found to have a P-value of less than 0.3 in univariate analysis were entered into regression models for each of the questions.

## **Results**

#### PARTICIPANT DEMOGRAPHICS

The 116 participants were aged from 22 to 86 with a mean age of 49.4 (SD 13.7). The sample contained more males (66.4%) than females (33.6%). The majority of participants were from the central-west (56.9%) and south-east (41.4%) areas of Brazil. Participant demographics are summarized in Table 2.

Table 2. A summary of participant demographics

Participant Demographics					
Leprosy Type ( <i>n</i> = 98)	%	CI	Employment Status ( <i>n</i> = 114)	%	CI
Multibacillary	91.8	86.37 to 97.23	Full-time work	24.6	16.69 to 32.51
Paucibacillary	8.2	2.77 to 13.63	Part-time work	4.4	0.64 to 8.16
<b>Leprosy Grade (<i>n</i> = 98)</b>			Unemployed	24.6	16.69 to 32.51
0	23.5	15.11 to 31.89	Retired	29.8	21.4 to 38.2
1	36.7	27.16 to 46.24	Receiving health benefits	12.3	6.27 to 18.33
2	39.8	30.11 to 49.49	Self-employed	4.4	0.64 to 8.16
<b>Age (<i>n</i> = 116)</b>			<b>Highest Level of Education* (<i>n</i> = 116)</b>		
Mean	49.4 (SD 13.69)		Low level of education	60.3	51.40 to 69.20
Range	22.0 to 86.0		High level of education	39.7	30.80 to 48.60
<b>Gender (<i>n</i> = 113)</b>			<b>Household Income** (<i>n</i> = 115)</b>		
Male	66.4	57.69 to 75.11	Low income	52.2	43.07 to 61.33
Female	33.6	24.89 to 42.31	High income	47.8	38.67 to 56.93
<b>Region of Residence (<i>n</i> = 116)</b>			<b>Year of Diagnosis (<i>n</i> = 112)</b>		
South-east	41.4	32.44 to 50.36	Median	2009 (IQR 10-0)	
Central-west	56.9	47.89 to 65.91	Range	1947 to 2014	
South	0.9	-0.82 to 2.62	<b>Age at Diagnosis (<i>n</i> = 113)</b>		
South-west	0.9	-0.82 to 2.62	Median	42.0 (IQR 20-0)	
			Range	6.0 to 72.0	

\* Level of education was grouped as 'low level' (educated up until the age of 10)<sup>14</sup> or as 'high level' (educated beyond the age of 10)<sup>14</sup>

\*\*Household income was grouped as those receiving less than 3 minimum salaries as 'low income' and those receiving 3 minimum salaries or more as 'high income'.  
1 minimum salary is approximately R\$724 (£193), paid 13 times a year.<sup>15</sup>

PATIENTS' EXPERIENCES OF BEING TESTED FOR LEPROSY

Participants reported about a variety of different tests including testing of sensation, muscle strength, peripheral nerve enlargement, and biopsies in a number of different states in Brazil. Almost half of participants (47.7%, 52/109 (CI: 38.3% to 57.1%)) reported being worried about what would be done in the tests to diagnose leprosy. However, nearly one-third of participants (32.1%, 27/84 (CI: 22.1% to 42.1%)) reported not being told anything about the tests before they were undertaken. A similar proportion of participants (30.3%, 33/109 (CI: 21.7% to 38.9%)) reported not having the chance to ask questions about the test, when most of these participants (65.6%, 21/32 (CI: 49.1% to 82.1%)) would have liked the opportunity. On being tested, one-quarter of participants (25.6%, 23/90 (CI: 16.6% to 34.6%)) reported not being told anything about what would happen if they were found to have leprosy.

PATIENTS' EXPERIENCES OF BEING TOLD THAT THEY HAD LEPROSY

Participants reported about experiences from 1947 to 2014 and from being aged 6 to 72. The majority of participants were diagnosed by a doctor (88.8%, 103/116 (CI: 83.1% to 94.5%)) in a location that the participant found sufficiently private (83.6%, 102/116 (CI: 76.9% to 90.3%)). Almost one-fifth of participants (19.3%, 22/114 (CI: 12.1% to 26.5%)) would have liked someone else present at diagnosis. Of these participants, almost all (95%, 19/20 (CI: 85.5% to 104.5%)) would have liked a family member present.

The majority of participants (61.2%, 71/116 (CI: 52.3% to 70.1%)) reported being worried about having leprosy. Common concerns included the reactions of other people (26.8%, 19/71 (CI: 16.5% to 37.1%)), physical effects of the disease such as deformities (23.9%, 17/71 (CI: 14.0% to 33.8%)) and transmitting the disease to others (15.5%, 11/71 (CI: 7.1% to 23.9%)). Other common concerns are presented in Figure 1.

Despite the majority of participants being worried about leprosy, less than half (41.2%, 42/102 (CI: 31.7% to 50.8%)) reported telling staff their concerns. Of those who reported being able to share their concerns, most indicated this helped them to feel better (85.7%, 36/42 (CI: 75.1% to 96.3%)).

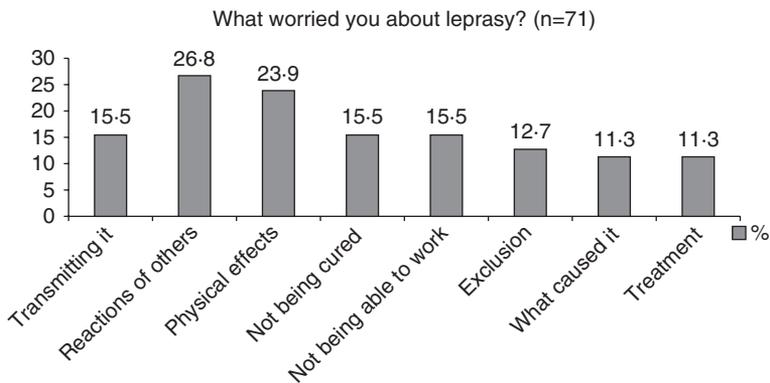


Figure 1. Common concerns about leprosy reported by participants.

Participants reported a wide range of times from being tested for leprosy to being diagnosed. The median and mean time waited was between 15 days and 1 month. 16.4% (18/110 (CI: 9.5% to 23.3%)) of participants reported being diagnosed with leprosy on the same day as being tested for it, whereas 10.0% (11/110 (CI: 4.4% to 15.6%)) reported waiting 2 to 6 months and 3.6% (4/110 (CI: 0.1% to 7.1%)) reported waiting over 1 year.

INFORMATION PATIENTS RECEIVED ABOUT DIAGNOSIS AND TREATMENT

*Understanding the disease*

The majority of participants received some information about diagnosis and treatment. However, most participants felt under-informed at diagnosis. Additional information would improve the diagnostic experience for many patients.

When first told the diagnosis of leprosy, 39.7% (46/116 (CI: 30.8% to 48.6%)) of participants did not understand what the disease was. Almost half of participants (47.8%, 55/115 (CI: 38.7% to 56.9%)) did not recollect being asked if they understood what would happen next. Nearly one-quarter of participants (23.3%, (27/116 (CI: 15.6% to 31.0%)) reported feeling unable to ask questions when most of these participants (65.6%, 21/32 (CI: 49.1% to 82.1%)) would have liked to have the opportunity.

Some participants (31.9%, 30/102 (CI: 22.5% to 41.3%)) reported not wanting any more information about leprosy, reflecting a positive experience. However, most participants (68.1%, 72/102 (CI: 58.7% to 77.5%)) would have liked more information about the disease. Information participants would have liked is shown in Figure 2.

INFORMATION ABOUT TREATMENT

Patients are being given information about treatment: most participants (90.4%, 104/115 (CI: 85.0% to 95.8%)) were told how the leprosy would be treated and most (91.4%, 106/116 (CI: 86.3% to 96.5%)) were told how long they would be treated for. However, 37.4% (43/115 (CI: 28.6% to 46.2%)) of participants did not recollect being told that treatment might make them feel unwell and 39.1% (45/115, (CI: 30.2% to 48.0%)) were not aware of being told how they might feel unwell. Of those who remembered being told, almost all (95%, 57/60 (CI: 89.5% to 100.5%)) recollect being informed of specific side effects of the drug but only 8.3% (5/60 (CI: 1.3% to 15.3%)) reported being told about leprosy reactions. 31.6% (36/114 (CI: 23.1% to 40.1%)) of participants did not recollect being told how much their condition could be improved.

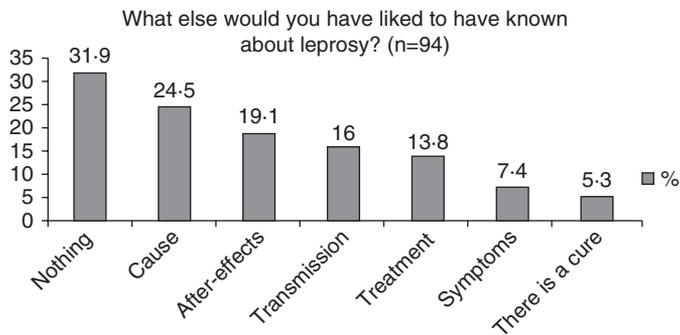
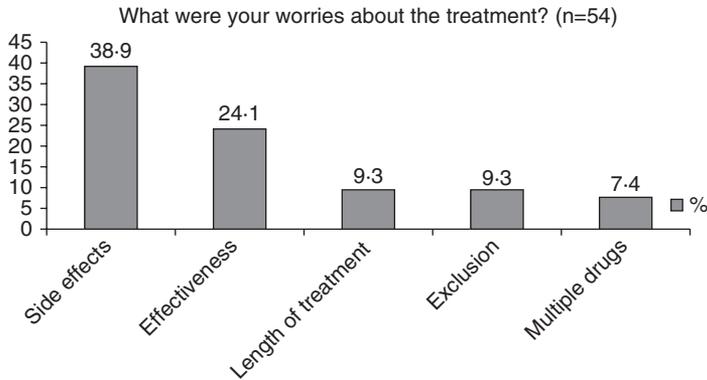


Figure 2. Information participants reported that they would like to have known.



**Figure 3.** Common concerns reported by participants about leprosy treatment.

#### CONCERNS ABOUT TREATMENT

Almost half of participants (49.6%, 57/115 (CI: 40.5% to 58.7%)) reported being worried about treatment. A large proportion of participants (43.3%, 45/104 (CI: 33.8% to 52.8%)) reported not having the chance to talk about their worries. The most commonly expressed concern was drug side effects (38.9%, 21/54 (CI: 25.9% to 51.9%)) followed by the effectiveness of treatment (24.1%, 13/54 (CI: 12.7% to 35.5%)). Other common concerns are shown in Figure 3.

#### WRITTEN INFORMATION

The majority of participants (59.5%, 69/116 (CI: 50.6% to 68.4%)) reported not being given any written information to take away with them, and most of these patients (70.7%, 65/92 (CI: 61.4% to 80.0%)) would have liked information. Participants mentioned particularly wanting written information about the disease, such as where leprosy comes from, symptoms and transmission (63.9%, 39/61 (CI: 51.9% to 76.0%)). Over one-third (34.4%, 21/61 (CI: 22.5% to 46.3%)) wanted written information about treatment, its length and side effects. 18.0% (11/61 (CI: 8.4% to 27.6%)) wanted information about preventing damage as a consequence of the disease.

#### SUPPORT PATIENTS RECEIVED WHEN DIAGNOSED

Nearly one-fifth of participants (18.9%, 20/106 (CI: 11.5% to 26.4%)) reported family support as a main form of help received when they were diagnosed. Yet, 37.4% (43/115 (CI: 28.6% to 46.2%)) of participants did not recollect being offered help for family members. 36.5% (42/115 (CI: 27.7% to 45.3%)) reported not being given advice about how to reduce the chance of other family members becoming ill with leprosy.

#### RESULTS OF ANALYSIS OF SECONDARY AIMS

The results of five questions were analysed to identify characteristics of those who reported feeling unable to ask questions, being worried and unable to talk, not receiving written information and not being advised about protecting family members. These questions were

**Table 3.** Significant variables on multivariate analysis

Did you feel you could ask questions?			
	Yes	No	
Time since diagnosis	Median = 3.0 (IQR 7.0)	Median = 10.0 (IQR 33.0)	U = 1525.0, p = 0.007
Did you have the chance to talk about your worries?			
	Yes	No	
Time since diagnosis	Median = 3.0 (IQR 7.3)	Median = 8.0 (IQR 21.0)	U = 1627.5, p = 0.009

selected because they were felt to be of most potential use in advising improvements to the diagnostic process. Characteristics found to be significant predictors after multivariate analysis are presented in Table 3.

Secondary analysis highlighted characteristics that were statistically significant predictors of participants who reported feeling unable to ask questions, talk about their concerns and not being given advice to prevent transmission to family members.

Participants who were younger at the point of diagnosis were less likely to report feeling able to ask questions (OR = 0.955, CI = 0.916 to 0.996,  $P = 0.091$ ) and report talking about their concerns (OR = 0.942, CI = 0.896 to 0.991,  $P = 0.022$ ). Interestingly, participants of older current age were also found to be less likely to report feeling able to ask questions (OR = 1.051, CI = 1.007 to 1.096,  $P = 0.023$ ) and report talking about their concerns (OR = 1.063, CI = 1.008 to 1.120,  $P = 0.023$ ). It is thought that the variable current age may be acting as a proxy for time since diagnosis. This finding generated the need for post-hoc exploration. A new variable of time since diagnosis was created. Univariate analysis was completed to investigate whether time since diagnosis differed significantly between groups answering 'yes' or 'no' to the five questions used in secondary aims analysis. Results supported the hypothesis that current age is acting as a proxy for time since diagnosis. Statistically significant results showed that participants who reported feeling unable to ask questions and not having the chance to talk about their worries had, on average, been diagnosed longer ago. Results from this analysis that were statistically significant at a 5% level are shown in Table 4.

Participants who reported being given advice on protecting family members from transmission were less likely to be female (OR = 0.241 CI = 0.084 to 0.691,  $p = 0.008$ ), and less likely to be younger at the point of diagnosis (OR = 0.956, CI = 0.922 to 0.990,  $p = 0.012$ ).

No characteristics were significant predictors of answers to the questions 'were you worried about the treatment?' and 'were you given any written information about leprosy to take away with you?' Surprisingly, income, leprosy grade and education level were not significant predictors of any of the selected patient experiences.

## Discussion

### PATIENTS' EXPERIENCES OF BEING TESTED FOR LEPROSY

Results showed that being tested for leprosy is a process surrounded by anxiety for many patients. Participants reported a lack of information about the testing process and a lack of

**Table 4.** Results from univariate analysis for time since diagnosis that were statistically significant at 5%

	Univariate analysis		Multivariate analysis		P-value	
	Yes	No	OR	CI		
Did you feel you could ask questions? *						
Current age	Mean = 47.8 (SD 13.0)	Mean = 54.6 (SD 14.9)	t = -2.31, p = 0.023	1.051	1.007 to 1.096	0.023
Age at diagnosis	Median = 42.0 (IQR 18.0)	Median = 35.0 (IQR 29.0)	u = 883.5, p = 0.091	0.955	0.916 to 0.996	0.033
Did you have the chance to talk about your worries? **						
Current age	Mean = 46.4 (SD 12.6)	Mean = 52.1 (SD 15.6)	t = -2.062, p = 0.042	1.063	1.008 to 1.120	0.023
Age at diagnosis	Median = 42.5 (IQR 18.3)	Median = 37.0 (IQR 27.0)	u = 1030.5, p = 0.137	0.942	0.896 to 0.991	0.022
Was any advice given about how to reduce the chance of other members of your family becoming ill with leprosy? ***						
Age at diagnosis	Median = 43.0 (IQR 18.0)	Median = 35.0 (IQR 24.5)	u = 1160.5, p = 0.075	0.956	0.922 to 0.990	0.012
Gender	Male = 59.2%, female = 40.8%	Male = 78.0%, female = 22.0%	$\chi^2 = 4.139$ , OR = 0.407, CI = 0.169 to 0.980, p = 0.042	0.241	0.084 to 0.691	0.008

\* Other factor entered into the model was leprosy grade

\*\* Other factors entered into the model were leprosy grade and household income

\*\*\* Other factor entered into the model was gender

opportunity for questions. To reduce anxiety surrounding leprosy testing, it is suggested that effective explanations are given to patients about what the tests involve and patients be invited to ask questions about the tests. Patients should be told what to expect if the tests do confirm a leprosy diagnosis to help reduce patient fears.

#### PATIENTS' EXPERIENCES OF BEING TOLD THAT THEY HAD LEPROSY

Almost one-fifth of participants would have liked someone else to be present at their diagnosis. Of these, almost all wanted to bring a family member. This is in agreement with the findings of a systematic review of the literature of the preferences of patients receiving bad news.<sup>7</sup> This found a high proportion of patients (40–78%) wanted relatives to be present.<sup>7</sup> Therefore, it is suggested that staff encourage patients to bring along a family member for support. The majority of participants were worried about leprosy for a variety of reasons, but most participants did not report talking to staff about their concerns. Staff should invite patients to speak about their worries and try to address their concerns. Reassurance was found in the literature to be important to patients receiving bad news.<sup>7</sup> Providing reassurance to patients may require spending more time with patients at the time of diagnosis. This was a key recommendation from a literature review of patient preferences when receiving bad news.<sup>7</sup>

Inconsistency in the amount of time between testing and diagnosis was highlighted. Staff should follow a set procedure for testing and diagnosis of leprosy that should involve a standard time between testing for leprosy and making a diagnosis. Patients should also be made aware of this standard time in order to know how long to expect to wait for results.

#### INFORMATION PATIENTS RECEIVED ABOUT DIAGNOSIS AND TREATMENT

Participants felt under-informed at diagnosis. A high proportion of participants lacked understanding about leprosy and wanted more information about it. To increase the understanding of patients, it is important that staff spend time clearly explaining the disease and what will happen next. This is supported by the literature where a systematic review found most patients receiving bad news preferred clear explanations with carefully chosen words and avoiding medical jargon.<sup>7</sup> It is recommended that staff ensure they check patients have understood the information and encourage patients to ask questions. This may require increased consultation time, more staff and financial resources.

Patients are receiving some information about leprosy treatment but remain unaware of some important issues. Patients should be fully informed about treatment, any adverse effects they might experience and leprosy reactions to ensure that they remain compliant. One study in Brazil reported that 45% of patients experienced side effects during treatment and that 24% of patients interrupted treatment because of these.<sup>11</sup> Almost one-third of patients reported not being told how much their condition could be improved with treatment. Informing patients fully about how they may feel during treatment will help to ensure that patients have realistic expectations and help to motivate them to comply with treatment.

Leprosy diagnosis is surrounded by anxiety; almost half of participants reported being worried about the treatment of leprosy. A variety of worries about treatment were expressed but a large proportion did not recall having the chance to talk to staff about their concerns. Additionally, a substantial number of participants didn't feel they could ask questions about

leprosy, despite wanting to. Participants of a younger age at the time of diagnosis were most likely to report feeling unable to ask questions and not talking to staff about worries. Therefore, staff should make a particular effort to encourage younger patients to ask questions and to invite them to talk about any concerns they might have and provide reassurance. This preference is supported by the literature where, younger patients in particular, preferred being able to express their feelings and be reassured by staff.<sup>7</sup> As proposed by a literature review of patient preferences when receiving bad news, two recommendations are to encourage patients to ask questions and make sufficient time available. These recommendations are also suggested to improve leprosy diagnosis.

Interestingly, this study also found that those of older current age were more likely to report feeling unable to ask questions and to report not speaking about their concerns with staff. It is likely that the 'current age' demographic is acting as a proxy for the time since participants were diagnosed. This hypothesis was supported by post-hoc exploration that showed participants who reported feeling unable to ask questions and not having the chance to talk about their worries had, on average, been diagnosed longer ago. This measure, therefore, represents historical change and a gradual shift in patient experiences over time. Results suggest that diagnosis experiences have improved, with more participants feeling able to ask questions and talk about their concerns. This indicates there has already been progress in the area of improving diagnostic experiences. This may be due to a change in the doctor-patient relationship dynamic, with patients becoming increasingly empowered and doctors becoming more open and accessible.<sup>16</sup> However, continued improvements need to be made. This finding also suggests that there is a large group of patients who are currently living with the consequences of leprosy who are likely to have questions that were never answered during diagnosis and may not have ever been answered. It is suggested that such patients should be asked if they are satisfied with the information they have about the disease. If not, additional information should be provided to these patients. Accurate information about the disease may help to reduce stigma, such as self-perceived stigma.<sup>17</sup> Self-perceived stigma is often present, even when a patient is cured of leprosy, and misinformation is a common contributing factor to self-perceived stigma.<sup>17</sup>

The majority of participants did not recall being given written information to take away with them when most of these patients would have liked this. This preference for written information is supported by the literature on patients receiving bad news where patients also expressed a preference for receiving written explanations.<sup>7</sup> It is recommended that a simple information leaflet, suitable for those with limited literacy, be given to all patients. This could improve the patient experience of diagnosis significantly.

#### SUPPORT PATIENTS RECEIVED WHEN DIAGNOSED

Results show limited involvement of family members in the diagnostic process despite a high proportion of participants reporting family support as a main form of help received when they were diagnosed. Help and advice should be given to all families of patients with leprosy. Older males were more likely to report being given advice for protection of family members. This is surprising given that females are the primary caregivers in most households and are more likely to be in close contact with family members. It is important that advice is given to all patients, particularly those at highest risk of transmitting the disease to family members.

#### APPLICATION OF FINDINGS

Findings from the study show that enhancing the diagnostic experiences of patients requires the provision of more information and spending more time with patients to allow them to ask questions and talk about their concerns. To allow medical staff to implement these recommendations, more financial resources, more staff and longer consultations may be required. The infrastructure for treatment and diagnosis is already in place. The facilities are good and there is a core of highly trained personnel with extensive knowledge. The cost of effecting these changes would be relatively small but is likely to result in improved outcomes. A cost benefit analysis is likely to confirm a good return on a fairly modest investment.

Introducing the recommendations should improve patient satisfaction, compliance and therefore improve the effectiveness of treatment. This could result in improved outcomes for Brazil by reducing the social and financial burden of patients who are unable to work due to leprosy.

#### LIMITATIONS

Recall bias may have influenced results as the questionnaire required patients to recall a past event that may have occurred a number of years ago. This may have affected the accuracy with which patients recalled information to answer questions. Recruitment at health centres in Dourados and Sinop was performed by healthcare staff at the centre; therefore staff could have influenced patient selection. Many patients had limited literacy and these patients often preferred the questionnaire to be verbally delivered. This may have affected answers given compared to those who completed the questionnaire themselves. Data were collected from patients attending health centres in only three states in Brazil. Results, therefore, may not be representative of the experiences of the whole country. The questionnaire has not been validated. It is, however, an explorative study so the research is still of value and the questionnaire could help to inform other studies.

#### FURTHER RESEARCH

Qualitative research involving analysis of the initial consultation would provide additional insight. An objective view of what information patients are given during diagnosis would offer a useful comparison with this study's exploration of the patient perspective. This could offer insight into the amount of information patients can retain from the initial consultation and how best to provide information to patients.

#### **Conclusion**

The findings of this study can be used to help inform health services and health service policy. It found that patients do not feel fully informed during the diagnostic process for leprosy. Substantial numbers of participants wanted more information, reported feeling unable to ask questions, were worried but reported feeling unable to talk about it and did not recall receiving written information to take away with them. It is recommended that patients are encouraged to ask questions and invited to talk about their concerns. It is recommended that all patients be provided with a simple information leaflet, suitable for those with limited

literacy, to take away with them. These suggestions may require some financial input, more staff and longer consultations but should significantly improve the diagnostic process. This should improve patient satisfaction and compliance and therefore make treatment more effective. This could result in improved social and financial outcomes for Brazil.

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## **Competing Interests**

All authors declare that the answer to the question on competing interest form are all 'no', and therefore have nothing to declare

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## **Contributorship**

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Dr Gilles de Wildt, General Practitioner, Lecturer (International Health), BMedSc Population Sciences and Humanities (PoSH) Intercalated Degree Course, University of Birmingham, UK – involved in the planning and write-up of the research project.

Dr Lesley Roberts – involved in the planning, data analysis and write-up of the research project.

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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 facilitating the delivery of questionnaires at the ILSL where he is the director, and at the other health centres. Also involved in the process of gaining ethical approval in Brazil and translation of questionnaires.

Ms Noemi Garcia de Almeida Galan, Nurse, Scientific Researcher, Therapeutic Clinical Techniques Team, Instituto Lauro de Souza Lima, Brazil – involved in conducting the research project including input into the questionnaire, delivering questionnaires and liaising with staff members in Brazil to facilitate the research.

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Ms Harpreet Kuar Amar, University of Birmingham student – involved in delivery of questionnaires.

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