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The Impact of Leprosy on the Quality of Life of Patients Undergoing Treatment

O Impacto da Hanseníase na Qualidade de Vida dos Pacientes em Fase de Tratamento

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Abstract

The individuals with Hansen's disease experience situations of prejudice that, together with stigma and discrimination, culminate in social isolation and restrictions in social relationships. The aim of this study was to assess the perception of leprosy patients about their quality of life. This is a cross-sectional, quantitative study, whose convenience sample consisted of 94 leprosy patients, undergoing treatment, who attended health units in the city of Cuiabá, MT, Brazil. A structured questionnaire with sociodemographic data and information about the patient's knowledge about leprosy, prejudice, self-esteem and quality of life, was applied between April and August 2018.The results showed in the investigated population a predominance of males (55.3%), individuals with high school education (28.7%) and with an income ranging from 1 to 3 minimum wages (67%).The interviewees pointed out the side effects (44.7%) and the duration period (28.7%) as the greatest difficulty in the treatment. Most of the investigated (72.3%) had great knowledge about the disease, among which 26.6% had already suffered the leprosy reaction.40.4% of individuals were depressed and sad, and 69.1% had problems in employment after the diagnosis of the disease. When the quality of life was investigated, 45.7% of leprosy patients classified the domains evaluated between bad and very bad. Physical pain was associated with 43.7% of the individuals being unable to perform daily tasks. It can be concluded that leprosy causes suffering beyond pain and discomfort, with great social and psychological impact.

Keywords: Leprosy. Quality of Life. Combined Modality Therapy.

Resumo

Os pacientes com hanseníase vivenciam situações de preconceito que, com o estigma e a discriminação, culminam para o isolamento social e a restrição dos relacionamentos sociais. O objetivo do presente estudo foi avaliar a percepção do paciente com hanseníase sobre sua qualidade de vida. Trata-se de um estudo transversal, quantitativo, cuja amostra de conveniência foi composta por 94 pacientes hansenianos, em fase de tratamento, que frequentavam as Unidades de Saúde do município de Cuiabá/MT, Brasil. Um questionário estruturado com dados sociodemográficos e informações sobre o conhecimento do paciente sobre a hanseníase, preconceito, autoestima e qualidade de vida, foi aplicado entre abril e agosto de 2018. Os resultados mostraram, na população investigada, um predomínio de indivíduos do sexo masculino (55,3%), com ensino médio completo (28,7%) e com renda entre 1 e 3 salários mínimos (67%). Os entrevistados apontaram como maior dificuldade do tratamento os efeitos colaterais (44,7%) e o período de duração (28,7%). A maioria dos investigados (72,3%) apresentava grande conhecimento sobre a doença, dentre os quais 26,6% já haviam sofrido a reação hansênica. 40,4% dos indivíduos encontravam-se deprimidos e tristes e 69,1%, tiveram problemas no emprego após o diagnóstico da doença. Quando a qualidade de vida foi investigada, 45,7% dos hansenianos classificaram os domínios avaliados entre ruim e muito ruim. A dor física foi associada ao impedimento do desempenho das tarefas diárias por 43,7% dos indivíduos. Pode-se concluir que a hanseníase causa sofrimento aos indivíduos que ultrapassa a dor e o mal-estar estritamente vinculados ao prejuízo físico, com grande impacto social e psicológico.

Palavras-chave: *Hanseníase. Qualidade de Vida. Terapia Combinada.*

1 Introduction

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae*, which preferably affects the skin and peripheral nerves, with great potential to develop physical disabilities and evolve to visible deformities[1]. However, its transmission occurs through the upper airways, clinically manifested by skin lesions with reduction or absence of sensitivity, and the most common ones are pigmented spots, plaques, infiltrations and nodules[1,2]. The lesions may affect any place of the body, including the nasal mucosa and the oral cavity[2].

The manifestation of Hansen's bacillus is insidious, taking a prolonged incubation time between infection and skin reactions[2]. The time elapsed between contact with the bacillus and the development of the disease is estimated between two and seven years, with an average of between three and five years. Although the number of new cases detected worldwide shows a certain decline, some regions of Angola, Nepal, India, Brazil, Madagascar, Mozambique, the Republic of Central Africa and the Democratic Republic of Congo remain endemic[4]. Brazil recorded 30 thousand to 33 thousand cases of leprosy in 2013, according to estimates by the Ministry of

Health[3].

The geographical distribution of leprosy in Brazil is quite irregular and follows the poverty map, with a higher incidence in the North, Northeast and Central-West regions. The States of Mato Grosso, Tocantins and Maranhão were identified with a higher incidence of the disease in the country [5]. The State of Mato Grosso occupies the first place in the detection of new cases with the index of 7.69 cases for each group of 10 thousand inhabitants; a prevalence index 38% higher than that of the second place, the State of Tocantins and 34.9% higher than the Brazilian average. In the State of Mato Grosso, leprosy is highly endemic and is expanding[5].

The disease presents a millennial characteristic and is loaded with stigmas and taboos, referring to death and mutilation, prejudice, discrimination and social exclusion, culminating in a great mental suffering for the affected individuals, with serious repercussions on their personal and professional life[6]. At the beginning of the last century, due to the lack of knowledge of the forms of treatment, or even of the possibility of healing, the disease was an instrument of a series of actions performed by the State, which were currently seen as segregators and exclusionary. These actions consisted of the "sanitary exile" of the people who were committed by pathology in colony hospitals distributed throughout the country[1].

Leprosy is a disease of prolonged evolution and can lead the individual to physical disability, often caused by leprosy reactions. These reactions are changes in the immune system, exteriorized as acute and subacute manifestations, responsible for the functional loss of peripheral nerves and aggravating physical disabilities. Infections, hormonal disorders and emotional motivations are indicated as triggering factors for these reactions[7]. Although the implications of leprosy reactions directly on the quality of life of these people are recognized, since they produce pain, deformities, and work abstentions, there are still few prevalence studies about this problem[8].

Taking into account the hypothesis that the prejudice and degree of patient information about the disease may alter its healing process[9], the present study aimed to describe the feelings and perceptions involving the leprosy patient such as: prejudice, fear, the feeling of exclusion and the quality of life of Hansen's disease persons in an endemic area of the Central-West region of Brazil.

2 Material and Methods

This is a cross-sectional study with a quantitative approach. The study was carried out in a Reference Center for treatment of individuals with leprosy, from the Municipal Health Department of Cuiabá, Mato Grosso, Brazil. The study was conducted in accordance with the standards required by Resolution 466/12 of the National Health Council and approved by the Ethics Committee in Human Research of the School of Dentistry of Araçatuba- UNESP (CAEE: 36331714.0.0000.5420).

The sample size was calculated from the eligible population, considering the significance level of 5% and statistical power of 0.80, with a minimum confidence interval from 0.05 to 0.10 (*National Statistical Service & sample Size Calculator Definitions - NSS*). One hundred and eighty-five patients who attended the Reference Center from April to August 2018 were invited to participate in the study. The minimum population required was 63 patients.

As inclusion criteria, patients should reside in Cuiabá, have a civilian majority, the diagnosis of leprosy defined by the service's leprosy physician, be in polychemotherapy treatment (PQT) and sign the informed consent form. As exclusion criteria, patients with auditory or cognitive problems that made it difficult to understand the questionnaire.

Based on the inclusion and exclusion criteria, the population consisted of 94 patients.

After clarification of the purpose of the research and subsequent use of the data collected, the patients who agreed to participate in the study were informed of the purpose and confidentiality of the information collected and signed the informed consent form.

The instrument used for data collection consisted of a structured questionnaire built specifically for this research, with closed questions divided into categories and the following items were included in the interview: sociodemographic data, knowledge of the disease, social participation, stigma, self-esteem and quality of life. The first part consisted of data concerning the characterization of the subjects, related to their living conditions. The second was composed of questions about their knowledge about leprosy, treatment, perceptions and changes that occurred in daily life because of the disease. Finally, questions about the presence of leprosy reactional episodes throughout the patient's clinical evolution and whether these reactions interfered with the patients' quality of life. To validate the questions, 19 individuals with leprosy were interviewed. The interviews were then conducted by a single researcher and, individually, in a room reserved at the polyclinic itself, on the day of the patient's scheduling.

The data obtained were described in frequencies for the characteristic variables of the disease and sociodemographic data. The statistical analysis was carried out by highlighting the most relevant dimensions, using the frequency of the percentage index of the variables studied, using the bivariate analysis technique with the chi-square test, considering a significance level of 5%.

3 Results and Discussion

Leprosy is a millennial disease that leads to the patient's family and social isolation resulting from prejudice and discrimination. The history of isolation of leprosy disease persons is remote from time to time, where treatment was not known and the disease was uncontrolled. The stigmas of disease are distinguished from other diseases because they are always present in different times and societies[10,11]. The following individuals attended the current study, carried out in Cuiabá/MT: 94 patients who were in leprosy treatment, most of them male (55.3%), with ages ranging from 24 to 82 years, where 5 (5.3%) individuals were in the age range from 24 to 29 years, 17 (18.1%) from 30 to 39 years, 22 (23.4%) from 40 to 49 years, 18 (19.2%) from 50 to 59 years and 32 (34%) above 60 years old.

The poor health conditions of the population caused by social factors and socioeconomic conditions, such as the low educational level, make it prone to the development of incapacitating forms of the disease. [12-14] The predominance of leprosy diseases persons with low level of schooling was verified in this study, where most presented at most complete elementary education. As for the level of schooling, 23 (24.5%) were illiterate, 10 (10.6%) had incomplete elementary school, 19 (20.2%) had complete elementary school, 10 (10.6%) had incomplete high school, 27 (28,7%) had complete high school, 4 (4.3%) had incomplete higher education and only 1 (1.1%) had complete higher education. As for the employment situation, the majority was waged employees (41.5%), unemployed (25.5%), retired (19.2%), self-employed (11.7%), or student (2,1%). Regarding family income, 8 (8.5%) reported being less than one minimum wage, 63 (67%) from 1 to 3 wages, and 23 (24.5%) from 3 to 10 minimum wages.

In addition to the painful process of acceptance of the condition of having a contagious disease, the patients must face the challenge and difficulties of treatment for leprosy. When asked about the discovery of the disease, most 48 (51.1%) said they discovered why someone from the family, or close to social life, advised about the need to go to the doctor to have an appointment. However, 55 (58.5%) took time to seek care and the delay occurred because they thought it was not important (56.4%). All of them were treating, most of them to be cured (66%). Regarding the greatest difficulty in treatment, 42 (44.7%) reported to be the side effects caused by the medicines they were using. All the patients interviewed were undergoing treatment with polychemotherapy (PQT).

Leprosy produces changes in the body, making it possible to visualize it, and the body image is one of the fundamental components in the construction of the identity of the individual, which largely depends on the individual's relationship with his or her body[15]. In the present study, it was observed that Hansen's disease individuals showed discomfort due to changes in physical appearance, influencing their perception of themselves. Some study participants reported that after diagnosis their life changed dramatically. Regarding self-esteem, 63 (67%) of the interviewees reported to be depressed and 38 (40.4%) depressed and sad. 36 (38.3%) were no longer vain, 26 (27.7%) were afraid to die, and 87 (92.6%) were afraid to remain with some sequel. At work, 65 (69.1%) had problems, where 8 (12.3%) were dismissed, 16 (24.6%) were on leave, 33 (50.8%) suffered prejudice and 8 (12.3%) other types of problem.

Some study participants reported that after diagnosis their life changed dramatically. These changes are directly associated with the undesirable effects of drug treatment, such as skin darkening. Regarding the perception of the disease, most believed to be contagious (52.1%) and causing loss of sensitivity (21.3%). Regarding contagion, 64 (68.1%) of the patients stated that they were ill due to contact with a relative, or with a well-known patient and 25 (26.6%) of the patients had leprosy reactions (Chart 1).

Table 1 – Sample characterization: absolute and percentage numbers

Variables	N	%
How did you find out the disease?		
Went for an appointment for another reason	30	31.9
Someone has advised to have an appointment	48	51.1
Means of communication	8	8.5
Others	8	8.5
Did it take long to seek assistance?		
Yes	55	58.5
No	39	41.5
Why did it take long?		
It was not important	31	56.4
Difficulty scheduling in UBS	6	10.9
Fear of discovering serious illness	18	32.7
Total	55	100.0
Are you doing the treatment?		
Yes	94	100.0
No	-	-
Why?		
To be healed	62	66.0
Fear of transmitting to someone	15	16.0
Fear of physical disability	16	17.0
Others	1	1.1
Total	94	100.0
What is the greatest difficulty in treatment?		
Transportation	16	17.0
Delay in scheduling	4	4.3
Delay in care	2	2.1
Side effects	42	44.7
Treatment time	27	28.7
There is no difficulty	3	3.2
Have you ever had leprosy reaction?		
Yes	25	26.6
No	69	73.4
Did you know the disease?		
Yes	68	72.3
No	26	27.7
Do you know another person who had the disease?		
Yes	68	72.3
No	26	27.7
Total	**94**	**100.0**

Source: Research data.

The disease awakens fear, discrimination and stigma to patients. This perception was shared by the great majority of patients (93.6%) who believed there was prejudice regarding the Hansen's disease persons. The lack of knowledge that the population has makes it difficult to accept, even those who abandon or refuse to treat themselves, and do not admit that they have the disease[14]. In our studies, interviewees reported that they omitted the condition of having the disease at work, because of shame or fear of isolation by their colleagues and of losing their employment, agreeing with another finding[16].

The main patient's reaction to discover the disease was the fear of physical deficiencies (39.4%) and rejection (25.5%) (Table 2). The individuals' knowledge about the disease is low[17]. It was observed in this study that a high percentage did not know the disease and that a small portion had discovered the disease through the media, which indicates the need for greater dissemination of information about leprosy by the media. As a disabling disease, some carriers have shown that the disease caused moderate pain through the body, jeopardizing the harmony of their life. On the other hand, in another study, the majority of respondents said that there were no difficulties concerning the treatment[9].

Table 2 – Sample characterization: absolute and percentage numbers

Variables	n	%
Do you think people in general know this disease?		
Yes	37	39.4
No	57	60.6
What did you know about the disease?		
I did not know	8	8.5
It was contagious	49	52.1
It caused loss of sensitivity	20	21.3
Incurable	16	17.0
Every patient is disabled	1	1.1
Did you know that after the beginning of treatment with PQT, the disease is no longer transmitted?		
Yes	94	100.0
No	-	-
Why do you think you got sick?		
Contact with sick relative	52	55.3
Contact with sick acquaintance	12	12.8
Does not know	30	31.9
Do you think there is prejudice with whom has the disease?		
Yes	88	93.6
No	6	6.4
When you found out that you had the disease what reaction did you have?		
None	9	9.6
Fear of dying	7	7.4
Fear of not being healed	7	7.4
Fear of rejection	24	25.5
Fear of physical disabilities	37	39.4
Fear of prejudice	8	8.5
Another	2	2.1
Total	**94**	**100.0**

Source: Research data.

It was observed in the population investigated that there was a significant delay for the beginning of treatment, and in most cases it took years to diagnose the disease, mainly because they thought it was not a serious disease. The delay in obtaining the diagnosis also constitutes a failure in the health system, which can be verified by the lack of professionals qualified for the early and accurate discovery of leprosy[18]. The early diagnosis of leprosy and the institution of adequate treatment prevent the evolution of the disease, thus preventing the installation of the physical disabilities caused by it[3].

The treatment using polychemotherapy (PQT), usually composed of Dapsone (sulphone) in association with Rifampicin, started in 1980 and is used by all people with leprosy in the world, since it generates a better result, faster, lower risk of drug resistance and is economically viable. It is important to emphasize that treatment is a right and is available in all SUS health units, and that from the moment the patient ingests the medicine, he or she stops transmitting leprosy [3]. According to Opromolla[19], in cases of Sulfone resistance, it is replaced by Clofazimine. All three drugs can produce side effects, which comprise from cutaneous to digestive alterations. In the specific case of Clofazimine, Opromolla[19] points out that, because it is a dye, there is the skin darkening, which is accentuated with the sun, and the drying of the same, leaving it more subject to eczematizations.

Individuals affected by a disease may suffer feelings of denial, anger, depression, frustration, emptiness, anxiety, which are behaviors and feelings that vary in intensity, duration and expression[17]**,** a fact observed in the present study, in which most patients became depressive. People with stigmatizing diseases have a life of double standards, because only a few people close to the bearer are chosen to know about their state. The concern for confidentiality is a very common situation among these individuals, caused by the fear of being seen as having an incurable disease, or leaving them sequels, thus leading them to isolation by fear of bad treatment and rejection[20]. Concern with prejudice was also perceived in the fear of telling the disease for the family itself (52.1%). Of these, fear was that of rejection (63.3%), shame (26.5%), or isolation (10.2%). 90 (95.7%) felt that people were afraid to come closer. However, 91 (96.8%) reported having support from the family, or from the companion (66%).

The concealment of the disease occurs mainly due to the fear of the individuals experiencing situations of exclusion. This attitude may encourage social isolation as a defense and protection against suffering[21]. In the present study, one patient revealed that she suffered prejudice in employment after the diagnosis of the disease, because she had to leave the work once a month to perform the treatment and because it was treated for leprosy, she was dismissed without a just cause. The number of individuals made redundant from work, or on leave after diagnosis, shows the great human suffering resulting from exclusion and prejudice in the working environment, corroborating other authors [9,22]. The stigma that accompanies the disease since the most remote times continues to be part of the individuals' psychism with them, and a clear prejudice exists in the way in which individuals see themselves and are seen by the others[18,22].

In the specific case of leprosy, this characteristic of beliefs acquires significant complexity. Because it is a disease recognized as being present for centuries in the history of humanity, beliefs with strong stigmatizing content have been constructed, which have caused violent situations of which one is known in the present day, based on records in several sociocultural groups[23].

In order to determine the reliability and discriminant validity of the WHOQOL-BREF questionnaire, leprosy patients were included in a study as a comparison of the groups, since the previous reports showed a low quality of life in leprosy patients[24]. Leprosy presents a great potential to cause physical disabilities that may evolve to deformities, and as a result of a lower quality of life. In the present study, impairment in the quality of life of leprosy patients was detected, especially in the domains physical aspect limitation, pain, emotional aspect and capacity for work, in agreement with another study[25]. These findings are associated with the installation of disability and physical deformities that result in severe disabilities, disadjustments and marginalization of these individuals, and may exclude them from social life[26].

In the interview on quality of life, most patients presented the "bad" dimension (37.2%). Regarding the hindrance of activities due to physical pain, 39.4% presented the "quite" dimension. Still, 62.8% were dissatisfied with health, 48.9% thought that life had "little", or "small" meaning, 46.8% often had negative feelings and 46.8% were dissatisfied with the ability to work (Table 3).

Table 3 – Sample characterization: absolute and percentage numbers

Variables	n	%
How would you assess your quality of life?		
Very bad	8	8.5
Bad	35	37.2
Neither bad nor good	24	25.5
Good	27	28.7
How much do you think your pain (physical) prevents you from doing what you need?		
Nothing	8	8.5
Very little	11	11.7
More or less	34	36.2
Quite	37	39.4
Extremely	4	4.3
How satisfied are you with your health?		
Very dissatisfied	9	9.6
Dissatisfied	59	62.8
Neither satisfied nor dissatisfied	24	25.5
Satisfied	2	2.1
How much do you think your life has a meaning?		
Very little	7	7.4
More or less	39	41.5
Quite	48	51.1
How often do you have negative feelings such as bad mood, despair, anxiety, depression?		
Never	2	2.1
Sometimes	34	36.2
Always	3	3.2
Often	44	46.8
Very often	11	11.7
How satisfied are you with your work capacity?		
Very dissatisfied	16	17.0
Dissatisfied	28	29.8
Neither satisfied nor dissatisfied	23	24.5
Satisfied	22	23.4
Very satisfied	5	5.3
Total	**94**	**100.0**

Source: Research data.

Leprosy reactions are changes in the immune system, which are externalized as acute and subacute inflammatory manifestations, caused by the immune system performance. In the present study, 25 (26.6%) of the patients had already had this reaction. A statistical association was observed between the presence of leprosy reaction with some degree of impairment of quality of life, with these patients presenting a bad or very bad dimension in almost all of them. The majority of those without reaction history presented without prejudice to the quality of life (p=0) (Table 4).

Table 4 – Results of the crossing among the questions

How would you assess your quality of life?	**Have you ever had leprosy reaction?**				**p-value**
	Yes		**No**		
	N	**%**	**n**	**%**	
Very bad	8	32.0	-	-	<0.001**
Bad	15	60.0	20	29.0	
Neither bad nor good	1	4.0	23	33.3	
Good	1	4.0	26	37.7	
Total	**25**	**100.0**	**69**	**100.0**	**-**

** Ratio of maximum likelihood.

Source: Research data.

An association was also found between perception of work capacity and problems in employment (p=0.001) (Table 5). A study that evaluated the quality of life in patients with leprosy concluded that this disease causes great damage to people's daily lives and interpersonal relationships, causing suffering that exceeds pain and malaise linked to physical injury, which causes great social and psychological impact. This damage in quality of life is more important associated with the most severe forms of the disease, such as multibacillary, leprosy reaction and physical disabilities[25].

Table 5 – Results of the crossing among the questions

How satisfied are you with your work capacity?	Problems at work?				p-value
	Yes		No		
	N	%	N	%	
Very dissatisfied	6	9.2	10	34.5	<0.001**
Dissatisfied	17	26.2	11	37.9	
Neither satisfied nor dissatisfied	17	26.2	6	20.7	
Satisfied	21	32.3	1	3.4	
Very satisfied	4	6.2	1	3.4	
Total	**65**	**100.0**	**29**	**100.0**	**-**

** Ratio of maximum likelihood.

Source: Research data.

Health education aimed at making information clear and simplified about leprosy should be part of the educational programs developed for the population. Lack of information makes the patients to take long to seek assistance. Therefore, it is of paramount importance to guide and clarify all health professionals regarding care in treatment of people living with leprosy, especially that the professional-patient bond be humanized, based on sincerity and trust, favoring the treatment and improving the patient's quality of life.

In order to fully recover the health of leprosy patients, a multidisciplinary approach is needed to seek the physical, psychological and social restorations of these individuals and effective prevention actions that reduce the impact of the disease. It becomes healthy and of fundamental importance to offer a work in the public network with a health team, which promotes health education to the general population and contributes significantly to the discovery of the values of these subjects as being members of society, helping them in their process of reintegration and social reinsertion.

4 Conclusion

It can be concluded that leprosy causes suffering beyond pain and discomfort, with great impact on the quality of life of the individual affected by the disease. The Hansen's disease people need to rescue their bonds and values, recover their self-esteem, share feelings and connect, seeking reintegration into the real world.

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