Motives and determinants for residence change after leprosy diagnosis, central Brazil

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Accepted for publication 9 August 2011

Summary

Objective: To determine the extent of population movement after diagnosis with leprosy and to describe the underlying motives and determinants for relocation.

Design: A cross-sectional study was conducted among those newly diagnosed with leprosy in 79 endemic municipalities in the state of Tocantins, central Brazil. Individuals were identified through the National Information System for Notifiable Diseases (SINAN) database and interviewed with structured questionnaires.

Results: In total, 224 (20-9%) out of 1070 individuals relocated after their diagnosis with leprosy. Respondents moved to another neighbourhood in the same municipality (n = 178, 79.5%), followed by another municipality in Tocantins state (n = 26, 11.6%) and in another state (n = 11, 4.9%). The primary motives and/or determinants for relocation were: home ownership (n = 55, 28.4%), familial reasons (n = 43, 19.2%), to seek better living conditions (n = 27, 13.9%), employment (n = 26, 11.6%), and better neighbourhood (n = 22, 9.8%). Other motives were related to

This publication is part of the MAPATOPI study (an interdisciplinary project providing evidence for improving the Brazilian leprosy control program), co-financed by the Brazilian Research Council (CNPq) and the Department of Science and Technology of the Brazilian Ministry of Health (DECIT).

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better access to leprosy diagnosis/treatment (n = 11, 4.9%), owner-terminated rental (n = 5, 2.2%), personal finances/could not afford housing (n = 4, 1.8%). Perceived stigma due to leprosy was mentioned by one participant (0.5%).

Conclusion: In Tocantins state, population movement is lower among individuals recently diagnosed with leprosy, as compared to the overall population. The primary motives for relocation after leprosy diagnosis were related to lifestyle changes. Stigma and treatment-related reasons did not appear to be common motives for population movement. These results may reflect policy changes instituted from the Brazilian Program of Leprosy Control to decentralise leprosy services and intensify health education campaigns within a broader concept of Information, Education and Communication.

Introduction

Recent research surrounding population movement and infectious diseases has centered on exposure, 1-3 risk 4-6 and transmission to and from communities of origin and destination, 7-10 and the combination of these factors. 11-12 The institutional burden of imported disease, patient management and environmental control of disease in non-endemic areas, imported disease in conflict settings, restricted access to health facilities, and reduced migration due to disability have been discussed for malaria, hepatitis, chagas disease, HIV/AIDS and other serious life disrupting and/or stigmatising diseases. 13-17 However, there has been limited research on the motives for population movement after disease diagnosis. The extent to which the personal choice to move is influenced by the disease itself, stigma, lifestyle, macroconditions such as access to treatment, or as a response to health policy or other socioeconomic conditions is largely unexplored.

The International Federation of Anti-Leprosy Associations (ILEP) review of leprosy research (2002–2009) found that despite cultural differences across countries with a high incidence of leprosy, areas of life affected were similar. ¹⁸ Leprosy research in Nepal, ¹⁹ Bangladesh, ¹⁸ India, ²⁰ Nigeria, ²¹ Indonesia, ²² and Brazil ²³ highlights issues associated with social exclusion. While individuals with leprosy may be separated from family and community activities, in some cases they leave the community entirely – as migrant labourers or otherwise – until symptoms subside. ¹⁹

In the present paper, we investigated the motives and determinants for population movement after leprosy diagnosis as part of a major epidemiological study in North Brazil. The data show that stigma and health-service related factors played only a minor role in this setting where leprosy control activities are established and decentralised.

Methods

STUDY AREA

Tocantins, the newest Brazilian state located in the north region, is a leprosy hyperendemic area with the highest case detection rate in Brazil (88·54/100,000 inhabitants in 2009).³⁷ With one of the fastest growing agriculture-based economies, Tocantins attracts labour migration with more than a third of the population from a different state and more than a half born in different municipalities.^{24–26}

STUDY DESIGN AND DATA COLLECTION

This study is an integral part of an epidemiological investigation among 79 municipalities in Tocantins. All municipalities were located in an endemic cluster identified by the Brazilian Ministry of Health as high risk areas for leprosy transmission.²⁷ The target population included all newly diagnosed individuals between 2006–2008 who were living in the endemic municipalities. Individuals living outside the cluster, those with mental illness or other characteristics that hindered interviews, including those under the influence of alcohol were excluded. In addition, relapsed cases and those who died after diagnosis were also not included.

Municipality Health Secretariats were informed by the Tocantins State Health Secretariat about the study and field visits were coordinated for data collection. The target population was identified through the database of the National Information System for Notifiable Diseases (Sistema de Informação de Agravos de Notificação – SINAN). Patients were invited through Community Health Agents to participate in the study. The study was conducted between September to December 2009. Clinical data (degree of disability) were collected from patients' charts and the disease notification forms. Demographic data (such as gender, age, place of birth) and questions for migration before and after diagnosis were investigated by interview using a structured-questionnaire. The individuals who changed residence after diagnosis were asked whether they moved to another neighbourhood, municipality and/or state and their reasons and motivations for that. To reduce interview bias, questionnaires were applied by two previously trained field investigators (OAC, ARO).

DATA ANALYSIS

Data were entered twice, using Epi Info software version 3.5.1 (Centers for Disease Control and Prevention, Atlanta, USA) and cross-checked for entry-related errors. Answers of openended questions to motivations for moving after diagnosis were grouped into categories according to similarities. Frequency distributions were examined only for those who changed residence after diagnosis with leprosy. Data analysis was done using STATA version 11 (Stata Corporation, College Station, USA).

ETHICS

The study was approved by the Ethical Review Board of the Federal University of Ceará (Fortaleza, Brazil) and by the Ethical Review Board of the Lutheran University of Palmas (Palmas, Brazil). Permission to perform the study was also obtained by the Tocantins State Health Secretariat, the State Leprosy Control Program and the municipalities involved.

Informed written consent was obtained from all study participants after explaining the objectives of the study. In the case of minors, consent was obtained from those responsible for them. Interviews were in private, and the diagnosis of leprosy was not given to family members or other community members.

Results

In total, 1074 interviews were conducted; 555 (51·7%) individuals were male and 519 (48·3%) female; the ages ranged from 5 to 98 years (mean = $41\cdot8$; standard deviation:

Motive/determinant	N	%
Home ownership	55	28.4
Familial reason	43	22.2
Better living conditions	27	13.9
Employment	26	13.4
Better neighbourhood	22	11.3
Leprosy diagnosis/better access to treatment	11	5.7
Owner terminated rental/asked for house	5	2.6
Personal finances/could not afford housing	4	2.0
Leprosy discrimination/stigmatisation	1	0.5

Table 1. Motives/determinants for moving after leprosy diagnosis (n = 194)

19·01). Disability status at the moment of diagnosis was available in 751 cases. Of these, 75% (n=566) were diagnosed with Grade 0 disability, 20·6% (n=155) with Grade 1, and only 4·0% (n=30) with visible impairments (Grade 2). Eight hundred (76·2%) individuals were born in another municipality, and 179 (16·7%) had lived in another municipality or state 5 years prior to their leprosy diagnosis.

In total, 224 (20·9%) of 1070 participants with available information relocated after their diagnosis with leprosy. Of these, more than half (n = 121, 54%) were males; the ages ranged from 5 to 83 years (mean = 36·1; standard deviation: 16·1). The majority of the migrants after diagnosis (n = 215; 96%) had lived at their current residence for 5 years or less. Of the 30 patients diagnosed with visible impairments, seven (23·3%) migrated after diagnosis, as compared to 134 (18·6%) of those diagnosed with Grade 0 or 1 (P = 0.48).

After diagnosis, the majority of the migrant cases moved to another neighbourhood in the same municipality (n = 178, 79.5%), followed by other municipality in Tocantins (n = 26, 11.6%), and other state (n = 11; 4.9%); eight respondents (3.6%) did not specify a location.

Among 194 (86.6%) of the migrant cases, information was given regarding motives. Motives for relocation after leprosy diagnosis are detailed in Table 1.

The primary motives for changing residence were related to lifestyle changes (home ownership, better living conditions, better neighbourhood), making up 53.6% of all responses. Conversely, some individuals lost housing through other circumstances including not being able to afford housing or because the home owner requested the house or terminated the rental agreement. Employment related relocation included moving 'for work' or 'for better work' in the destination, or due to unemployment or limited employment opportunities in the residence of origin. Familial reasons for moving (22.2%) was the second most common motive given and included, change in civil status due to separation (n=8), marriage (n=6), caring for family members (n=6), moving due to spouse's employment (n=3), besides other reasons (n=20).

Few cited moving because of their leprosy diagnosis and/or for the purpose of accessing health services. Two individuals moved to access treatment and three for better treatment. Only one individual pointed to discrimination and feeling stigmatised as a reason for moving after leprosy diagnosis.

Discussion

This study shows that patients recently diagnosed with leprosy changed residence primarily as a result of lifestyle changes and to a much lesser extent for better access to treatment or as a result of stigma and discrimination. In fact the Brazilian Ministry of Health, through the Office of Leprosy Control, has placed a strong emphasis on reducing incidence by integrating leprosy services into the municipal level public health system (decentralisation) and minimising stigma through public health campaigns. Decentralisation allows for community health centres to be the patient point of contact for both diagnosis and treatment, provided free of charge. Our findings suggest that these policies have resulted in a reduced burden of disease management and relocation for treatment so that patients can divert their attention to positive lifestyle changes. The broad age range of newly diagnosed cases from 5 to 98 years indicates ongoing transmission, but also the positive impact of control efforts and early diagnosis.

According to the Brazilian National Household Study (PNAD), approximately 40% of the residents in Tocantins were born in a municipality other than where they were residents between 2006 to 2008. Another 10% were born in the municipality where they were residing, but have also lived elsewhere. 24-26 Thus, the results from the study indicate that although many were born in another state or municipality and one-third migrated prior to diagnosis, population movement is significantly lower among individuals recently diagnosed with leprosy, as compared to the overall population in Tocantins. This finding may have positive implications for treatment adherence if translated effectively into public health practice, particularly the Information, Education and Communication (IEC) approaches. An earlier publication in the same study area found that residence change was associated with lower treatment adherence because patients would lose contact with community health workers and other health professionals in municipal clinics.²⁹ As such, the current decentralised service provision for both diagnosis and treatment, offered through the network of community health centres, enhances leprosy control in Tocantins and improves new cases detection. This potentially reduces incidence through retention and treatment of new cases in health care facilities, over the long run. There is a clear indication that the current leprosy diagnostic capacity is related to access to health centres.³⁰

The data further indicate that the majority of individuals moved within the same neighbourhood. The primary motivation was to purchase a home, which was strongest among those who stayed in the same neighbourhood. For those who remained in Tocantins, but moved to a different municipality, the purchase of a home was less often a motive and determining factor. In this context, it is important to remember that Brazil has a strong history of home ownership, with 74% of the population living in privately owned homes. Home ownership in Tocantins is comparable to the national average (71%), however home ownership among low income residents in Tocantins (those living on one minimum salary or less) is higher than the national estimates. The prevalent low-income status among more than half of the respondents could account for the importance of home ownership as a motive for residence change. An important finding of this study is that leprosy diagnosis does not seem to present a significant financial barrier in this regard.

In terms of living conditions, sanitation in Tocantins is less well-off than the country overall. Both rudimentary (57%) or no waste disposal (13%) are significantly higher in Tocantins compared nationally at 21% and 4% respectively. Poor household structure could precipitate movement for health reasons or otherwise. Future research should identify

whether better sanitation services and improved environment are important determinants for mobility among those diagnosed with infectious diseases.

Familial reasons were also a strong motive for moving, primarily for marriage or separation, caring for family members and to a lesser extent for spousal employment. Study estimates for relocation due to change in civil status is difficult to compare to governmental estimates as this process is often informal and outside of the judicial system. In Tocantins, 84% of cohabitation arrangements are unmarried spousal relationships.³⁸ Interestingly, the small number of residence changes due to divorce or separation in the context of the overall sample did not appear to be a significant reflection of stigma from intimate partners due to leprosy diagnosis. Additionally, this concept is strengthened by change in residence due to marriage after recent diagnosis.

Internal migration for employment has traditionally been a significant factor in migrant flow in Brazil. ³³ Despite new leprosy diagnosis, employment remained an important motive for migration among respondents in the study. Socioeconomic changes in Brazil over the last 10 years include a stabilised Brazilian economy, increased household income, and improved job market also in the North and Northeast of the country ³⁴ where the majority of clusters of highly endemic areas for leprosy transmission have been identified. ²⁷ These influences have changed the landscape of migration in Brazil, historically from the North and Northeast to Southeast metropolitan centres. ³³ A decrease in long-distance migration, particularly among the low income population with a preference for the North and Northeast urban centres, has made population movement less costly but perhaps more accessible. ³³ Growth in construction nationally ³⁴ and the agricultural sector has played a significant role in attracting labour, with agriculture employment reversing migration to rural-rural and urban rural flow. ³³ Shorter distance migration often allows labour migrants to maintain relationships with their home municipality health centres where relationships have been established.

Few respondents changed residence to seek better treatment and/or due to stigma. Stigma is common in countries most affected by leprosy, ¹⁸ sometimes prompting complete temporary or permanent withdrawal from the community. Both self-imposed withdrawal and complete banishment from family and social networks has been noted in research in India ³⁵ and Nepal. ¹⁹ Recent policy change in Brazil has likely had an impact on early diagnosis and stigmatization as a result of visible physical symptoms and disability. The majority of respondents presenting with Grade 0 disability at diagnosis demonstrates early diagnosis in most cases. Additionally, the adoption of the term 'Hansen's disease' instead of 'leprosy' by the Ministry of Health, and IEC campaigns consistently implemented throughout Brazil, may have been a contributing factor to reducing stigma and thus population movement as a consequence of discrimination. ³⁶ While it could be argued that subconscious motivations or implicit actions in changing residence for employment or family may be a protective factor for the individual and as a response to culturally constructed social stigma, the majority of respondents' focus on movement as an effort to make positive improvements to their life conditions appears to be consistent with the overall population in Brazil.

Our study is subject to some limitations. We only included those respondents living inside the endemic cluster where the study was conducted and did not analyse data from other municipalities such as the state capital. Those respondents who moved to a municipality outside the cluster after diagnosis could therefore not be included in the sample.

In conclusion, Brazilian policy changes offering decentralised leprosy control and treatment campaigns accompanied by IEC efforts aimed at reducing stigma, appears to have affected the reduction in residence change/mobility among those newly diagnosed with

leprosy in central Brazil. Improved socioeconomic conditions in the country facilitating employment, opportunities to improve the quality of life, and strong socio-cultural influences in Brazil, such as home ownership and strong familial bonds in individuals with leprosy appear to be comparable to the population in general. Serious illness is often a turning point in the life course of an individual leading to overall life changes that include the taking of personal responsibility for both the physical and emotional self and family. The extent to which positive motives for personal change are influenced by leprosy in newly diagnosed patients provides an opportunity for future research. Continued measurement of the impact of policy changes to decentralise services can surely support future interventions aimed at reducing the burden of leprosy. A focus on migration in future research could provide a fertile ground for policy assessment and development.

Acknowledgements

We thank Adriana Cavalcante Ferreira, Suen de Oliveira Santos and the entire team of the State Health Secretariat of Tocantins. Collaboration of the Municipalities' Health Secretariats and Primary Health Care Centers is acknowledged. We are also grateful to all patients that kindly agreed to participate in the study. The research project 'MAPATOPI' was financed by the *Conselho Nacional de Desenvolvimento Científico e Tecnológico* (CNPq) and the Department of Science and Technology of the Brazilian Ministry of Health (DECIT), Brazil. JH is research fellow from CNPq. OAC received a 'PEC-PG' scholarship from CNPq, ARO a Master's scholarship from *Fundação Cearense de Apoio ao Desenvolvimento Científico e Tecnológico* (FUNCAP), and CHA a PhD scholarship from *Coordenação de Aperfeiçoamento de Pessoal de Nível Superior* (CAPES), Brazil. Charles Kaplan of the School of Social Work at the University of Southern California provided insightful comments on the manuscript.

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