



Perception of leprosy in patients and their families

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Abstract

This research purpose was to verify if declines the patient's quality of life and the disease perception by this and their families through questionnaires. It was used Dermatology Life Quality Index questionnaire in 50 patients and other semi-structured questionnaire to 21 family members attending a Reference Health Center in leprosy of Ceara, Brazil. The majority of patients reported that were little or not at all affected in different points raised. There were differences in the responses of family members according to their level of education. It was concluded that the structured questionnaire did not portray the reality of patients because in listening to these, it was noticed that they suffer in many ways, and their quality of life is affected by the disease, even with support of family and having more insight into the disease.

Keywords: Leprosy; Prejudice; Rejection.

Introduction

The prevalence of 5,2 millions in 1980 decade to 200.000 in the last 8 years, although was considered an eradicated disease, it is still a public health problem. 81% of new cases are concentrated in countries like Brazil, India and Indonesia⁽¹⁾. Leprosy is a chronic infectious disease with big repercussions in patient's life like: physical disability, bad social representations, psychological traumas and stigmas. Leprosy has a medical, a psychological, a social and a public health dimension. For all these reasons, is relevant to investigate Health-Related Quality of Life, to know which aspects of Life Quality are being reduced by the treatment or the traumas⁽²⁻³⁾.

Leprosy seems to have a tendency for the detection rates to stabilize in Brazil, although still keeps high levels in the North, Midwest and Northeast. Ceara State in 2012 had 2.136 new cases with the detection rates ranged from 24.82 cases per 100,000 population and in Fortaleza capital with rating 24.4/100,000 in 2012⁽⁴⁾.

Stigma may lead persons to a social segregation similar to a non racial, but sanitarian apartheid, directly related to adherence and success treatment. The adherence to treatment it is related to how the leprosy patient deals with the disease in their social and family context. Right after the patient starts the therapy, the disease is not transmitted^(2,5).

Stigma is not only a visual perception of a body deformation, this is the public side of stigma. When stigma is internalized with prejudices and the persons became negative about themselves the stigma reached the moral reputation of who has that perceived body deformation⁽⁶⁾.

This public side of stigma was always connected sanitary practices, sometimes segregating leprosy in colonies and accepted for majority of society. In Ceara State there are two old leprosy disable colonies: Antônio Diogo e São Bento. They had leprosy patients. They were separated from their families and social groups. Today, these old disable colonies are in peripheral neighborhoods of the State capital. Although recently, a study, found recently the persistence of stigma in Ceara's interior⁽⁶⁻⁷⁾.

In Sobral, a county in Ceara State, a study called attention for the stigma reproduced through a call for the participation of people in the 6 local clinics for the "skin spot day" to awareness of symptoms to early detection of leprosy. In this small city, leprosy patients were associated to a skin spot and the ambiguity of this term may have had the effect of stigma in bible: leprosy associated to spots and social segregation⁽⁶⁾.

For the World Health Organization health concept is not an absence of disease, but is a mental, social and physical well being. The health is not only a biological prism, but is also a social perception about health too. ⁽¹⁾.

In leprosy disease, the social perception, the physical problems affects mental health and the prejudice lead these persons to low self esteem, shame and a necessity to hide from society. When the most affected is psychological, you need to treat ideas and concepts patient has about the disease too, together with the diagnosed illness.⁽⁶⁻⁸⁾

Identifying these ideas about the disease it may be possible to fight the burden of social and internalized stigma in patients and their families⁽⁶⁾.

This study used a questionnaire to understand about patient's quality of life and to know if personal and familiar life it was affected in aspects related to stigma's problem.

Method

It was conducted an epidemiological cross-sectional quantitative and qualitative research at the Centro de Referência Nacional em Dermatologia Santiária Dona Libânea, Fortaleza, Ceara, approved by the ethics committee, with protocol number 027/09.

Fifty patients and 21 familie members of both sexes participated and were heard in semi-structured interviews.

Patient inclusion criteria for the study it was the leprosy clinical or histological diagnosis and have started the multi-drug therapy treatment who voluntarily agreed to participate in the study. No selection was made based in the different clinical forms of leprosy.

Dermatology Life Quality Index questionnaire was used to the patients, validated to brazilian portuguese, made with 10 questions about everyday life and scores are interpreted as: no reduction in quality of life (0-1) ou low reduction (2-5), moderate (6-10), severe (11-20) ou very severe (21-30)⁽⁹⁾.

Patient's family inclusion criteria used it was being with a patient who have started the leprosy treatment. To the families it was used a questionnaire elaborated by the researchers with questions about about knowledge, prejudice and relation with the patient.

In this study was applied Dermatology Life Quality Index and there was some informal conversations with patients.

Results

In 50 patients who participated of study, 56% (N=28) it was female and 44% (N=22) male, the age vary between 8 to 88 years old. Dividing them into five age range approximately of 10 years groups, 10% (N=5) who participated had between 8 to 17, 26% (N=13) had between 18 and 29 anos, 18% (N=9) had between 30 to 39, 28% (N=14) had between 40 and 59 anos and others 18% (N=9) had between 60 to 88 years old.

About patient's educational level, 74% of them have not started the high school. Of these 74%, only 6% ended the elementary school. Only 26% of them have ended high school and none had higher level or have started a college or university.

Half (50%) of Dermatology Life Quality Index results was that disease has a small or moderate effect on patient's life, 26% was that disease affected very large or extremely large their lives and 22% was that disease has no effect at all on patient's life. Most of male (71%, N=16) answered that the disease had a little or moderate effect, 20% (N=4) answered that the disease had a lot or very much effect on their lives and 9% (N=2) answered that the disease had no effect at all. Most of female 39% (N=11) has a small or moderate disease effect on their lives, 29% (N=8) has a very large or an extremely large effect on their lives and for 32% (N=9) disease had no effect at all on their lives. These differences between male e female has statistical significance according to Fisher's exact ($p < 0,05$).

Dermatology Life Quality Index evaluates several aspects of patient's life as symptoms feelings, emotions, daily activities, leisure, word or school, personal relationships and treatment. Each of these was categorized according to this several aspects of Dermatology Life Quality Index. For 26%, symptoms feelings was a lot or very much bothering, 32% was a little bothered and 42% was not bothered about it. About the emotions, 26% felt a lot or very much affected and other 26% felt a little affected and 48% was not affected.

In daily activities as perform activities inside or outside home, 20% felt a lot or very much affected, the other 20% felt a lot or very much affected and 60% felt no effect. On daily activities like to dress up and clothes choice, 20% have changed a lot the way they dress, 10% have changed a little and 70% haven't changed. In leisure and social activities, 28% felt affected a lot or very much, 20% a little affected and 52% was not affected. Regarding the practice of sports, 20% was affected a lot or very much, 10% a little affected and 72% was not affected.

At work or at school, 28% felt a lot or very much affected, 16% felt a little affected and 56% was not affected. In personal relationships (with friends and family) 20% a little affected and other 20% felt a lot or very much affected. In sex life, 86% said was not affected, 8% a little and 6% a lot or very much affected. In the loss of time because of the treatment, 18% was a lot or very much affected, 18 % a little affected and 64% was not affected.

The majority of the family member who accompanied the patient was between 30 and 80 years old, most of them between 40 and 59 years old (43%, N=9), 81% (N=17) was female and have not secondary education (62%, N=13). 39% (N=13) of family patients who had only primary education level, knew about leprosy transmission. Only 12% (N=1) of family patients who had secondary education, new about leprosy transmission.

Regarding the leprosy cure, all family members knew had a cure. When asked about heredity, 23% (N=3) who had primary education level said they believe leprosy is hereditary. Only 12% (N=1) who had ended secondary education said they believe leprosy is hereditary. Asked if they heard about leprosy before they relative gets sick, 31% (N=4) who had primary education level said they heard about the disease before and 63% (N=5) who had secondary education said they heard about the disease before.

Who had primary and secondary education level have not changed their relation with the family member who has leprosy and was not shame of having a family member who has leprosy. Right after they knew diagnosis, 15% who had primary education level, said they felt prejudice, who had ended secondary education said they never felt prejudice (100%). When asked if was shame of having leprosy disease, 37% (N=3) who had secondary education level answered they would be ashamed, as who had primary education level 23% (N=3) would be ashamed.

Discussion

In this study both male and female accepted to respond the questionnaire. But the answers about leprosy disease in female and male lives was very different: 32% of female answered that leprosy disease had no effect in their lives and only 9% of male answered the disease had no effect in their lives, these values has statistical significance according to Fisher's exact ($p < 0,05$).

The majority of respondents (28%) was between 40 and 59 years old. This age was already expected because leprosy is a disease caused by a bacillus with a long incubation period, on average, is 5 years ⁽¹⁰⁾. A small part of respondents was children under ten years of age, but it doesn't mean there was only few cases of children, but it meant it was difficult to reach this group in the research because the children should have shown interest in participate by themselves and parents should have authorized the participation too.

Some patients, in this study, said they had moved away from places they used to go or live in Ceará's interior, to treat their disease in Capital because they suffered prejudice from neighbors and co-workers. Leprosy treatment is considered easy to access for all patients, but there is a lack of information for general population, letting false concepts and prejudices still persists in society. This reflects on daily activities like to dress up and clothes choice, which 20% felt a lot or very much affected, and 28% answered have felt affected in activities like leisure and in work or school, demonstrating to be affected in social interaction aspects or having difficulty in socializing with people.

Regarding the practice of sports, only 20% answered have felt affected a lot or very much. However, many of interviewed said they have not practiced sports before the disease and after fall ill, have not begun to practice sports. It is important to considerate that even validated to Brazilian Portuguese, the Dermatology Life Quality Index questionnaire, it is restricted to general questions about dermatological patient's life and is limited, unable to reach moral, socioeconomic or contextual matters that can deepen these topics involved in life quality as a concept, or an area of knowledge.

The result of having been affected in relationship with friends or relatives is in agreement with friends or sexual life because only 6% responded that they were very or very much affected. Among these, some said they had been left by their partners and had no sex life.

Majority of patients' companions were housewives, mothers or patients' wives and the answers had different moral values according to the educational level. This different moral value according to the educational level was very clear when 100% who had secondary education level said they never felt prejudice and 15% who had primary education level said felt prejudice. And about the transmission of disease the values were different too, according to education level. Currently much research is being done on genetic factors of the host that may be associated with susceptibility to leprosy or the more severe form of the disease,⁽¹¹⁻¹²⁾, which may be framed as a genetic disease, produced by changes in DNA, but not acquired by the parents, which causes conflict in popular knowledge about the transmission of the disease.

In specialized literature there is still much discussion about transmission, with the airways transmission being established, but it is already known that environmental and genetic factors of the host and strain are involved, requiring further research in these areas⁽¹²⁻¹⁵⁾. Thus, companions of patients with higher education level, had already questioned information on the transmission was provided to them and had doubts about the correct answers, while a bigger number of individuals with primary education level affirmed to know how the disease was transmitted, but their responses were often based on associations to real life experiences, not to official informations, like when they were questioned about heredity, some (23%) answered they were sure leprosy could be transmitted from generation to generation. When were companions of patients with secondary education level, only (12%) said it is heredity.

Leprosy patients sometimes don't believe in cure and fear to contaminate other people who they are closely^(6,7,16). However, all companions of patients of all education level, when asked about this fear, answered they are not afraid of contamination after the beginning of treatment, what reveals the companions are very elucidated about contamination, more than about transmission.

When asked about how they react to leprosy diagnosis, the majority of respondents ⁽⁷⁾ said they felt sadness, discouragement, surprise, amazement, shock, worry and fear, mainly due to the prejudice that still permeates this disease, these feelings can be extended to family members by explaining the fact that at the time of the diagnosis, some of these members reacted with prejudice, those who were primary educational level.

When a physical illness occurs, represents a loss of control over your own body and your own life and in a chronic disease, people have an altered view of themselves, their relation to the future and to their projects of lives, so In this study it was observed how human being reacts differently about yourself ^(6,7,16).

During the course of this study, many of leprosy patients complained about social relationships, for example, taking a bus, some people were moving away or looking strangely. Even in church interactions some of them felt distancing coming from other people, some prefer not to go out home to be secret about the illness. Some women complained about have been left by their husbands, and some husbands said their wife were more close to them. By these narratives during the conversations when the questionnaires were applied, it could be well-marked the both sides of stigma: the public side, when the patient feel bothered about other people behavior, look or attitude with the person and stigma internalized, when the patient prefers not to go out from home to avoid a stigma already felt by the patient.

Leprosy is a millennial disease known and feared mainly for its deforming characteristics, it was hoped to find, in this research, obvious answers as to know how much or very much the disease affected the patient's life. However the results were very different than many surveys^(16-19, 7). This can be explained by the evaluation tool chosen, the Dermatology Life Quality Index, because this only refers to the last week of patient's life. In this way, it is perceived that Dermatology Life Quality Index at least is not a sufficient tool to assess quality of life and stigma this patients suffer. For WHO quality of life is measured in six broad domains (physical health, psychological, level of independence, social relations, environment and personal beliefs).

Conclusions

O Dermatology Life Quality Index is not a tool that encompasses the concept of life quality, although this is its denomination. Dermatology Life Quality Index is used as one of the information tools on the quality of life of the patient when the doctor and other health professionals want to inform themselves, but it is perhaps exaggeration to name the tool of qualification of patient's life, even because questions are chronologically about the last week of the patient, not replacing the idea of quality of life to be subjective and, especially in diseases that are linked to stigma, the quality of life should be evaluated in conversations rather than by index. Despite all, results demonstrated that patients undergoing treatment for leprosy suffer in several aspects (social, psychic, everyday, etc.), and their quality of life is affected by the disease, even if they have family support and these familiars are more informed about the illness.

Referências

- [1] World Health Organization. Weekly epidemiological record. 2014; 89(36): 389-400.
- [2] Batista TVG, Vieira CSD A, Paula MABD. - Body image in educational actions in self-care for people who had leprosy. *Physis: Rev de Saúde Coletiva* 2014; 24(1): 89-104.
- [3] Cid RDDS, Lima GG, Souza AR, Moura ADA. - Percepção de usuários sobre o preconceito da hanseníase. *Rev Rene* 2013; 13(5): 1004-14.
- [4] Secretaria de Saúde do estado do Ceará. Informe Epidemiológico Hanseníase. 2013.
- [5] Lustosa AA, Nogueira LT, Pedrosa JI, Teles JB, Campelo V. - The impact of leprosy on health-related quality of life. *Rev Soc Bras Med Trop* 2011; 44(5): 621-6.

- [6] Nations ML, Lira GV, Catrib AMF. - Stigma, deforming metaphors and patients' moral experience of multibacillary leprosy in Sobral, Ceará State, Brazil. *Cad. Saúde Pública* 2009; 25(6): 1215-24.
- [7] Lopes CB, Carmo TMD, Nascimento E, Maia MAC, Goulart MJP. - Percepções e Significados do Diagnóstico e Convívio com a Hanseníase. *Ciência et Praxis* 2010; 3(6): 13-8.
- [8] Alencar OM, Heukelbach J, Pereira TM, Barbosa JC. - Trabalho do Agente Comunitário de Saúde no controle da hanseníase. *Rev. Rene* 2012; 13(1): 103-13.
- [9] Ekelund M1, Mallbris L, Qvitzau S, Stenberg B. - A higher score on the dermatology life quality index, being on systemic treatment and having a diagnosis of psoriatic arthritis is associated with increased costs in patients with plaque psoriasis. *Acta Derm Venereol* 2013; 93(6): 684-8.
- [10] Rodrigues LC, Lockwood DNj. - Leprosy now: epidemiology, progress, challenges, and research gaps. *Lancet Infect Dis* 2011; 11(6): 464-70.
- [11] Misch EA, Berrington WR, Vary JC Jr, Hawn TR. - Leprosy and the human genome. *Microbiol Mol Biol Rev* 2010; 74(4): 589-620.
- [12] Cardoso CC, Pereira AC, de Sales MC, Moraes MO. - Leprosy susceptibility: genetic variations regulate innate and adaptive immunity, and disease outcome. *Future Microbiol* 2011; 6(5): 533-49.
- [13] Alter A, Grant A, Abel L, Alcaïs A, Schurr E. Leprosy as a genetic disease. *Mamm Genome*. 2011; 22(12): 19-31.
- [14] Pushpendra SP, Cole ST. - *Mycobacterium leprae*: genes, pseudogenes and genetic diversity. *Future Microbiol* 2011; 6(1): 57-71.
- [15] Hall BG, Salipante SJ. - Molecular Epidemiology of *Mycobacterium leprae* as Determined by Structure-Neighbor Clustering. *J Clin Microbiol* 2010; 48(6): 1997-2008.
- [16] Marinho FD, Macedo DCF, Sime MM, Paschoal VDA, Nardi SMT. - Percepções e sentimentos diante do diagnóstico, preconceito e participação social de pessoas acometidas pela hanseníase. *Arq. Ciênc. Saúde* 2014; 21(3): 46-52.
- [17] Nunes JM, Oliveira EM, Vieira NFC. - Hanseníase: conhecimentos e mudanças na vida das pessoas acometidas. *Ciência & Saúde Coletiva* 2011; 16(Supl 1): 1311-8.
- [18] Sá MB, Siqueira VHF. - Hanseníase, preconceito e parrhesia: Contribuições para se pensar saúde, Educação e educação em saúde. *Ciência & Educação* 2013; 19(1): 231-47.
- [19] Palmeira IP, Queiroz ABA, Ferreira MA. - Marcas em si: vivenciando a dor do (auto) preconceito. *Rev Bras Enferm* 2013; 66(6): 893-900.