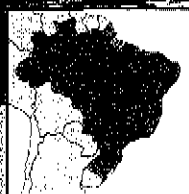


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The effects of leprosy on men and women: a Gender Study

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ABSTRACT

This study investigates the impact of leprosy on men and women in a sample of 202 leprosy patients in Ribeirão Preto, Brazil. The study found that leprosy exacerbated existing gender inequalities. The diagnosis caused an intensely negative emotional reaction among both sexes, but self-stigmatization was greater among women. Women also expressed greater concern than men about their physical appearance and more often refrained from social activities. The economic activities of women were also more severely affected, both within and outside the home. Women hid the disease more from their families, but once they had reported for treatment, they were slightly more likely to complete treatment regimens than men. Although the majority of all patients were on multidrug therapy (MDT), a slightly higher proportion of men were on MDT. Women were more concerned about the side effects of MDT in relation to alteration in skin pigmentation. The study demonstrates how a gender approach can improve understanding of the constraints facing men and women in relation to leprosy and it makes useful recommendations for health providers and the families of leprosy patients.

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The **Gender and Tropical Diseases Resource Papers** appear as part of a series of unedited final reports resulting from projects supported by the UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases (TDR). These reports are submitted to the TDR Task Force on Gender and Tropical Diseases for review and evaluation upon completion of a project. Project reports included in this series have not been published in their entirety elsewhere.

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Foreword

The UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases (TDR) is a globally coordinated effort to bring the resources of modern science to bear on the control of major tropical diseases. The Programme has two interdependent objectives:

- To develop new methods of preventing, diagnosing and treating selected tropical diseases, methods that would be applicable, acceptable and affordable by developing countries, require minimal skills or supervision and be readily integrated into the health services of these countries;
- To strengthen - through training in biomedical and social sciences and through support to institutions - the capability of developing countries to undertake the research required to develop these new disease control technologies.

Research is conducted on a global basis by multidisciplinary teams of researchers on the six diseases selected for special attention: malaria, schistosomiasis, filariasis (including onchocerciasis), the trypanosomiasis (both African sleeping sickness and the American form, Chagas disease), the leishmaniasis and leprosy, and "trans-diseases" areas, including Applied Field Research. The Gender and Tropical Diseases Task Force is one of the initiatives of the Applied Field Research Steering Committee.

The Gender and Tropical Diseases Resource Papers series represents a new communication venture undertaken by TDR's Gender and Tropical Diseases Task Force. This series has been launched to facilitate and increase communication among social and health scientists, and others interested in gender issues in health, and to disseminate findings from TDR studies to disease control personnel and government officials concerned with improving the effectiveness of tropical disease control.

Resource papers published in this series are final reports of projects funded by TDR and usually include more material than ordinarily published in peer review journal articles. TDR considers this material to be valuable, especially for researchers and disease control personnel in tropical disease endemic countries who require more complete information on a topic than is generally provided in shorter journal articles.

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Preface

This paper, the fourth of the Gender and Tropical Diseases Resource Paper series, was submitted as an entry in the Fifth IDRC-TDR Award on Gender, Health and Technology. The paper did not specifically address technology issues but it was considered to be a useful contribution to the area of gender and tropical diseases, and hence to merit inclusion in this series.

The study demonstrated that clear gender differences existed in the impact of leprosy, treatment and treatment-seeking behaviour in men and women. Though at opposite sides of the globe, the Brazilian research substantiates findings in India to the effect that women suffer more social stigma as a result of the disease and that their lives are more adversely affected than those of men.

Leprosy is one of the diseases earmarked for elimination as a public health problem by the year 2000. Understanding the gender issues that may inhibit women from early detection and treatment, and finding ways of coping with these constraints, are key to the successful attainment of this goal.

This study was funded by the Latin American Small Grants Programme for Social and Economic Research in Tropical Diseases, and demonstrates that a relatively small investment can bear significant fruits in terms of research and implications for improved disease control.



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INTRODUCTION

Several factors have motivated this study. Brazil has the world's second highest leprosy prevalence and incidence rates. This places a great number of people at risk of leprosy with potential accompanying biological, psychological, social and economic problems (Glatt et al., 1995; WHO 1993). The increase in prevalence of leprosy in Brazil and the consequent social and economic repercussions for those who have the disease are becoming recognized as devastating. There is also a general lack of knowledge about the disease, and specifically, about how it affects women and men differently. Current studies reveal a greater incidence of leprosy in men, although the number of reproductive age working women becoming infected is climbing.

Eliminating leprosy as a public health problem is a WHO goal for the year 2000, and the Brazilian government is working closely with the health services to meet this target. Nevertheless some regions have great difficulty developing programmes for leprosy treatment and control. There is a need to intensify efforts in the fight against the social stigma associated with the disease and to improve attitudes and knowledge of health workers caring for leprosy patients (Nogueira et al., 1995).

A gender perspective on the impact of leprosy recognizes the importance of family life and its role in socialization, as well as the development of health and social practices (Gomez, 1993; Rios, 1993). Where health is concerned, men and women have different needs and access to health care. The disease may cause changes in family structure, women suffering the greatest disadvantage (Srirak, 1997; Vlassoff et al., In press).

The purpose of this paper is to investigate, from a gender perspective, the effects of leprosy on men and women, as well to understand the biological, psychological and cultural implications of the disease for people's lives. It is hoped that the outcome of this paper may contribute to improved educational measures on the part of health services, thus reducing misconceptions and biased attitudes towards the disease.

METHODOLOGY

This study used both quantitative and qualitative research methodologies. Quantitative data was useful in characterizing the socio-economic profile of leprosy patients, whereas the qualitative information revealed private issues that could not be easily quantified.

Research was conducted during 1994 and 1995 in the city of Ribeirão Preto, São Paulo State, Brazil. The clinics studied encompassed 649 patients with active records enrolled in leprosy control and treatment programmes, distributed throughout the health services network. A sample of 202 leprosy patients (132 males and 70 females) above the age of 15 were selected for the study from the total patient population.

The study utilized two sets of procedures. First, a sample group of leprosy patients answered a structured, pretested questionnaire. While the patients waited for routine medical appointments, the researcher privately explained the objective of the survey. After the patient's consent was obtained, interviews were carried out.

In the second stage, 20 in-depth interviews (10 men and 10 women) were conducted and recorded.

Interviews offered patients a chance to describe their everyday lives. The interviews were transcribed and analysed under the following empirical categories: impact of the disease; patient's perception of appearance; marital relationships/support; and employment.

FINDINGS

Most of the sample (66%) was between the ages of 31 and 60. Some of the characteristics of the sample are presented in Table 1. The majority of the respondents received multi-drug therapy (MDT).

Table 1 - Characteristics of sample of leprosy patients according to sex

	Men		Women		Total	
	N	%	N	%	N	%
Clinical Form						
Virchowian	101	77	46	66	147	73
Tuberculoid	19	14	12	17	31	15
Undetermined	12	9	12	17	24	12
Treatment						
MDT	100	76	44	63	144	71
Conventional	32	24	26	37	58	29
Marital Status						
Single	22	17	16	23	38	19
Married/Cohabiting	98	74	39	56	137	68
Other (divorced, widowed, separated)	12	9	15	21	27	13
Religion						
Practicing	31	23	43	61	74	37
Non-practicing	101	77	27	39	128	63
Education						
Illiterate	12	9	14	20	26	13
Elementary schooling incomplete	58	44	46	66	104	52
Elementary schooling complete	41	31	4	6	45	22
Secondary schooling incomplete	12	9	1	1	13	6
Secondary schooling complete	9	7	4	6	13	6
Tertiary education incomplete			1	1	1	1

Most patients were married, and had lived in Ribeirão Preto for over 10 years at the same address.

The majority of respondents were Catholics living in large families with two or three of their own children. Most had not completed elementary school, and were employed as salaried workers with monthly family incomes between three and six times the minimum wage. Just over half of those surveyed lived in their own homes with up to five rooms, averaging 5.3 persons. The homes were located on the outskirts of the city with minimal comfort and lacking hygienic conditions. Those who did not own homes either rented or borrowed houses. Few patients reported knowing how they had contracted leprosy.

Gender differences in profile of leprosy in Ribeirão Preto

Based on the quantitative data, gender differences relating to the situational experiences were observed (see Table 1). The statistical tests revealed significant gender differences. Women were more likely to remain single, separated or widowed; living with children or relatives, and for longer periods at the same address. Men more commonly remained married or in cohabitation relationships, living with their children. Women were more dedicated to religion, and attended religious services more frequently than men. Although the men reported being religious, they were less likely to attend religious services on a regular basis.

Men were often the sole breadwinners, working regularly at occupations that entitled them to social security benefits. Monthly family incomes for men averaged 6 times the minimum wage. Unpaid domestic tasks which did not entitle women to social security and benefits were the most common occupations. Women who worked outside the home reported an average family income of 3.3 times the minimum wage. The majority of women contributed to the domestic economy regardless of their age, and only four of those interviewed received retirement benefits. Men had higher overall levels of education than women. The number of men who stopped working due to leprosy was higher than the number of women, as women were not registered workers.

Gender differences in treatment-seeking

In the health services dermatologists performed the clinical diagnosis and follow up on the evolution of the disease in patients. The dermatologists worked with a team of health workers who helped to control the medication, and guide health education. Therapy took place on an outpatient basis, in accordance with the criteria of the Ministry of Health's control and treatment programme. While the majority of the leprosy patients received MDT a considerable proportion of women were on a traditional less effective scheme. This difference was attributed to the women's preference to avoid the alteration in skin pigmentation, a side-effect of MDT treatment, which compromised their aesthetic appearance.

With respect to compliance to the treatment and clinic attendance, 70% of women and 60% of men complied with treatment. Forgotten appointments, undesirable side-effects, fear of medication, preference for alcoholic beverages, loss of work, and disbelief of the diagnosis were the reasons men gave for their absences. Women mentioned adverse reactions to treatment as the main impediment, followed by forgetfulness. Interestingly 24% of patients of both sexes lived in other cities, and travelled to Ribeirão Preto for treatment. These patients perceived the quality of treatment to be better in Ribeirão Preto. In addition, men reported fear of losing their jobs as a reason for going elsewhere for treatment, while women mentioned fear of the stigma attached to leprosy.

Among the leprosy patients studied, 64% of men and 51% of women ignored the initial signs of disease. The patients who suspected particular causes of leprosy pointed to relatives (father, mother, brothers, grandparents, aunts and uncles) as transmitters of the disease. In-laws were felt to be responsible for transmission by 12% of the men, and a further 13% attributed responsibility to their wives and children. Of women, 24% felt their husbands were responsible for giving them the disease.

The interviewees (54% of women and 46% of men) mentioned having other illnesses associated with leprosy such as arterial hypertension (more prevalent among women), gastric ulcers, epilepsy, sexually transmitted diseases (syphilis, gonorrhea, and AIDS), Chagas disease, diabetes, tuberculosis, dengue fever, scabies, emphysema, and others (Table 2). Poverty, poor living conditions, malnutrition and stress are known to enhance the existing illnesses whether contagious or not.

Perceptions of the impact of leprosy

The impact of the disease was clearly felt in the patients' everyday life. They considered leprosy a constant threat due to the uncertain outcome of the treatment. Social prejudices contributed to emotional and physical suffering, abandonment, deformities and psychosocial problems. Women were more likely to describe the disease as causing guilt and embarrassment, and many reported the desire to die. The contradiction encountered in the performance of gender-prescribed roles in the face of physical limitations resulted in feelings of guilt, and hence the search for religious absolution.

Religious beliefs appeared as a powerful panacea in helping individuals face physical and emotional afflictions. Geertz (1978) points out that belief does not preclude suffering, but rather provides meaning and significance to people's experience. Women appeared to hold on to religion as a source of support and understanding. They carried out rituals, which varied according to prevailing beliefs and were viewed as a means of repentance to reduce the punishment they believed they deserved. Loyola (1994) in a study of doctors and healers found "that being sick is being distant from God... and that God is not the cause, but has the power to cause the disease." Similarly in this study, the search for religion was markedly prevalent, as can be observed in the following statements:

"When I found out I had the disease I wanted to commit suicide, I wanted to die, I went crazy, I didn't work...I didn't want to feel guilty, it was horrible...from then on I clung to God... I am devoted to this day. I go to church three times a day. I made a lifelong promise. I devoted my son to God, my only son, the youngest... he is studying to become a priest." (Female, 49 years old)

Women worried about deformities as the disabling injuries made the disease visible, and daily functioning was impaired. For these reasons, women's position within the family and at work was jeopardized. For women failing to carry out domestic tasks, child care, and difficulty in fulfilling other family roles often led to abandonment by husbands and companions. This resulted in emotional breakdowns and a sense of being stripped of their attributes as competent women capable of completing gender-ascribed tasks (Whitaker, 1995; Vlassoff & Bonilla, 1994; Vlassoff et al., In press).

Men reacted to the impact of the disease with revolt, preoccupation, nervousness, distrust, anger, fear, and some with indifference. Their recognition of the disease represented a threat to their role as family providers. Fears of the loss of virility, weakness and loss of sexual potency were also reported. The 'invisibility' of the disease caused distrust and men, more than women, questioned

the reliability of the diagnosis, the effectiveness of treatment, and the care provided by the health services. These were reasons used to justify the irregular attendance, non-compliance with treatment, or the excessive use of alcohol as a means to escape. Some men, however, reported that the experience of the illness was a reason for reflection and restructuring their lives, creating a positive outlook towards the future and a sense of making up for lost time: *“I try to face life more seriously and savour more what I do.”* (Male, 37 years old)

Table 2 - Incidence of secondary illnesses in leprosy patients according to sex

Secondary Illnesses*	Male	Female	Total
Arterial hypertension	15	13	28
Intestinal worms	16	7	23
Cardiac deficiencies	6	1	7
Gastric ulcers	5	2	7
Sexually Transmitted Diseases	5	2	7
Chagas disease	1	4	5
Hepatitis	4		4
Diabetes	4		4
Arthritis	2	1	3
Herniated disc	2	1	3
Epilepsy	3		3
Mental illness		3	3
Anaemia	1	1	2
Dengue fever	2		2
Psoriasis	1	1	2
Tuberculosis	2		2
Labyrinthitis		2	2
AIDS	2		2
Other	6	3	9
Total	77	41	118

*some of the leprosy patients presented with more than one secondary illness

Perceptions about appearance

Almost all of the patients interviewed reported feeling distressed about the altered appearance caused by the disease and treatment. Often their appearance provoked speculation, curiosity and prejudice in others. It was these reactions to changes in appearance which patients reported to be causes for poor adherence to treatment programmes. The interviews revealed that patients blamed the occurrence of symptoms on physical and behavioural changes caused by the treatment. Patients

reported isolating themselves from society to avoid having to explain changes in their appearance:

“My mother would ask me what was wrong and I would tell her it was the sun. When I went out people would ask me what was wrong and I was always explaining myself, saying they were sun spots, that it was because of the beach and that bothered me. People wanted to know out of curiosity, but I didn't tell anybody, you know, I am very prejudiced too.” (Female, 50 years old)

Both men and women worried about their appearance, although this feeling was stronger among the women who preferred to conceal the problem with excuses or simply to hide themselves.

In Brazilian culture, standards of physical beauty are linked to moral standards; thus beauty is closely linked to goodness and ugliness implies evil. Changes in skin pigmentation as a side-effect of the medicine is considered a social burden since it requires explanations and drawing attention to reactions means that patients risk revealing the presence of leprosy. In this study women were more likely than men to hide the disease from their family. Health services should be aware of these factors, in order to guide and explain to patients that these side-effects are a part of the treatment process and tend to disappear after the completion of the treatment.

Perceptions about marital relationship/support

The family is a unit of society where people are linked by ties of affection and common interests. When a member of the family is threatened by an illness, it is the family that offers the necessary support to deal with the suffering. Leprosy can disturb sexual intimacy and cause negative consequences in the family. This may lead to a breakdown of the family and social relationships.

Reports of marital stresses caused by leprosy varied according to gender roles. Women said that the disease did not impede sexual relationships, but acted as a barrier to other manifestations of affection, such as kissing and caressing:

“The only thing that changed was the fact that I separated everything.. I sleep in the same bed as my husband, but I use separate sheets. After he asked the doctor, my husband and I have sex but we don't kiss. It's been two years since I kissed my husband and my daughter...” (Female, 33 years old)

Feelings of isolation, particularly from touching others, were also expressed by Indian patients (Vlassoff et al., In press).

For women, leprosy may result in decreased interest in sex, either because their own lack of interest or because of self-rejection. However, the disease did not prevent them from carrying out the sexual roles demanded of them by men. The sporadic refusal of women to fulfill their sexual roles due to physical exhaustion of excessive work, coupled with fatigue, often led men to seek sexual satisfaction elsewhere. This deepened women's feelings of rejection, lowered self-esteem and generated their fear of being abandoned, which in fact often occurred. Women were more likely to hold self-stigmatizing attitudes, giving rise to serious problems in their everyday lives, including hostility and the neglect of themselves or their families.

For the husbands/partners of the ill women, leprosy was not a reason for the cessation of sexual relations, but for the separation of personal items as a protective measure against contracting the disease. These measures constitute a paradox, considering that after medication is taken, *M. Leprae* is destroyed. These findings should be translated into educational programmes for leprosy patients

and their relatives.

Alterations to testicles and hormone levels may lead to the reduction of sexual activity and fertility for men. These are palpable changes with different effects from those of women. In Brazil, men are perceived as sexually active individuals, and the absence of an erection as a result of pain or oedema in the testicle region can lead to serious problems, often fulfilling preconceived fears and unleashing new ones. Men rarely knew of, or were prepared for, these possible changes. For many health workers, discussing human sexuality is problematic because of their own perceptions and prejudices. Patient sensitivity is required by health workers in order to facilitate an openness to acquiring new knowledge about sexuality.

In the face of sexual failure, men identified medication and age as the responsible factors and even transferred their guilt to women. Sexual malfunction constituted a greater problem to younger patients, as “the gender identity demands their active heterosexual activities” (Giffin, 1994). An inability to have sexual intercourse for the male partner raised the question of fidelity and often caused distrust: *“My wife keeps on demanding, fighting, saying that I have another woman; my life has turned into a living hell.”* (Male, 34 years)

In the face of the emotional instability caused by leprosy, the support of family members is important in fighting the disease and the suffering caused by the disease (Vlassoff et al, 1996). In accordance with the reports of women in this study, married couples had difficulty expressing their problems; as they often remained silent and avoided talking about the issue. For example, one woman from another city commented:

“My husband brings me here. He has already spoken to the doctor, but we haven’t spoken about it... it’s as if one didn’t know that the other one knows, a strange situation. I don’t say anything, we keep quiet, as if nothing was happening... our sexual relationship deteriorated a lot after the disease... He says: ‘Complete your treatment first, then we will go back to doing it’..” (Female, 25 years)

Women reported that they depended on the support of other women such as their mothers or sisters. At no time was the involvement of husbands or companions in the sharing of household tasks or worries mentioned as support in everyday life, nor were there words of tenderness, comfort or solidarity. In contrast, men counted on the support of their wives or mothers, since, in accordance with their gender roles, it was considered women’s responsibility to tend the sick. According to Vlassoff & Bonilla (1994), women are the major care providers in terms of family health.

Women live in an environment of uncertainty concerning the possibility of transmitting the disease to their children, and as a result preferred to hide the disease from them. Children tended to be angry or disappointed when they learned that their mothers were ill. As shown in Table 1, nearly three-quarters of men remained married or living with a companion as compared to just over half of the female respondents.

Perceptions about work

The majority of leprosy-affected women were married and had children. Despite their low salaries, women contributed to the family budget. Women were placed in a precarious position when they remained self-employed without registration. The emergence of the disease, along with physical manifestations made their activities in the home more difficult, and they were in greater danger of losing outside jobs when the disease manifested itself and became known in their place of work.

Some women preferred to quit their jobs before being identified as leprosy-affected. The same did not occur with men. Some men, however, mentioned difficulties in their jobs after the onset of the disease. In addition to physical manifestations, indisposition, depression and worries limited their productivity, which together with their treatment absences, put their jobs at risk. Therefore, many preferred to hide the disease in order to avoid being fired or given early retirement.

DISCUSSION

In this study, leprosy highlighted several gender imbalances. On one hand, it made the existing inequalities in the society more evident, and in contrast, it served as a catalyst for the occurrence of other problems in the biological, psychological and economic spheres. The disease resulted in both sexes living with similar situations, yet affected their relationships with "healthy" people differently. The experience of becoming ill has for centuries been stigmatizing to leprosy patients, and in Brazil, this situation has not changed.

Leprosy results in different manifestations among males and females. The diagnosis causes an intensely negative emotional impact. Especially for women, leprosy diagnosis causes self-stigmatizing attitudes and disturbs their psychological integrity. Stigma towards the disease has been influenced by historical attitudes that are filled with negative beliefs and values. Understanding that there are gender differences in the physical, psychological and social impact of leprosy can help to minimize this negative impact.

Identifying and analyzing data from a gender perspective can provide health workers with a more enlightened approach in terms of the care and treatment of leprosy patients. More comprehensive and caring attitudes and approaches to patients and their families is needed. These should help patients to understand that the physical changes, different for men and women, are related to the disease and that the medication may result in undesirable side-effects which decrease as the treatment progresses. It is also important that health workers be aware of the special sexual consequences of leprosy for men and women.

Since the prolonged intake of the medication often contributes to irregular attendance, or termination of treatment, it is important for families to understand that they must lend a great deal of support and motivation to patients. Health services should involve the patient's relatives in the treatment and control of the disease by supporting self-care and encouraging health maintenance (see also Vlassoff et al., 1996). Family members could be trained to help with the medication and to encourage compliance with follow-up visits. Health services could aid family members to help with the medication and to encourage compliance with follow-up visits. Health services could aid family members to provide care to family members, thus helping to prevent and control disabling lesions.

Understanding the physical changes in men and women is important when developing gender-sensitive information for patients. This could also relieve tension for patients and others and enable a more scientific comprehension of the consequences of leprosy. A gender-sensitive approach could contribute to greater acceptance of patients by the community and family. Clinics where leprosy is treated must also be attentive to the possibility of secondary infections that may present in patients, and conduct appropriate clinical examinations.

Health workers should encourage patients to express their concerns, in order to avoid descent into emotional instability. This could also decrease tension and crisis, which often lead to physical, psychological and social problems, including the breakdown of family and social relationships. It

is important that the health services be aware of the vital role that women play within the family, and take into consideration their predicaments in the development of leprosy control programmes. Another venue to pursue could be the mobilization of women to participate in community education programmes to help remove common misunderstandings regarding leprosy. By offering the general public simple and easily understandable knowledge regarding the disease, early diagnosis could be increased. Educational programmes should be directed towards the family as well as the patient.

As the diagnosis of the disease does not require sophisticated technology, leprosy is not viewed as a priority by institutions responsible for the training of health workers. In this study, the majority of leprosy patients had undergone a series of referrals, including several embarrassing examinations before a correct diagnosis was made. Such experiences, as well as unnecessary expense, time wastage, and emotional upset are largely responsible for negative feelings towards health services among leprosy patients. The results of this study may be used for the development of educational programmes for health workers, leprosy patients and their families, and as a basis for future investigation.

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