

Improving Treatment Outcomes for Leprosy in Pernambuco, Brazil: A Qualitative Study Exploring the Experiences and Perceptions of Retreatment Patients and their Carers

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Abstract

Background

Brazil has a high leprosy burden and poor treatment outcomes (TOs). Pernambuco, an impoverished Brazilian state suffering from notable geographical health inequalities, has '*hyperendemic*' leprosy. Although current literature identifies the barriers and facilitators influencing leprosy treatment compliance, there is inadequate investigation into other factors influencing TOs, including carers' roles. This qualitative study explores the experiences, perceptions and beliefs of leprosy patients and their carers in Pernambuco, Brazil; to identify location-specific factors influencing TOs, and consequently appropriately inform future management strategies.

Methods

27, semi-structured, in-depth interviews were conducted with 14 patients and 13 carers. Participants were recruited using maximum variation and snowball sampling from three clinics in Petrolina, Pernambuco. Transcripts and field notes from both participant groups were separately analysed using conventional thematic and deviant case analysis. Ethical approval was obtained from the University of Birmingham Internal Research Ethics Committee and the Instituto Lauro de Souza Lima, Brazil.

Results

Two homologous sets of four, primary, interdependent themes influencing leprosy TOs emerged: '*personal factors*'; '*external factors*'; '*clinical factors*'; and '*the HCP-patient-carer relationship*'. Poor participant knowledge and lack of symptomatic relief caused patients to distrust treatment. However, because participants thought HCP-led interventions were vital for optimal TOs, patients were effectively persuaded to adhere to pharmaceutical treatments. High standard patient and population education facilitated treatment engagement by encouraging evidence-based medicine belief, and dispelling health myths and stigma. Healthcare, on occasions, was perceived as disorganised, particularly in resource-scarce rural areas, and for those with mental health needs. Participants additionally experienced incorrect/delayed diagnoses and poor contact tracing. Leprosy's negative socio-economic impact on employment – together with stigma, dependency and changing relationships – caused an altered sense of identity, negatively impacting TOs. Better dialogue between patients, HCPs and carers facilitated individualised patient support.

Conclusion

This study highlights the importance of: effective evidence-based leprosy education; communication between HCPs, patients and carers; state-funded support; and healthcare resource distribution. These findings, if prioritised on governmental scales, provide the valuable insight needed to inform location-specific management strategies, which are required to improve TOs. Future research should evaluate the effectiveness of these implementations. Failure to address these findings will hinder regional elimination efforts.

Background

Leprosy is a chronic, highly stigmatised, neglected tropical disease, caused by *Mycobacterium leprae*, with dermatological, neurological and ophthalmic complications [1–3]. While leprosy's transmission risk is low (with only 2–5% of those exposed becoming symptomatic), its slow progression poses permanent disability risks [2]. The World Health Organisation (WHO) has been instrumental in global leprosy elimination campaigns, through their endorsement of a freely available, antimicrobial-based '*multidrug therapy*' (MDT) for patients of endemic countries [4]. Since 1981, over 16 million patients have been cured globally through these WHO efforts [5–7]. However, despite MDT easing leprosy's global burden notably, the infection remains endemic in several low and middle income countries worldwide [8].

In 2018, Brazil, a middle-income South American nation, reported the second highest leprosy incidence globally; responsible for 13.7% of worldwide cases [8, 9]. Brazil's leprosy incidence rose by 14% between 2015 and 2018, despite initially declining post-2009, indicating a recently worsening endemic [8]. Further scaling the problem, in 2018, Brazil also reported the second highest number of both '*grade two disabilities*' (visible deformities/severe visual impairment secondary to leprosy) and '*retreatment cases*' (patients re-diagnosed with leprosy after receiving treatment in the past) worldwide [8, 10].

Pernambuco, a state in North-East (NE) Brazil where 27.17% of all households live in poverty, has a '*hyperendemic*' leprosy status. Healthcare access in Pernambuco is '*poor*', due to geographical inequalities present in Brazil's state-funded, primary care focussed healthcare system, and high costs associated with better resourced private healthcare [10–17]. In 2010, Pernambuco had almost double the national leprosy prevalence (3.01/10,000 inhabitants, compared to 1.62/10,000 nationally), cure rates 3% lower than national rates, and the highest percentage of MDT-discontinuing patients countrywide (8.2%) [18, 19].

These statistics indicate poor treatment outcomes (TOs) in Pernambuco [18]. The interdependent implications of poor TOs, however, go beyond mere statistics. Firstly, poor TOs, alongside the stigma and negative religious connotations associated with leprosy in Brazil, impact patient quality of life, mental and physical health, and socioeconomic status [21–23]. Furthermore, while antimicrobial resistance (AMR) currently causes only 5% of Brazil's retreatment cases, poor TOs will encourage this percentage, and the global AMR concern, to rise [20, 24, 25]. Poor TOs in Pernambuco also increase patient infectiousness; promoting disease transmission and hindering regional WHO elimination efforts [10].

As for any disease, improving leprosy TOs in Pernambuco requires a location-specific insight into the population's experiences, perceptions and beliefs of leprosy and its treatment [26]. Literature on other diseases shows carer support has a symbiotic relationship with TOs; therefore, their views should be appreciated alongside those of patients [27–31]. To gauge the depth of evidence currently available, a MEDLINE literature search for English and Portuguese language literature, or literature with English and Portuguese language abstracts, was conducted. Because experiences and perceptions require probing and prove difficult to quantify, only qualitative literature was searched [29]. The following search terms were used: 'leprosy AND therapy' AND 'patient OR family OR carer' AND 'attitude OR perception OR patient

dropout OR noncompliance OR relapse'. Results were limited to those published post-2009, as this year limit coincides with the time frames of the most recently published WHO global leprosy statistical analysis [8]. Reference lists of identified papers were searched for 'grey' literature.

Six studies were identified [32–37], of which one was identified when searching for 'grey' literature [37]. One systematic review (SR) of 20 qualitative studies published between 2005 and 2013 identified numerous facilitators and barriers of treatment compliance, which they grouped into two categories to form a theoretical framework: '*personal factors*' (sub-divided into '*life quality*', '*socio-economic factors*', and '*cultural needs*') and '*medical factors*' (sub-divided into '*treatment regimen*' and '*health services*') [32]. However, the five further studies found facilitators and barriers of treatment compliance that are neither mentioned in, nor can be grouped into, the SR's theoretical framework, including concepts surrounding: quality of knowledge on leprosy; importance for one's own health; health beliefs; personality and behaviour; and experiences of stigma [33–37]. This indicates that the SR's theoretical framework is not comprehensive.

There are further limitations to these studies beyond the lack of a comprehensive theoretical framework. Some studies used qualitative questionnaires, which restricted the depth and breadth of participant responses [32, 35, 36]. Others recognised that their findings are not transferable, and therefore proposed the need for further, location-specific research, in order to effectively inform local healthcare policy-making [32–35, 37]. Brazil, a nation with unique socio-economic profiles, cultural attitudes, political climates and healthcare delivery structures, would benefit from this, as factors such as: the quality of leprosy-related knowledge; side effect impact; health beliefs; and religion have only been explored in non-Brazilian participants [18, 32]. Additionally, findings of the last published Brazilian study may no longer be relevant, as viewpoints may have shifted with the recently increasing national leprosy incidence [8, 32]. The research-deprived NE region would also benefit from location-specific research, as the geographical density of leprosy research in Brazil is not distributed proportionally to the geographical density of disease; with most studies conducted in the less affected, wealthier South-East region [38]. No literature exists on carers, despite their impact on TOs documented in studies of other diseases; [39–41] or on retreatment patients, who form an information-rich subgroup of leprosy patients with first-hand experiences of disease relapse, and therefore poor TOs [42]. Finally, apart from one Portuguese study which focussed on stigma [37], the present literature focuses primarily on facilitators and barriers of medication compliance. Novel research is therefore required, as medication compliance and stigma are only two of the factors influencing TOs [40–41]. These evidence gaps collectively justify the WHO's decision to make investigation into factors influencing leprosy TOs their research priority [20].

Overall, the literature search indicates poor understanding on the barriers and facilitators of leprosy TOs in Pernambuco. This study, a part of a wider study titled "*Which other factors explain therapeutic failure, since bacillary resistance is not always present in regularly treated patients*", [43] aims to address the evidence gap alongside the WHO research priority, by exploring retreatment patients' and carers' experiences, perceptions and beliefs of leprosy and its treatment in Pernambuco.

Methods

Design

A qualitative, in-depth interview study design, employing semi-structured topic guides, was used for a holistic, profound exploration of the study aim. While quantitative methods have more rigour and yield generalizable, statistically significant numeric data, this qualitative design was best suited to gather rich data on the complex, multifaceted, sensitive topics being explored [44–48]. Focus groups presented issues of confidentiality, unequal participant input, and peer influence, and therefore were not chosen [47].

Setting

This study was conducted in Petrolina: a densely populated, agricultural city of Pernambuco, NE Brazil, with a 2010 population of 293,962 [49]. Petrolina was chosen due to similar and therefore representative demographics to Pernambuco [18, 49]. Three, free, state-funded clinics were used to identify patients: *Unidade Básica de Saúde Miguel de Lima Durando*, *Ame Gildevania de Oliveira Silva*, and *Serviço de Infectologia de Petrolina*. The two former sites were rurally-located, while the latter was in the urban city centre.

Sampling and recruitment

AF, DK, LD and PR used maximum variation purposive sampling to intentionally identify information-rich patients from clinic registers [50]. Snowball sampling was additionally used to identify carers [51]. Participants were selected based on the following eligibility criteria: a) leprosy retreatment patient, or such a patient's carer; b) residing in Petrolina; c) aged over 18 years old; and d) fluent in Portuguese or English. Participants were excluded if they: a) had an illness which affected their ability to conduct a meaningful interview; b) could not provide informed consent; or c) felt interviewing would cause significant harm/stress to them. After each interview, participant demographics (such as occupation, age, gender, socioeconomic status and urban/rural residence) were discussed, to identify characteristics missing from the sample. To facilitate maximum variation, individuals with the identified missing characteristics were sought after in further sampling, [50] until data saturation was achieved. For comparative purposes, balanced numbers of a) patients and carers, and b) participants from urban and rural clinics were recruited.

Recruitment was undertaken in February and March 2020. AF, DK, LD and PR approached eligible participants and explained the study aim and design using participant information sheets. Participants were made aware that partaking was voluntary, and would not impact healthcare professional (HCP) care provisions.

Data collection

Semi-structured, one-to-one, face-to-face interviews were guided by separate topic guides, formulated uniquely for the purpose of this study, for patients and carers (Tables 1 and 2) [see Additional File 1]. The topic guides incorporated factors shown to influence TOs in previous literature; factors deemed important

by the study supervisors; and Patton's six types of interview questions (behaviour/experience, opinion/belief, feelings, knowledge, sensory, background/demographic) [52]. The semi-structured nature permitted flexibility in interviews for the discussion of ideas unanticipated by study personnel (for new theme synthesis), whilst enabling interviewers to re-orientate discussions if participants digressed [53, 54]. Pilot interviews were conducted on Day 1 to overcome translational difficulties and allow topic guide familiarisation across the study personnel. The topic guides were iteratively revised between interviews using the constant comparative method to incorporate questions on unanticipated ideas, until no new ideas surfaced, which indicated data saturation [55].

Interviews were conducted in Portuguese by PR and LD. Although it is appreciated that using a single interviewer is preferable, PR, LD and DK compared questioning styles and discussed issues arising from pilot interviews to ensure similarity in interviewing technique.

Informed written/thumbprint consent was obtained from all participants prior to interviewing, which took place in private consultation rooms at the three aforementioned clinics, or at participants' homes. Interviews were audio-recorded on a password-protected, encrypted device, with DK writing down field observations immediately after interviews. Interviews were transcribed into English by LD. A random sample of three transcripts were checked by an independent translator to gauge translation quality. Minimal, grammatical changes were made. Participation withdrawal was permitted at any point during interviewing or within 48 hours of interviewing, to ensure a minimal negative impact on the constant comparative method [53, 55].

Table 1
Topic guide for patient participants

Topic	Subtopics
Questions exploring personal factors	<ul style="list-style-type: none"> ◆ Knowledge about leprosy and treatment ◆ Beliefs about leprosy transmission and cure ◆ Experiences of restarting treatment ◆ Importance of health ◆ Leprosy manifestations ◆ Medication side effects ◆ Medication compliance and coping mechanisms ◆ Psychological impact
Questions exploring external factors	<ul style="list-style-type: none"> ◆ Employment and future aspirations ◆ Experiences of diagnosis ◆ Access to healthcare ◆ Importance of HCP ◆ Contact tracing
Questions exploring support network	<ul style="list-style-type: none"> ◆ Sharing diagnosis with community ◆ Stigma ◆ Family and social circle ◆ Religion

Table 2
Topic guide for carer participants

Topic	Subtopics
Questions exploring personal factors	<ul style="list-style-type: none"> ◆ Knowledge about leprosy and treatment ◆ Beliefs about leprosy transmission and cure ◆ Experiences of patient restarting treatment ◆ Importance of health ◆ Leprosy manifestations in the patient ◆ Medication side effects and coping mechanisms ◆ Medication compliance ◆ Psychological impact on self and carer
Questions exploring external factors	<ul style="list-style-type: none"> ◆ Experiences of carer role ◆ Employment and future aspirations ◆ Access to healthcare ◆ Importance of HCP ◆ Contact tracing
Questions exploring support network	<ul style="list-style-type: none"> ◆ Sharing diagnosis with community ◆ Stigma ◆ Family and social circle ◆ Religion

Data analysis

Analysing interview data ensued alongside its collection iteratively using the constant comparative method, [55] which determined the point of data saturation. Provisional themes emerging from this were discussed with PR and LD to gain a more culturally astute insight, minimising risks of cross-cultural bias [56]. Conventional thematic analysis and deviant case analysis were conducted by DK after interviewing finished to produce accurate reflections of the participant voice [57–60]. This method was suited due to the lack of an existing comprehensive theoretical framework, and because of its capacity to yield rich narratives on the relationships between the most pertinent themes influencing TO [58]. Braun and Clarke’s six step guide, Saldana’s two step cycle and NVivo 12 software were used to systematically approach coding the data [59, 60].

10% of transcripts were triangulated with JL and MB to introduce an unbiased, fresh perspective on coding [61]. Triangulated data was compared with DK’s coding to increase credibility, [61] with

discrepancies and unexpected findings facilitating theme revision. Themes were reviewed by the study personnel to ensure interpretations represented the yielded data, thereby reducing bias associated with a single analyst. Member validation was not practiced due to the study time constraints. DK appreciated the impact of researcher bias throughout analysis as part of a reflexive approach [62]. Findings were reported with consideration of the Consolidated Criteria for Reporting Qualitative Research [63] [see Additional File 2].

Ethical considerations

The study was approved by the Instituto Lauro de Souza Lima, Brazil on 11/12/2019 (3.746.443), and the University of Birmingham Internal Research Ethics Committee, United Kingdom on the 06/01/2020 (IREC2019/1636664). Data was stored according to the University of Birmingham data protection policy and the Data Protection Act, 2018 [64, 65].

Results

28 interviews were conducted in February and March 2020. Tables 3 and 4 summarise patient and carer participant demographics, respectively. One interview (011 – Patient) was discarded due to poor recording quality. Interviews lasted on average for 20 minutes, and ranged in length from seven minutes (013 – Carer) to 46 minutes (026 – Patient). All carers were family members of patients. No participants chose to withdraw from the study.

Table 3
Summary of patient participants' demographics

Identifier	Clinic type	Age bracket	Education	Gender	Job	Number of people in household	Consent type
001	Urban	$35 \leq x < 45$	Incomplete elementary school	Female	Unemployed	4	Written
002	Urban	$45 \leq x < 55$	Incomplete elementary school	Male	Unemployed	5	Thumbprint
004	Urban	$65 \leq x < 75$	No formal education	Male	Farmer	3	Thumbprint
005	Urban	$35 \leq x < 45$	Completed elementary school	Male	Public agent	2	Written
009	Urban	$35 \leq x < 45$	Incomplete elementary school	Male	Self-employed	9	Written
010	Urban	$35 \leq x < 45$	Completed elementary school	Male	Farmer	3	Written
012	Rural	$75 \leq x < 85$	Incomplete elementary school	Female	Housewife	1	Written
016	Rural	$25 \leq x < 35$	Completed high school	Female	Housemaid	5	Written
018	Rural	$45 \leq x < 55$	Completed elementary school	Male	Self-employed	3	Written
019	Rural	$35 \leq x < 45$	Completed elementary school	Female	Unemployed	5	Written
021	Rural	$35 \leq x < 45$	University education	Female	Unemployed	2	Written
022	Rural	$65 \leq x < 75$	Completed elementary school	Male	Retired	2	Written
026	Urban	$45 \leq x < 55$	Completed high school	Female	Housewife	5	Written
027	Urban	$55 \leq x < 65$	Incomplete elementary school	Male	Unemployed	9	Written

Table 4
Summary of carer participants' demographics

Identifier	Clinic type	Age bracket	Education	Gender	Job	Number of people in household	Consent type
003	Urban	35 ≤ x < 45	Incomplete elementary school	Female	Housewife	7	Written
006	Urban	35 ≤ x < 45	Completed high school	Male	Self-employed	1	Written
007	Urban	45 ≤ x < 55	Completed elementary school	Female	Farmer	2	Written
008	Urban	65 ≤ x < 75	No formal education	Male	Retired	2	Thumbprint
013	Rural	55 ≤ x < 65	Completed elementary school	Male	Truck driver	5	Written
014	Rural	35 ≤ x < 45	Completed elementary school	Male	Mechanic	5	Written
015	Rural	55 ≤ x < 65	Incomplete elementary school	Female	Housewife	5	Written
017	Rural	25 ≤ x < 35	Incomplete elementary school	Female	Hairdresser	3	Written
020	Rural	55 ≤ x < 65	No formal education	Female	Housewife	2	Thumbprint
023	Rural	18 ≤ x < 25	Completed elementary school	Female	Unemployed	3	Written
024	Urban	55 ≤ x < 65	Incomplete elementary school	Female	Housewife	3	Written
025	Urban	35 ≤ x < 45	University education	Female	Estate agent	4	Written
028	Rural	75 ≤ x < 85	Incomplete elementary school	Female	Housemaid	4	Written

Separate analysis of the two groups produced two homologous sets of four interdependent themes: 1) 'personal factors'; 2) 'external factors'; 3) 'clinical factors'; and 4) 'the HCP-patient-carer relationship'.

Tables 5 and 6 summarise coding for the patient and carer participant groups, respectively. Due to maximum variation sampling, the frequency of a specific view being mentioned is not indicative of the view's importance, but rather its popularity and presence within the study sample [50].

Table 5
Patient themes representing factors influencing leprosy TOs

Theme	Facilitators of optimal TOs (frequency out of 14)	Barriers to optimal TOs (frequency out of 14)
Personal factors	<ul style="list-style-type: none"> ◆ Belief in pharmaceutical treatment (11) ◆ Use of an education source (14) ◆ Health is important to the patient (12) ◆ High standard patient knowledge on resistance or the importance of compliance (13) ◆ Normal nature or lifestyle of participant did not change (4) ◆ Perceptions of leprosy as a 'dangerous' or 'contagious' (10) ◆ Positive patient attitude, desire to be cured (13) ◆ Positive perceptions of the future, and hope in a cure (14) ◆ Psychological resilience (13) ◆ Witnessing another getting better or worse (7) 	<ul style="list-style-type: none"> ◆ Belief in traditional medicines (4) ◆ Belief medication is 'strong' (1) ◆ Change in the normal nature, appearance or lifestyle of patient (12) ◆ Change in identity, feeling labelled (8) ◆ Contradicting sources of education (11) ◆ Distrust of pharmaceutical medications (8) ◆ Experience or fear of stigma and discrimination (11) ◆ Feeling helpless (8) ◆ Isolation or distance (9) ◆ Myths and misinformation (12) ◆ Other comorbidities (6) ◆ Poor quality or limited knowledge (13) ◆ Psychological impact of leprosy (14)

Theme	Facilitators of optimal TOs (frequency out of 14)	Barriers to optimal TOs (frequency out of 14)
External factors	<ul style="list-style-type: none"> ◆ Ease of access to treatment (10) ◆ Education to empower social circle to help the patient/reduce stigma (9) ◆ Social circle support (emotional, nutritional, psychological, financial) (11) ◆ Family makes sacrifices for patient (6) ◆ Holistic care by HCP team (4) ◆ Individualised, patient-led care (5) ◆ Pragmatic approach to a high standard care in a resource scarce setting (1) ◆ Religion forms psychological support (10) 	<ul style="list-style-type: none"> ◆ Care is not holistic (5) ◆ Difficulty accessing treatment (5) ◆ Disorganised care (6) ◆ Social circle has poor or limited knowledge of the disease (3) ◆ Financial impact (8) ◆ Impact of illness on social circle (social, psychological, financial) (11) ◆ Impact on aspirations for the future (5) ◆ Lack of political will to tackle leprosy (5) ◆ Living in the countryside away from services (2) ◆ Resource scarce health system (2) ◆ Impact on employment (12)
Clinical factors	<ul style="list-style-type: none"> ◆ Contact tracing (4) ◆ Mental or physical preparation for treatment (10) ◆ Seeing or feeling improvement (10) ◆ Strategies reducing side effects (6) 	<ul style="list-style-type: none"> ◆ Late diagnosis (10) ◆ Long duration of treatment, high frequency doses (12) ◆ Comorbidities (6) ◆ Painful/distressing diagnosis (6) ◆ Progression or persistence of disease (14) ◆ Side effects of treatment (12)
HCP-patient-carer relationship	<ul style="list-style-type: none"> ◆ Clear information provided (diagnosis, treatment, prognosis) (12) ◆ Good communication with HCP (9) ◆ Good quality care (6) ◆ Good, open, trusting HCP-patient-carer relationship (11) ◆ Patient feeling valued (7) ◆ Patient feels HCPs are important in their care (14) 	<ul style="list-style-type: none"> ◆ Clear information not provided on diagnosis, treatment and prognosis (11) ◆ Poor communication or relationship with HCP (4)

Table 6
Carer themes representing factors influencing leprosy TOs

Theme	Facilitators of optimal TOs (frequency out of 13)	Barriers to optimal TOs (frequency out of 13)
Personal factors	<ul style="list-style-type: none"> ◆ Belief in pharmaceutical treatment (10) ◆ Use of an education source (12) ◆ Health is important to the patient (7) ◆ High standard patient knowledge on resistance or the importance of compliance (11) ◆ Normal nature or lifestyle of participant did not change (11) ◆ Perceptions of leprosy as a 'dangerous' or 'contagious' (10) ◆ Positive patient attitude, desire to be cured (9) ◆ Positive perceptions of the future, and hope in a cure (13) ◆ Psychological resilience (7) ◆ Witnessing another getting better or worse (7) 	<ul style="list-style-type: none"> ◆ Belief medication is 'strong' (2) ◆ Change in the normal nature, appearance or lifestyle of patient (6) ◆ Change in identity, feeling labelled (1) ◆ Contradicting sources of education (7) ◆ Distrust of pharmaceutical medications (4) ◆ Experience or fear of stigma and discrimination (3) ◆ Feeling helpless (1) ◆ Isolation or distance (4) ◆ Myths and misinformation (8) ◆ Other comorbidities (6) ◆ Poor quality or limited knowledge (11) ◆ Psychological impact of leprosy (11)

Theme	Facilitators of optimal TOs (frequency out of 13)	Barriers to optimal TOs (frequency out of 13)
External factors	<ul style="list-style-type: none"> ◆ Ease of access to treatment (14) ◆ Education to empower social circle to help the patient/reduce stigma (9) ◆ Social circle support (emotional, nutritional, psychological, financial) (11) ◆ Family makes sacrifices for the patient (6) ◆ Holistic care by HCP team (4) ◆ Individualised, patient-led care (5) ◆ Pragmatic approach to a high standard care in a resource scarce setting (1) ◆ Religion as a source of psychological support (10) 	<ul style="list-style-type: none"> ◆ Care is not holistic (2) ◆ Difficulty accessing treatment (4) ◆ Disorganised care (2) ◆ Financial impact (7) ◆ Impact of illness on social circle (social, psychological, financial) (5) ◆ Impact on aspirations for the future (4) ◆ Infected family members (3) ◆ Lack of conversation about leprosy with patient (4) ◆ Lack of political will to tackle leprosy (3) ◆ Living in the countryside away from services (2) ◆ Impact on employment (6)
Clinical factors	<ul style="list-style-type: none"> ◆ Contact tracing (3) ◆ Mental or physical preparation for treatment (9) ◆ Seeing or feeling improvement (7) ◆ Strategies reducing side effects (5) 	<ul style="list-style-type: none"> ◆ Late diagnosis (3) ◆ Long duration of treatment, high frequency doses (11) ◆ Painful/distressing diagnosis (3) ◆ Progression or persistence of disease (9) ◆ Side effects of treatment (5)
HCP-patient-carer relationship	<ul style="list-style-type: none"> ◆ Clear information provided (diagnosis, treatment, prognosis) (7) ◆ Good communication with HCP (6) ◆ Good quality care (7) ◆ Good, open, trusting HCP-patient-carer relationship (8) ◆ Patient feeling valued (3) ◆ Carer feels HCPs are important in their care (12) 	<ul style="list-style-type: none"> ◆ Clear information not provided on diagnosis, treatment and prognosis (4) ◆ Patient fear or experience of stigma or discrimination from HCP (1) ◆ Poor communication or relationship with HCP (4)

Quotes have been selected to aid understanding of themes and subthemes, and illustrate similarities/differences in the sample's opinion.

Theme 1: Personal factors

This theme explores factors which depend solely on the participant, and has been subdivided into the three subthemes: *'knowledge and information quality'*; *'health beliefs'*; and *'psychological impact and character'*.

Subtheme A: Knowledge and information quality

13 patients and 11 carers exhibited limited overall understanding of leprosy, with a sizeable proportion unable to provide even simple explanations about the disease, and almost all unable to identify the cause of leprosy transmission.

Researcher

'What do you know about leprosy?'

Participant

'I have virtually no knowledge' (018 – Patient)

Researcher

'How do you think you get the disease?'

Participant

'I never shower with hot water and then suddenly with cold, or after eating, because I thought that's what causes leprosy. I don't know how I got it.' (018 – Patient)

Participant

'Because of cockroaches.' (019 – Patient)

Participant

'The sun. Petrolina is hot, and [the patient] was out at midday.' (020 – Carer)

Despite all participants either experiencing leprosy relapse, or caring for a relapse patient, relapse was poorly understood in all but one participant. Many patients and carers did not realise that the treatment they/the patient was receiving at the time was a separate, second course of medications, targeting relapsed leprosy. Some patients perceived education as part of their HCPs' responsibilities, and consequently blamed their poor knowledge of relapse on inadequate HCP-led education.

Researcher

'Do you know what relapse is?'

Participant

'No, sorry. Nobody at the clinic ever told me about that.' (009 – Patient)

Participant

'... my sister-in-law said it was when her leprosy came back.' (017 – Carer)

Some carers had poor knowledge because they perceived the patient as the primary knowledge source, and did not use other means accessible to them to obtain further information. Carers with good knowledge were proactive and resourceful when searching for information.

Participant

'We are curious, but [the patient] never told me about leprosy, so I never asked.'

Researcher

'Did you look online or in health centres instead?'

Participant

'No.' (013 – Carer)

Participant

'I like to learn more about leprosy so I can take better care of [the patient].' (003 – Carer)

More knowledgeable participants agreed that the internet, for those able to access it, and television programmes, were useful, information-rich sources supplementing HCP-given knowledge between clinic visits. Programmes dedicating airtime to Brazil's national leprosy campaign, *'Purple January'*, were effective in raising public awareness [66]. Some participants expressed the importance of mass, societal education on leprosy, and alluded to schools being an effective medium.

Participant: *' After the appointment I searched the internet and learnt a lot of things.'*

Researcher

'Were you more relieved when you had more information?'

Participant

'I was ... when we don't know things, it feels like a shock, right?' (001 – Patient)

Participant

'The thing about 'Purple January' is that people talk about it. It is necessary for school to teach about leprosy. These campaigns are needed.' (026 – Patient)

Some felt that knowledge gained via 'word of mouth' was less reliable than HCP advice, which was greatly valued. However, others gained rich, anecdotal knowledge through speaking with 'expert patients'.

Participant

'People get in the way, saying this, saying that. And [the patient] just gets confused. But the clinic doctor, she studied for this, she knows what is right and wrong.' (023 – Carer)

Participant

'... I know the woman in the waiting room. She told me about her nerves. They became defective. Others I know are on crutches, they can't walk.' (001 – Patient)

Some participants were familiar with leprosy's biblical associations [66]. However, these participants agreed that the Bible is not an accurate source of information concerning treatment.

Participant

'I read about leprosy, about Job, in the Bible, where it is a chronic disease and difficult to treat. Job had itchy wounds but there was no treatment then. Now it's different.' (006 – Carer)

Subtheme B: Health beliefs

Many perceived leprosy as a dangerous or contagious disease posing threat to health. Consequently, when asked to hypothesise about why other patients may have poor medication compliance, participants felt this was due to a poor regard for personal health.

Participant

'It's contagious, and it causes numbness, which is scary, because you cut yourself but can't feel it.' (017 – Carer)

Participant

'[Patients who are non-compliant] don't want to be healed.' (016 – Patient)

Carers believed their health was of elevated importance, due to their patient responsibilities.

Participant

'The importance of my health is everything because ... I dedicate myself to [the patient].' (003 – Patient)

Most participants felt positively towards pharmaceutical leprosy medications. Participants who witnessed their own or another's leprosy improve more commonly expressed belief in the medication.

Participant

'Because others have healed, why won't I?' (022 – Patient)

Conversely, those who had not witnessed symptomatic improvements expressed distrust in the medication. Despite this, all patients, including those distrusting medication, stated that they were wholly compliant with their medication regime.

Participant

'People stop the medicines because it takes time to see effects. They don't believe in them because they give up before getting better.' (003 – Carer)

Participant

'I could have stopped taking the pills. But the clinic staff kept saying, "Don't stop, otherwise it comes back even worse.". So I kept going.' (010 – Patient)

Some participants, despite perceiving the medication positively, did not believe that the medication was curative. Some justified this belief by explaining that the medication could not possibly treat severely advanced leprosy, but only alleviate symptoms.

Participant: *' I want them to find a cure because these remedies, they combat, but don't cure.'* (003 – Carer)

Participant

'I think that at my stage, I don't know if I will be cured. It cures you only if you have a few lesions.' (027 – Patient)

Some interviews show evidence of people incorrectly believing that their medication side effects were instead a sign of their leprosy prognosis worsening. Numerous labelled the pharmaceutical medications as *'strong'*. Some hypothesised about the effectiveness of *'natural'* remedies, which were perceived as *'safer'*.

Participant

'All these new problems, the medicine isn't working because it gave me new problems.' (004 – Patient)

Participant

'I only take the medicines with food. They are so strong, they attack the stomach, kidneys, liver.' (019 – Patient)

Participant

'Maybe certain vegetables, or maybe herbal medicines [cure leprosy]? Would you know?' (026 – Patient)

The importance of medication compliance to participants became apparent when they were asked about what advice they would give to a newly diagnosed leprosy patients. Despite some participants expressing disbelief in treatment, almost all stressed the importance of compliance.

Researcher

'What advice would you give to a newly diagnosed leprosy patient?'

Participant

'Follow the treatment correctly so it doesn't come back and gets better.' (015 – Carer)

Participant

'It's a delicate treatment that has to be treated according to the doctor, so follow their advice.' (002 – Patient)

Subtheme C: Psychological impact and character

All patients and 11 carers described leprosy exhibiting significant psychological impacts. For most of these participants, this impact was prolonged, spanning from the time of symptom appearance and persisting indefinitely. Numerous patients felt they were no longer *'normal'*, and felt labelled as *'sick'*. Visual leprosy manifestations affected self-esteem. Participants expressed desperation for a cure.

Participant

'My beautiful legs, my lovely feet, suddenly looked bruised ... If there is no cure, I will jump off a bridge. Because I will not live life sick with this leprosy, like a loser. I just want to be the same as I was.' (018 – Patient)

Participant

'It did [have a psychological impact]. For two months, I wouldn't walk with anyone, only alone or in the night. I didn't sleep. I didn't realise, but I would go to shower and still have all my clothes on. I was upset, dejected.' (018 – Patient)

This altered sense of identity was augmented by the impact leprosy had on the roles and responsibilities of participants; due to issues surrounding the ability to work, fear of disease transmission, and dependency on others.

Researcher

'Do you think leprosy has a big impact on your life?'

Participant

'Yes. Because I use a crutch, I have to be with someone when I go out so they can help. It's annoying. The pain means I don't sleep well, and I don't have a normal day like others.' (010 – Patient)

Nine patients and four carers felt leprosy caused isolation and distance, causing further psychological impact. Isolation had the greatest psychological impact when experienced with close family members.

Participant

'My husband was scared. He was afraid of having sex ... my daughter said, "Mom, if you have leprosy, you have to separate.". She separated her glass, her plate, everything.' (026 – Patient)

11 patients, compared to only three carers, reported experiences of stigma. This shows a lack of conversation about stigma between the groups. Several participants reporting stigma were parents of infected school-going children. Leprosy's biblical links, widely recognised in Brazil as a predominantly Catholic country, [67, 68] caused experiences of shame and self-stigma.

Participant

'Someone I worked with asked me why I was dark. I said it was because of leprosy treatment. She stepped back. She welcomed me with a kiss. But once she knew it was leprosy, she was quick to leave.' (026 – Patient)

Participant

'They said it is not a disease of people, but of animals.' (012 – Patient)

Participant

'My son faced stigma. Some kids found out at school and made fun of his colour and called him names.' (025 – Carer)

However, almost all participants emphasised the importance of a positive patient outlook. Both groups recognised negative behaviours which could enhance leprosy's psychological impact, and agreed this could be combatted by a desire to be cured and an optimistic attitude. Many carers spoke of keeping patients positive and motivated towards being cured.

Participant

'I didn't speak to anyone for a month. Then my family told me being isolated is worse ... you have to talk with your loved ones.' (002 – Patient)

Participant

'I took the medication just how the doctor said. I gave myself every chance to get better.' (005 – Patient)

Participant

'He never stopped the medicine because he just wanted to get better, get back to work. I always said, "Don't give up!", because otherwise there is no point.' (003 – Carer)

Six patients mentioned the difficulties of managing their comorbidities alongside leprosy (namely aging, hypertension, alcoholism and drug use, mental health illness, obesity and diabetes), which resulted in new or worsening psychological symptoms. Further issues surrounding polypharmacy, worsening general health and poor treatment regimen commitment caused *'distress'* in patients.

Participant

'Leprosy made everything worse. It made me so upset. I had to close my business. Then I was even more upset so I started drinking cachaça even more, smoking marijuana ...'* (018 – Patient)

**Cachaça: a distilled spirit popular in Brazil*

Participant

'I have diabetes. I think the treatment made it worse. When I stopped taking the medicine, the doctor said my diabetes got better.' (027 – Patient)

Theme 2: External factors

External factors describe factors outside of patient control. This theme has been subdivided into three subthemes: *'socioeconomic factors'*; *'structural factors'*; and *'support factors'*.

Subtheme A: Socioeconomic factors

The socioeconomic impact of leprosy was mentioned by all patients and the majority of carers. Eight patients and seven carers felt leprosy had financially impacted them, as their ability to work was restricted due to symptoms and side effects, or carer responsibilities. Wider financial implications concerned rent payments, costs travelling to clinics, and household/family costs. One patient explained that *'Bolsa Familia'*, a Brazilian social welfare programme which provides financial aid to poor families on

the condition that their children are attending school and are vaccinated, partly supplemented lost earnings [69].

Participant

'I worked in grape farms. Today, I don't have the courage to work anymore, under the hot sun ... I am too weak. But if I don't go to the farm, how will I feed my children? Their lives will suffer.' (001 – Patient)

Participant

'I can't work ... I have to care for [the patient].' (003 – Carer)

Participant

'I got Bolsa Familia, because I couldn't work, right?' (003 – Carer)

Younger patient participants felt leprosy would impact them financially because their career aspirations would be affected, as they expected to face a lifetime of stigma in the working environment. Some felt these implications were exacerbated by local job shortages.

Participant

'Who will hire a person with leprosy? There is prejudice. I need to heal. I need to be cured. Because I have dreams, projects ...' (026 – Patient)

Participant

'Petrolina is a very bad place to get a job. He paid for expensive colleges and never got a job.' (028 – Carer)

Subtheme B: Structural factors

Structural factors concern organisational, regional and national level issues affecting the care patients receive. While four patients and six carers felt the care they received was holistic and individualised, numerous disagreed. Participants felt there was insufficient regional investment in services addressing the psychological needs of leprosy patients.

Participant

'I told the doctor I felt very weak. She did all the tests quickly, found out I was anaemic and gave me medicines for it.' (018 – Patient)

Participant

'The doctor does counselling, but there should be a psychologist. Petrolina has to invest more in this.'
(005 – Patient)

Six patients and two carers felt the health care system was disorganised, which consequently negatively impacted their perceptions of care. Two patients noted medication and healthcare equipment resource scarcity in clinics, with one participant explaining that rural clinics had an additional lack of specialised staff. Some participants blamed this on the government's poor national and regional healthcare decision making. One carer felt that despite this, resources were pragmatically distributed.

Participant

'Someone did a blood test last year. We never heard back. The results weren't here, so it looks like they were lost.' (020 – Carer)

Participant

'So, at my clinic, there was no health agent, no doctor ...' (019 – Patient)

Participant

'Previously it was difficult but nowadays if one health unit doesn't have treatment, they bring it from another unit. If I run out [of medication] and they don't have it, I just try again the next day.' (003 – Carer)

Participant

'The medication is made abroad; I think that is why sometimes there is a lack of medication. It depends on the government, but I don't think they take public health seriously in Brazil.' (006 – Carer)

Participant

'It is difficult in the countryside. There is a lack of awareness. Health care professionals need to visit us at home because it is hard travelling to clinics.' (005 – Patient)

Subtheme C: Support factors

Support from HCPs was reported by all participants. This came in the form of imparting knowledge, prescribing medication, and providing strategies to make side effects less noticeable.

Participant

'[The HCPs] helped me a lot. In everything. In giving advice, explaining things ...' (010 – Patient)

Participants felt family support was 'vital'. While both groups recognised that leprosy impacted family and societal relationships, due to stigma, transmission risk, and dependency, both groups also credited

their support. Patients and carers who had a lack of dialogue between them about leprosy reported less intimate, unreliable support provision. Conversely, open patients who educated their carers about leprosy empowered them to provide individualised support.

Participant

'Only my eldest boy works. I have another boy at school. He needs me as a mother, but I am not well.' (019 – Patient)

Participant

'My neighbour said, "Get away from him, that disease is transmissible!". So I isolated myself, but then, when his wife and children came out to talk to me, I told them, "No, I am not infectious."' (002 – Patient)

Support from the family and social circle came in emotional, nutritional, psychological and financial forms.

Participant

'People asked why [the patient] didn't leave the house. I said that he was ashamed of his leprosy. He had depression. So I said, "Since you won't go out, I'll invite everyone home."' (003 – Carer)

Researcher

'What is your role in the patient's life?'

Participant

'Her friend, her counsellor, her helper, her strength ...' (025 – Carer)

Participant

'My sister, she pays for my water, my light. She makes food for my house when I can't do it.' (019 – Patient)

Participants in both groups used their religion as another form of psychological support.

Participant

'I believe he will be cured. I believe in God and whoever believes in God has everything. You have to have faith. There are days when he at home is agonized, restless. I take the Bible and read to him.' (024 – Carer)

Theme 3: Clinical factors

Clinical factors refer to a patient's healthcare necessities. This theme is subdivided into two subthemes: *'treatment and side effects'*, and *'experiences of diagnosis'*.

Subtheme A: Treatment and side effects

Twelve patients and five carers experienced medication side effects. The most frequently occurring side effect was sunburn; due to a photosensitivity reaction associated with dapsone [70]. Other commonly reported side effects were headache, gastrointestinal problems, and weakness. Participants worked with HCPs to find strategies to overcome side effects, making the medications more agreeable to patients.

Participant

'It's hot here every day, and I'm exposed to the sun because I'm a farmer, so my skin became dark because of the medication.' (019 – Patient)

Participant

'I kept vomiting when I swallowed the pills, so the doctor gave me [dimenhydrinate].'* (010 – Patient)

**Dimenhydrinate: an antihistamine medication used to prevent nausea and vomiting.*

Participant

'She became weak. They said she had anaemia because of the medicines so the nurse gave her ferrous sulfate.' (025 – Carer)

Participant

'When you take it in the morning you feel that nausea, right? But when you take it before sleep, you don't feel anything.' (026 – Patient)

All participants commented on the long nature and dose frequency of the treatment schedule. Many felt that being mentally prepared to take the medication was important in remaining compliant. Carers encouraged patient compliance. The majority either saw or felt improvement with medication, while some, who did not, felt less motivated to stay compliant.

Participant

'The treatment has so many medications, so many pills every day.' (007 – Carer)

Participant

'Since the disease has a cure, you have to try to do everything to make things better.' (016 – Patient)

Participant

'She told me she had to restart treatment, and the only thing I said was, "Do it, don't stop, continue to the end, take the steps you have to take".' (017 – Carer)

Participant

'From the second day onwards, it was only improvement.' (012 – Patient)

Participant

'I have already been treated for two years and I still have the leprosy. Where is there result? I wanted to stop taking the medicines but the clinic staff said that wouldn't be good.' (010 – Patient)

Subtheme B: Experiences of diagnosis

10 patients recalled a delayed diagnosis. For some, this was due to receiving an initially incorrect diagnosis, which left patients *'distressed'*. For others, this was because they did not seek HCP advice until their symptoms significantly progressed. Only four patients and three carers recalled contact tracing within their household. Through these responses, it became apparent that contact tracing was not only uncommon, but, when done, too infrequent to be effective [71].

Researcher

'How long after seeing the first lesion did you wait before seeing a doctor?'

Participant

'A year or so passed. I went to the doctor when I became numb.' (010 – Patient)

Participant

'The hospital told me it was rheumatism. It got worse so I went to the clinic again. Then they told me I had advanced leprosy. If they told me sooner, maybe I would have suffered less.' (004 – Patient)

Researcher

'When [the patient] was diagnosed, were you examined?'

Participant

'No. Not me nor my children, no one. I didn't think about [contact tracing] until you just said.' (008 – Carer)

Participant

'The health professionals were concerned not only about me, but also my family. To prevent the disease, right?' (017 – Carer)

Theme 4: HCP-patient-carer relationship

This theme explores how the relationship between HCPs, patients and carers impacted TOs.

All participants felt HCPs were vital to their care, and recognised the importance of a strong HCP-patient-carer relationship. This relationship served as the foundation for good communication and trust. While nine patients and six carers felt that communication was good with HCPs, others disagreed. The clarity of information provided by HCPs similarly received mixed reviews, leading several to feel that the medication regime was *'complicated'*. Many reported that HCPs simply stressed the importance of treatment compliance, but did not offer deeper information.

Participant

'I learned a lot from the doctor. She said there are five types of leprosy, and mine attacks the nerves and causes me to have reactions.' (002 – Patient)

Participant

'The doctor said I have to take the medicine every day without fail, right?'

Researcher

'Did they tell you about the side effects, the reason why you need it, anything like that?'

Participant

'No.' (001 – Patient)

Participant

'I was surprised. How come the doctor stopped the medication if I still had a lesion? It bothers me a lot that I stopped the treatment then. Nobody told me exactly why.' (019 – Patient)

Opinions were also mixed concerning the trust between HCPs and participants. Some participants suspected HCPs of omitting important information during consultations. For others, outcomes desired by patients appeared misaligned with those desired by HCPs. The interdependence of trust and good communication becomes apparent through such responses.

Participant

'The doctor at my clinic, I tell her everything. My whole story of suffering, everything.' (019 – Patient)

Participant

'Maybe, the doctors don't tell me about everything I should know.' (006 – Carer)

Participant

'In the eyes of the doctors, I am better, but my leg still feels numb, that's the problem.' (002 – Patient)

Most participants, however, felt comfortable sharing worries with HCPs. A number mentioned specific staff members who were exceptionally helpful in their care. Participants felt valued by HCPs, and respected in the clinical environment.

Participant

'I was worried about my daughter. The doctor told me, "Look, she will live a normal life, study, date, everything." I felt relieved.' (025 – Carer)

Participant

'I am always welcomed in the clinic. All the staff take good care of patients; they are very polite, very excellent indeed.' (003 – Carer)

Participant

'The two doctors here are very good. If the doctors are worried about your health, they will find out what is wrong as soon as they can.' (026 – Patient)

Discussion

This study explored factors influencing leprosy TOs through interviews with 27 leprosy retreatment patients and carers. Separately analysing the two groups produced two homologous sets of four interdependent themes: *'personal factors'*; *'external factors'*; *'clinical factors'*; and *'the HCP-patient-carer relationship'*. These themes provide a comprehensive societal insight on TOs, and collectively challenge current leprosy management strategies in Pernambuco, Brazil.

Personal factors

This study's findings suggest that the psychological effects of leprosy, health beliefs, quality and extent of knowledge and character impact leprosy TOs.

Both participant groups displayed poor basic knowledge of leprosy. Poor knowledge surrounding the cause of leprosy facilitated distrust in pharmaceutical medications, as this knowledge is required to appreciate why the antimicrobials in treatments are effective in countering the infection [72]. This increased likelihood of belief in non-evidence based, traditional medicinal products, which themselves have poorer TOs [73, 74]. Poor knowledge surrounding relapse also fostered patient and carer distrust in pharmaceutical medications. Numerous participants did not distinguish their/the patient's current treatment as a separate, second round of medication for relapse, which facilitated perceptions of the medication regime being unnecessarily long, ineffective and a source of unwanted side-effects. Poor

leprosy transmission understanding was another barrier to optimal TOs, as it reduced preventative and symptom-presenting behaviours. Improving the study population's basic knowledge of leprosy and its treatment may increase belief in pharmaceutical medication, and facilitate psychological coping with the treatment length and side effects. Additionally, countering false transmission beliefs with evidence-based knowledge may dampen Pernambuco's '*hyperendemic*' status, by encouraging society to: seek contact tracing; become wary of transmission routes; and understand that treatment compliance makes transmission improbable [76–78]. This relationship between disease knowledge and positive TOs is supported by literature studying other diseases [79–85].

HCPs were perceived as the superior knowledge source. HCPs were persuasive and effective in endorsing treatment compliance, including in those expressing distrust in the medication. Future strategies should exploit the faith this population have in HCPs to increase leprosy TOs, by a) maximising the knowledge they directly provide to patients and carers, and b) encouraging them to increase health-seeking behaviours in individuals, by directing them to other reliable sources popular with the sample, such as the internet and television programmes. Pernambuco's financial burden of 'treatment drop-out' patients and avoidable retreatment cases could be tackled via HCP-led education, as literature investigating the effects of HCP-led education in other diseases suggests this as a cost-effective method on a larger, policy-making scale [19, 86–88]. 'Expert patients' were also perceived as a valuable source of knowledge. While the effectiveness of peer education has been recognised in previous literature, [89] this study suggests that 'expert patients' could be used alongside HCPs, the internet, and television, to improve societal leprosy awareness. Additionally, this study's findings promote the potential of exposing the positive treatment experiences of 'expert patients' to patients and carers yet to witness symptomatic improvements (a subgroup more likely to develop disbelief in pharmaceutical medications).

This study highlights leprosy's relationship with psychological wellbeing. The transition of a family member into another family member's carer altered relationship dynamics, due to changes in physical and emotional dependency levels, intimacy and financial support. The roles and responsibilities of patients and carers changed, with occupation almost always being impacted. This caused an altered, or loss of, identity in both patients and carers. External and self-stigma, fuelled by societal perceptions of leprosy as '*dangerous*', and biblical associations [67], exacerbated psychological distress; alongside coping with other psychological and non-psychological comorbidities. Given the recognised impact of mental wellbeing on TOs, [90–92] these findings promote the importance of psychological healthcare as a key part of the leprosy treatment package. Some strategies used by participants which protected psychological wellbeing, such as: mental preparation for treatment; maintaining a positive outlook; and having strong desires to be cured, could be promoted by HCPs to newly diagnosed leprosy patients and their carers. The worth of mental health specialist staff, who can provide a more individualised service, should not be overlooked [93]. Campaigns promoting leprosy as entirely curable, and non-transmissible during treatment, may blanket the present societal stigma, further reducing leprosy's psychological impact [94, 95]. Such campaigns, if executed on a mass scale, could target all pockets of society, with widespread positive implications.

External factors

This study's findings also indicate that socioeconomic, structural and support factors impact leprosy TOs.

Leprosy exhibited a multitude of negative, interdepending, socioeconomic consequences on patients and carers. Increases in disease and side effect severity made patients increasingly dependent on carers; impacting both groups' abilities to maintain employment. Participants implied that unless employment loss was compensated for by carers adopting additional earning responsibilities, household ability to afford rent, nutritious food, and travel to health clinics would be thwarted. Both of these consequences decrease patient treatment engagement, as either patient care is compromised, or patients progressively lose wealth and become impoverished. This results in a vicious cycle, of increasing dependency and consequent financial instability [96–101]. While Brazil's *Bolsa Familia* conditional cash transfer programme aims to protect households from this vicious cycle, [102, 103] it is perhaps inadequate as income replacement; because while several participants alluded to their household financial insecurity, only one participant felt supported by this measure. Participants with aspiring careers, and infected children, were not immune to this negative socioeconomic vicious cycle; as the stigma present in Pernambuco's occupational and educational settings, alongside job shortages and local poverty [18, 49], impacted pursuing vocational education and training. This study's findings promote location-specific financial support schemes for leprosy patients and their carers, to shield from continuous financial setbacks. Food vouchers in other Brazilian states, [104] and direct income replacement in Nigeria and China [105, 106] have shown promise, and therefore could be trialled in Pernambuco. Superior to financial or material help, vocational skills and disability-friendly workplace environments may enable patients and carers to permanently escape this socioeconomic vicious cycle, improving TOs [107].

This study exposes regional resource scarcity and healthcare disorganisation, particularly rurally. Possibly a direct consequence of Brazil's notable geographical healthcare inequalities, these findings underline the need for regional, and possibly national, changes in: Brazil's healthcare quality standards; public resource distribution; and spending in the healthcare subsector [15]. The sizeable proportion of avoidable retreatment patients in Pernambuco presents an unnecessary financial burden to healthcare policy makers [19]. Investing into improved resources and holistic care may be a cost-effective long-term solution; as the resultant improvement in TOs will generate smaller future resource expenditures on leprosy patients, and a larger, fit-to-work, economy-contributing population [108].

While the support role of HCPs is widely recognised in this study and in wider literature, [109, 110] this study provides novel insight on the breadth of the carer role. Overcoming stigma and transmission fears, family members adopted carer responsibilities for patients, by providing psychological, nutritional, and financial support. Some patients became their carers' personal 'expert patient', which fostered stronger, individualised support-giving; facilitating TOs. Although modifying patient motivation and attitude is inherently challenging, as behavioural change is a complex, multifactorial process, [111] this study shows that carer-led encouragement and reassurance increases patient psychological wellbeing and resilience.

Combatting the lack of conversations surrounding stigma between patients and carers by encouraging such dialogue may nurture trusting, open relationships; further supplementing carer-led psychological support [95]. HCPs could utilise their trustworthiness in this population to encourage more intimate patient-carer dialogue. Despite leprosy's biblical associations fuelling self-stigma for some [67], religion provided a personal support mechanism facilitating optimal TOs for many.

Once religion is identified as a supportive source for an individual, HCPs could further improve psychological wellbeing (and consequently TOs), by directing patients and carers to religious congregations and places of worship.

Clinical factors

This study and previous literature appreciate that treatment side effects negatively impact TOs [32, 112, 113]. This study additionally supports implementing side effect-reduction strategies (involving using more medication or modifying medication administration times) to facilitate TOs. Echoing previous literature findings, lengthy treatments and medication ingestion frequency, both inflexible, also negatively affected TOs, particularly in polypharmacy patients [32–37]. However, mental resilience and preparedness made treatment lengths and dose ingestion frequency more agreeable to patients. This is perhaps because such individuals were more compliant with medications, and consequently witnessed symptom improvement, which confirmed belief in the treatment. Delayed diagnosis was because of incorrect symptom recognition by HCPs, poor health-seeking behaviour, and absent or infrequent (hence ineffective) contact tracing.

HCPs, as the gateway to healthcare delivery, are key to facilitating optimal TOs through clinical factors [114]. The study findings suggest that HCPs should reassure patients that strategies to overcome side effects exist, promote psychological resilience, and endorse awareness campaigns similar to 'Purple January' to facilitate TOs [66]. HCP retraining on symptom awareness and contact tracing provisions may aid early disease diagnosis, which is recognised to produce more favourable TOs in wider literature [115]. Observations from a HCP retraining workshop held at the time of the field study (Fonseca A, personal communication, March 2020); alongside the findings of a simultaneously conducted study on HCP perceptions towards leprosy by co-author MB, indicate the urgent necessity for location-specific HCP retraining [116].

HCP-patient-carer relationship

Resonating with previous literature findings, the relationship patients and carers had with HCPs served as a basis for good communication and trust, which facilitated optimal TOs [32–37]. Patients and carers credited HCPs as vital for their care, and felt valued, welcomed and comfortable to share concerns with them. Some staff members were recognised numerous times for their care provisions. However, this study also exposes a scope to improve the depth and clarity of HCP-led communication. Patients' chose to remain compliant with treatment, although some participants felt HCPs provided dissatisfactory, surface-level communication. This points towards paternalistic medicine cultures, which presents additional barriers to TOs [117, 118]. Increasing dialogue and trust between HCPs, patients and carers,

through HCP retraining focussing on empathy and communication skills, could encourage more satisfying, individualised care experiences [117, 118]. This study stresses that the importance of cultivating a strong carer-HCP relationship should not be overlooked. Encouraging carers to attend appointments will enable them to interpret HCP advice with patients, which may develop the carer role into one providing even higher quality, individualised care.

Strengths and limitations

This study's primary strength is the deep insight it provides on the perceptions, experiences and beliefs of leprosy and treatment in Petrolina, a '*hyperendemic*' yet under-researched location. However, given this study's qualitative design, caution should be taken when generalising findings to populations beyond those explored [120]. Additionally, the use of small participant numbers, and the exclusion of 'treatment dropout' patients (due to recruitment difficulties), impact representativeness. This must be appreciated prior to applying these findings to similarly endemic locations [52].

As a cross-language study, translators and interpreters impacted data collection and analysis processes [121]. Braun and Clarke's method obtains meanings from collected textual data [59]. Therefore, using interpreters and translators increases the chance of these obtained meanings becoming dissimilar to those actually expressed by participants, which become at risk of being 'lost in translations' [121]. Some literature, however, shows that thematically analysing translated data largely does not impact thematic synthesis [122]. Strategies reducing biases relating with misinterpretation were undertaken regardless, and involved pilot interviews and secondary, independent translation checks. LD and PR, both Brazilian nationals, facilitated participant comfort during interviews, as they interviewed members of their own community; and additionally clarified cultural references in participant responses. DK, PR and LD were neutral, and uninvolved in patient care provision, however may have still evoked social-acceptability bias in responses.

In retrospect, further limitations exist in the lack of real-time translation during interviews. This would have allowed DK to delve deeper into desired topics, particularly surrounding participants' thoughts on governmental and regional strategies for leprosy eradication, and religious beliefs, which would have been worthwhile exploring in more depth.

Finally, the impact of DK, the lead researcher (British Indian, female medical student), conducting this cross-cultural investigation requires appreciation. Culture is outlined as a set of distinguishing, discriminating features of a social group [123]; therefore, as a foreigner to this community in Petrolina, DK's presuppositions and beliefs may have biased data interpretation and analysis. These effects, and therefore researcher bias, were minimised through LD and PR explaining cultural references, triangulation and discussions on theme formation.

Conclusion

This study identifies personal factors, external factors, clinical factors and factors relating to the HCP-patient-carer relationship to impact leprosy TOs. This study can contribute to location-specific, state and national levels by informing the development of more, higher quality health promotion; holistic, individualised care provision; and evenly geographically distributed financial investment into leprosy patients and the healthcare provisions they utilise. Failure to address these findings will hinder regional elimination efforts. Further studies, exploring the views of the 'treatment dropout' subgroup and evaluating the effectiveness of future, newly imposed interventions, may provide additional, highly relevant evidence.

Abbreviations

TO: treatment outcome

HCP: healthcare professional

MDT: multidrug therapy

WHO: World Health Organisation

AMR: antimicrobial resistance

NE: North East

SR: systematic review

Declarations

ETHICAL APPROVAL AND CONSENT FOR PARTICIPATION AND PUBLICATION

Ethical approval was obtained from the University of Birmingham Population Sciences and Humanities Research Ethics Committee (IREC2019/1636664) and the Instituto Lauro de Souza Lima, Brazil (3.746.443). Ethical issues identified by these bodies regarding this study were used to improve the study design. Data was handled sensitively, in a confidential manner, as outlined by the study protocol.

Recruited participants were given participant information leaflets outlining the study, the opportunity to ask the study personnel questions, and time to consider participation. Written or thumbprint informed consent was obtained from all participants, and was witnessed by at least two study personnel. Data was handled confidentially.

AVAILABILITY OF DATA AND MATERIALS

The datasets used and analysed during the current study are available from the corresponding author on reasonable request.

CONSENT FOR PUBLICATION

Not applicable.

COMPETING INTERESTS

The authors declare that they have no competing interests

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AUTHOR CONTRIBUTIONS

DK, the lead author, is a female University of Birmingham medical student, who conducted this study as part of a Bachelor of Medical Science intercalated degree in International Health.

GdW is a male Birmingham-based GP, and the course lead for the aforementioned degree, who was key in conceptualising this study, and provided constructive advice on study design, data interpretation and manuscript production.

LD is a male pharmacist and a Biosciences master's student at the Universidade Federal do Vale do São Francisco, based in Pernambuco, who provided cultural insight and aided with topic guide piloting. LD is bilingual in Portuguese and English. LD interpreted during interviewing and transcribed all audio-recordings into English text.

AF is a female infectious disease doctor based in Petrolina, who specialises in leprosy patients, who provided cultural insight during data collection and logistical help when conducting the study.

MB is a female University of Birmingham medical student completing a Bachelor of Medical Science intercalated degree in International Health, who was responsible for the second round of data triangulation.

JL is a female University of Birmingham medical student completing a Bachelor of Medical Science intercalated degree in International Health, who was responsible for a preliminary round of data

triangulation, and critiquing the final manuscript.

AL is a female teaching lead for the study design module of the aforementioned degree, who assisted with formulating the study design and critiqued the final manuscript.

PR is a female leprosy researcher based in Bauru, Saõ Paulo, Brazil, who has a PhD in Tropical Medicine from Universidade Estadual Paulista. PR provided constructive advice on the study design and topic guides. PR also provided cultural insight and logistical help conducting the study. PR is bilingual in Portuguese and English, and interpreted during interviewing. This study was conceptualised by PR, and is a part PR's wider study.

All authors have read and approved the manuscript.

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