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PERCEPTION OF STIGMA AND SOCIAL IMPACTS ON INDIVIDUALS WITH HANSEN'S DISEASE

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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. This study aimed to evaluate the perception of stigma in individuals with Hansen's disease and its social repercussions. It was configured as a qualitative study, by means of semi-structured interviews with 20 users registered to chemotherapy treatment in reference units of Zona da Mata Mineira, in the first half of 2014. The analysis was performed through content analysis and the following categories were defined: Lack of knowledge about the disease; Diagnosis and cure; Discrimination and fear; Concealment of the disease; Social support; and Bond and social participation. Lack of knowledge about the disease interferes with the individual's ability to cope with it, and coupled with fear of discrimination, it was enough for them to conceal their diagnosis from others. Thus, it was not possible to notice any changes in their social bonds. The different emotional reactions at the moment of diagnosis stood out, in addition to the emphasis on healing given by respondents. In this study, it became clear that the concealment of the disease and the social support acted as protective factors that prevented moments of discrimination and restriction in social participation.

Keywords: Leprosy; stigma; social issues.

PERCEPÇÃO DO ESTIGMA E REPERCUSSÕES SOCIAIS EM INDIVÍDUOS COM HANSENÍASE

RESUMO. Os portadores de hanseníase vivenciam situações de preconceito que, com o estigma e a discriminação, culminam para o isolamento social e a restrição dos relacionamentos sociais. Este estudo teve o objetivo de avaliar a percepção do estigma nos indivíduos com hanseníase e suas repercussões sociais. Caracterizou-se por um estudo qualitativo mediante aplicação de entrevistas semiestruturadas em 20 usuários cadastrados para tratamento poliquimioterápico nas unidades de referência na Zona da Mata Mineira, no primeiro semestre de 2014. A análise foi realizada por meio da análise de conteúdo e foram definidas as seguintes categorias de análise: Desconhecimento sobre a doença; Diagnóstico e cura; Discriminação e medo; Encobrimento da doença; Apoio social; e Vínculo e participação social. O desconhecimento sobre a doença interfere no enfrentamento por parte dos indivíduos e, aliado ao receio da discriminação, foi suficiente para que eles ocultassem seu diagnóstico para os outros. Dessa forma, não foi possível perceber nenhuma alteração em seu vínculo social. Destacaram-se as diversas reações emocionais no momento do diagnóstico além da ênfase dada à cura pelos entrevistados. Neste trabalho, ficou evidente que o encobrimento da doença e o suporte social atuaram como fatores de proteção que impediram momentos de discriminação e restrição de participação social.

Palavras-chave: Hanseníase; estigma; problemas sociais.

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PERCEPCIÓN DEL ESTIGMA Y EFECTOS SOCIALES EN PERSONAS CON ENFERMEDAD DE HANSEN

RESUMEN. Las personas con enfermedad de Hansen viven situaciones de prejuicio que, junto con el estigma y la discriminación, culminó con el aislamiento social y la restricción de las relaciones sociales. Este estudio tuvo como objetivo evaluar la percepción de estigma en personas con enfermedad de Hansen y sus repercusiones sociales. Caracterizado por un estudio cualitativo mediante la aplicación de entrevistas semiestructuradas con 20 usuarios registrados a tratamiento de quimioterapia en las unidades de referencia en la Zona da Mata Mineira, en el primer semestre de 2014. Se realizó el análisis mediante el análisis de contenido y las siguientes categorías del análisis se definieron: La ignorancia sobre la enfermedad; El diagnóstico y la cura; La discriminación y el miedo; El ocultamiento de la enfermedad; El apoyo social; y Enlace y la participación social. La ignorancia sobre la enfermedad interfiere con afrontamiento de los individuos y, junto con el temor a la discriminación fuera suficiente para ellos para ocultar su diagnóstico a los demás. Por lo tanto, no fue posible notar cualquier cambio en su enlace social. Destacado las diferentes reacciones emocionales al momento del diagnóstico, además del énfasis en la curación por los encuestados. En este estudio, se hizo evidente que el ocultamiento de la enfermedad y el apoyo social actuó como factores de protección que impedían momentos de la discriminación y la restricción de la participación social.

Palabras-clave: Lepra; estigma; problemas sociales.

Introduction

Leprosy, also called Hansen's disease, is still characterized as one of the greatest public health problems in Brazil, being highly incapacitating and able to evolve to deformities (Ministério da Saúde, 2008). According to data of the Ministry of Health (Ministério da Saúde, 2015), Brazil recorded an incidence rate of 15.32 per 100,000 inhabitants in 2014, a rating considered high. It is considered the second country in the world in numbers of cases of Hansen’s disease, only behind India (World Health Organization, 2014). Regarding the State of Minas Gerais (Ministério da Saúde, 2015), it presented an incidence rate of 5.86 per 100,000 inhabitants in 2014, considered as an average rating.

The clinical manifestations of Hansen’s disease vary regarding the immunogenicity of the bacillus and the individual’s immune system, since major manifestations are related to peripheral neurological deficits. It should be noted that this peripheral neurological deficit, acquired mainly during the episodes of reactions of the disease, is responsible for its high debilitating potential, resulting in physical disability, which might evolve into deformities. It is therefore essential that the diagnosis be performed early, in order to prevent the establishment of these disabilities (Ministério da Saúde, 2008).

The history of this disease in Brazil was marked by the compulsory isolation to which sick individuals were submitted, which was abolished after the introduction of polychemotherapy treatments in the 1980s. After the systematization of the treatment, there was a transition of the name leprosy to Hansen’s disease in order to reintegrate the patient into society and to reduce the stigma of the terms “leprosy” and “leper” (Maciel, Oliveira, & Gallo, 2010).

The transition of the name favored the formation of new cultural constructions concerning the disease, because the purpose of this change was to remove the present representation of leprosy, filled with a stigmatizing character, to insert the term Hansen’s disease, dissociated from the concept of stigma and associated with cure. However, this semantic game failed to eliminate leprosy from the popular conception, as well as the stigma associated with it. Hansen’s disease still suffers the influence of social constructions, where it emerges as a health problem and remains represented as a condition that results in social distress, centered in chronicity and stigma (Lira, Catrib, Nations, & Lira, 2005).

Goffman (2012) is one of the main authors to introduce the discussion about the term stigma. He refers to the Greeks, who created the term stigma to refer to the bodily signs some people presented, to evidence something extraordinary or evil about their moral status . Complementarily, Goffman (2012) describes three types of stigma,

> First of all, there are the abominations of the body – the various physical deformities. Second, the individual guilt, perceived as weak disposition, tyrannical or unnatural passions, false and rigid beliefs, dishonesty, which are inferred from known reports of, for example, mental illness, imprisonment,

> addictions, alcoholism, homosexuality, unemployment, suicide attempts and radical political behavior. Finally, there are the tribal stigmas of race, nation and religion, which can be transmitted through lineage and equally contaminate all members of a family. (p. 14)

In all these situations, there are individuals who could easily be received in a social relationship, but they present attributes that can be emphasized and drive out other individuals, preventing the focus of attention on their other attributes (Goffman, 2012). Link and Phelan (2001) extend the original concept of stigma, proposed by Goffman. According to these authors, the establishment of a stigma depends on the interaction of five components: labelling, association with a stereotype, discrimination and loss of status, all associated with a game of power.

The recent literature shows the concept of stigma not only dependent on an undesirable characteristic of an individual or a group, but also built by a social context to which this individual or this group belongs (Sermrittirong & Van Brakel, 2014). In this sense, the social context of Hansen's disease is also influenced by the disabilities this disease causes in its bearers, perpetuating their physical marks. Rafferty (2005) defines stigma as a real phenomenon in people's lives, leading to changes in the physical, psychological, social and economic domains.

Thus, another topic worthy of highlight is the social influence on the interpretation of Hansen's disease, emphasizing the social representation that is characterized by the practical knowledge that assists in the social construction of reality (Moscovici, 2012). Regarding relationships between groups, the social representation tends to fix an image of the other within a status, transforming the social differences into individual differences. Therefore, the prejudices and stereotypes are strongly entrenched, requiring time and new knowledge for the development of a new conception.

Hence, these representations are shared, they penetrate and influence the minds of each person; in other words – they are not conceived. They are the product of a sequence of elaborations and changes that occur over time, conducted through successive generations. They reflect a previous knowledge and weaken the ties of current information. In this sense, the past is more real than the present. Once the content is spread and accepted, it constitutes an integral part of the individuals, of their judgment and relationship with others, defining a position in social hierarchy and of their own values (Moscovici, 2012).

Therefore, we emphasize the relevance of the current relationship between Hansen's disease and stigma and its paramount importance in Brazilian public health, especially in the region of Zona da Mata Mineira. Thus, the objective of this study is to identify the perception of stigma of this population regarding Hansen's disease and the social repercussion it has in their lives.

Method

The study is characterized as a qualitative design, performed by means of semi-structured interviews. This methodology was applied in order to better understand the perception of stigma of the individuals and their implications, managing to capture their representations, meanings and senses.

The sample was constituted by users registered on polychemotherapy treatment for Hansen's disease in two reference units in the region of Zona da Mata, State of Minas Gerais, in the first half of 2014; be in polychemotherapy treatment in these units was considered an inclusion criterion. Initially, 21 individuals were selected; however, only 20 were included in this research, ten users from each of the reference centers. One individual was not included because he presented a medical statement attesting to a diagnosis of dementia, which would prevent him from answering the questions of the interview.

The individuals included were invited to participate in the research, and after their consent, the date of the semi-structured interview was scheduled. The interview was performed at the reference center were the individual was being treated, after consultation with the health team, in a private, quiet room, without interference of the unit staff.

The interviews were prepared following a methodology for scientific research (Bleger, 2011). They were recorded, transcribed and analyzed through content analysis using the categorical analysis technique, following the perspective of Bardin (2011). According to Bardin (2011), for the interpretation of messages and assertions, the content analysis is organized in three chronological poles, (1) pre-analysis, (2) exploitation of the material, (3) treatment of results, inference and interpretation.

Favorable report was presented by the Research Ethics Committee of the Federal University of Juiz de Fora (nº 714,507), according to Resolution No. 466/12 of the National Health Council.

Results

The study comprised 20 individuals, average age of 53 years, 11 males and 9 females, and 16 were classified with low educational level. Regarding Hansen's disease, 17 were considered multibacillary, 11 presented some degree of disability and 13 presented spots.

After reading the transcripts of the interviews, thematic analysis units were identified and defined; subsequently, the following categories of analysis were established: Lack of knowledge about the disease; Diagnosis and cure; Discrimination and fear; Concealment of the disease; Social support; and Bond and social participation.

In the category [Lack of knowledge about the disease], it was possible to notice how little patients knew about the disease; they were not able to explain the process of transmission, treatment and cure. This lack of knowledge can be represented by the statement of respondent 2, when asked about what he knew about the disease, *"I'll tell you the truth, I know nothing about it. Because... I didn't even know... I had this rash, this numbness, but I didn't know what it was [sic]"*; by respondent 9 *"Ah... I don't know anything... I don't know anything else... First time I see it this way, what the lady told me, the doctor talked to me like, see, this was leprosy in the past, it was called leprosy [sic]"*; and by respondent 17 *"Ah... I've been told so many things... there are so many things... I don't even know how to explain it to you..."*.

In [Diagnosis and cure], the moment of diagnosis was described, when most individuals reported negative feelings such as sadness, shame and suffering, though others also reported surprise and relief. This relief refers to the delay in diagnosis, and at that moment, they discovered the reason for their aches and complaints, for which a treatment was possible. The importance given to healing was also observed, along with fear of transmission to the immediate family.

In this category, we highlight the statement of respondent 2 *"Ah, when the doctor told me… when she told me like that, I wasn't afraid or anything. I just thought, is there a cure? [sic]"* and of respondent 4 *"Ah, I'm really sorry... really sad, really shaken, you know? Blessed Mother! Ah.. I don't know... for me it's the end. Blessed Mother! I fell really sad, really, really sad... [sic]"*.

In [Discrimination and fear] there was an emphasis in the fact that few have reportedly experienced moments of discrimination, which was exemplified by being looked at in a different way. However, almost all individuals interviewed reported that people diagnosed with Hansen's disease, in general, are discriminated. This prejudice can be perceived in the statement of respondent 6,

> *We are like, a little... some people are prejudiced, aren't they? Even the few people who know… only family… are prejudiced against us, right? I had an uncle who also had it, people were really prejudiced against him... sometimes they didn't even get close to him... [sic]*

Most respondents revealed they have not suffered discrimination due to their illness; however, the same respondents also concealed their diagnosis from others, not revealing their condition, thus presenting a good coexistence with other people. These aspects were included in the category [Concealment of the disease], which might be represented by the statement of respondent 17 *"No... because, well, I don't mention it to my colleagues.... it remains at home! [sic]"* and of respondent 20 *"I told nobody, right? I'm keeping it secret"*.

In the category [Social support], the support offered by others was evidenced, showing the family as the greatest source of support. As observed in the statement of respondent 15 *"Ah, I've been receiving support from my wife, right? From my sister..."* and of respondent 12 *"the support I receive is like this, my family is taking me to be treated [sic]"*.

Social bonds remained mostly unchanged, and the patients have continued with unaltered social participation, although some have reported to have withdrawn from social conviviality for various reasons, not necessarily due to their diagnosis, which was described in the category [Bond and social participation]. Among the statements in this category, we quote respondent 2, when questioned about possible changes in social conviviality, *"No, nothing has changed"*, of respondent 20 *"No, it's never bothered me"* and of respondent 10 *"I don't go out because I really don't like to, it's not because of Hansen's disease. Because I really don't want to go out. If I want to, I go, but… it doesn't really bother me"*.

Discussion

In reference to the results found in the categories obtained in the content analysis, [Lack of knowledge about the disease] can be highlighted. Virtually all respondents showed unawareness about the disease. The statements obtained corroborate what has been found in the literature (Eidt, 2004; Femina, Soler, Nardi, & Paschoal, 2007; Luka, 2010). This can be justified by the lack of dissemination of information regarding the disease, such as symptoms and routes of transmission.

In another study, conducted through interviews with Hansen's disease patients in the city of Campinas (Queiroz & Carrasco, 1995), it has been demonstrated that knowledge about the disease is rudimentary. The previous knowledge only includes the information contained in information posters of health centers.

Cid, Lima, Souza and Moura. (2012), while performing interviews with users of a Hansen's disease reference center in the State of Ceará, found that the ignorance about the disease is the cause of prejudice and discrimination, also pointed out by Femina et al. (2007). Only through knowledge about the disease and the possibility of healing the stigma will be minimized; with better-informed individuals, there will be less discrimination (Cid et al., 2012). Sinha et al. (2010) emphasize that educational level, social-economic issues, the presence of deformities and the degree of disability are crucial for the presence of stigmas regarding Hansen's disease. Cid et al. (2012) complement that prejudice is also fed by ignorance of the general public about the disease and by the stigma created in antiquity.

The respondents' lack of knowledge about Hansen's disease influences the way they receive the diagnosis. At the time of diagnosis, described in the category [Diagnosis and cure], most expressed negative feelings, such as fear, depression, sadness, shock, nuisance and suffering. Nevertheless, others seemed to be relieved, due to the difficulties and the time elapsed in the process of diagnosis, and some reported to have received the diagnosis in a natural way. In most statements, the great importance attributed to healing is noticed, and the fear of transmission.

> *I lost my mind. I was depressed for 2 or 3 days. I said, man, I thought this disease was extinct. And it's not. (laughs) And it had to be me... oh my God! But then I was able to deal with the depression... and I'm alive and kicking now. And I know there's a cure. [sic]* – R-01.

Many reactions or behaviors are perceived at the moment of diagnosis, such as surprise, fear and anxiety, reported by Silveira and Silva (2006) during their interviews in a city of the Northern State of Santa Catarina. Feelings of fear, despair, sadness, anger and shame were also reported by individuals with Hansen's disease in a study conducted at the Federal University of Espírito Santo (Marinho, Macedo, Sime, Paschoal, & Nardi, 2014). Queiroz and Carrasco (1995) sustain that reactions to the diagnosis might differ and are related to the educational level and the income of the carrier. Minuzzo (2008) explains that this diversity of reactions to the diagnosis is associated with the individuality of each patient, depending on previous experiences and values.

The meaning of having Hansen's disease is conditioned by the environment from which the individual emerges. In the study by Ayres et al. (2012), in order to analyze the effects of Hansen's disease in the everyday life of carriers, it was observed that it remains a disease that brings a hard and painful experience.

However, if diagnosis and treatment are performed early and clarifications and information about the disease are properly provided, individuals will have a less painful confrontation with it, better quality of life and better interaction with the disease (Ayres et al., 2012). Minuzzo (2008) shows that the respondents were afraid of discrimination, but after receiving information about the disease, they became more serene.

It may also be pointed out, through the statements of the respondents, the concern with the cure for Hansen’s disease. Families from lower social classes usually have doubts if the treatment for the disease can lead to full healing (Queiroz & Carrasco, 1995).

Another category described that presents a topic deserving of attention is [Concealment of the disease], which can be understood as the concealment of the diagnosis. In this study, we observed a concealment index of 80% of the participants, in which are included those who shared the diagnosis only with the family, but have not disclosed the information to others. This situation was also described by Silveira and Silva (2006) and Queiroz and Carrasco (1995). Eidt (2004) explains that this attitude of concealment arises as a result of other people’s prejudice against individuals with Hansen’s disease. This is exemplified in the following excerpt: *“[...] but I don’t think it is necessary to tell a lot of people... because it still has a great load of prejudice, innit? People are still afraid of contagion… contaminating… So I don’t think it’s necessary, no. [sic]”* – R-05.

When questioned about that attitude, the individuals reported that they had no interest in telling other people, that they feared the reaction of others, and some have said they were instructed to do so by the health team. Respondents reported that, when approached by others, they justified their visible signs as allergy, infection or spots caused by sunlight or by medications, hiding the true cause.

Cid et al. (2012) point out that individuals conceal the disease as a way of protecting themselves from the stigma of leprosy, for fear of suffering prejudice and discrimination, justification also defended by Nunes et al. (2008), who emphasize that such attitude might lead to social isolation, as a means of defense and protection against suffering.

Goffman (2012) adds that this concealment brings consequences to the individuals who, despite their situation, might have unforeseen needs that imply in providing information or having to explain more than they intend to. These individuals suffer a "deepening of pressures", as they are subjected to pressure to elaborate lies in order to avoid a revelation. These adaptive techniques can hurt feelings and give rise to misunderstanding on the part of other people.

The phenomenon of concealment always raised questions relating to the psychic state of the person who conceals. First, it is assumed that he/she should pay a high psychological price, resulting in a very high level of anxiety, by living a life that may collapse at any time. Second, the person who conceals will be torn between two loyalties: on the one hand, a feeling of alienation in their new “group” because there is no complete identification; on the other hand, the individual will feel disloyal and despicable for not responding to observations made by members of the category to which he/she belongs, and from which he/she is concealed. Third, the person who conceals must be attentive to aspects of the social situation that other people treat as routine. It is necessary to have a special control of time, it is the practice of “living holding on to a rope”, by which the person remains close to the place where his/her disguise can be retouched, or abandoned completely (Goffman, 2012).

In this study, due to the concealment of the disease, moments of discrimination have not been reported by most respondents and, consequently, stigmatization was not observed as a fact present in the lives of individuals with Hansen’s disease and as the real phenomenon described by Rafferty (2005). The situations of stigma are more pronounced when the individuals have visible spots on the body or physical deformities, showing that this visibility is regarded as a factor that can aggravate the symptoms of stigma and isolation (Luka, 2010; Queiroz & Carrasco, 1995).

Sermrittirong and Van Brakel (2014) conducted a review study to understand the concept, the causes and determinants of stigma on Hansen’s disease, and considered that the causes for stigmatization would be fear of transmission and visible negative manifestations caused by the disease. The risk factors associated with the increase in the level of stigma are low educational level, unfavorable economic conditions, change in occupation because of the disease and lack of knowledge and erroneous perceptions about it, as well as the presence of visible signs, ulcers and disabilities (Adhikari, Kaehler, Chapman, Raut, & Roche, 2014).

Since all the respondents of this study, except one, showed no sequelae of Hansen's disease and most presented only spots as visible signs, which could be hidden, they passed easily by other people without being noticed. It is clear that the absence of physical marks somehow ends up softening the presence of stigma, strengthening their carriers due to the absence of the risk of being exposed. At this point, the need for an early diagnosis can be emphasized, allowing proper treatment and possible prevention of sequelae due to the progression of the disease.

Though most of the respondents have not experienced moments of discrimination, the same majority agree that Hansen's disease patients are generally discriminated. These data compose the category [Discrimination and fear]: *"Well, sometimes I think so! Because sometimes people think... if someone else will catch it, sometimes they move away a little... they're like... thinking... if they'll catch it, if there's a cure. [sic]"* – R-03.

This image of prejudice is strongly linked to a social representation caused by Hansen's disease. The stigma exists and is more resistant than the disease itself (Cid et al., 2012). The disease is associated with a negative image and with the stigma (Silveira & Silva, 2006); thus, the carriers themselves create this association. The stigma of Hansen's disease is rooted in the religious, social, economic and cultural domains, which support the social theories (Rao, 2010). Rao (2010) states that Hansen's disease is more than a clinical condition, is a social condition.

Minuzzo (2008) points out that there are still remnants of the image of leprosy, which is responsible for social vulnerability, depending on the cultural context that the individual affected by the disease is inserted. Sermrittirong, Sermrittirong, Van Brakel and Bunbers-Aelen (2014) argue that the change in terminology form leprosy to Hansen's disease was not enough to change the stigma against it. The prejudice experienced or feared often leads to apprehension or social isolation, thus isolating the patient (Ayres et al., 2012).

To prevent exposure to situations of embarrassment and shame, the carrier of Hansen's disease conceals the illness. Thus, the concealment itself acts as a psychic and social protective factor.

Allied to this protective factor, this study entails the presence of social support, the support these individuals were receiving from their families and from the team of professionals in the reference units. Most respondents presented these two sources of support, which helps reducing the fear of rejection. Queiroz and Carrasco (1995) also noted that most of their respondents reported the absence of prejudice among family members, and this, together with the health service, results in an efficient support to patients. Several studies (Cid et al., 2012; Femina et al., 2007) also indicated conviviality as a source of support. As a justification for this support, Nunes et al. (2008) identified the emotional instability of individuals when performing the treatment for Hansen's disease, since this period triggers a state of crisis, causing tensions, situation in which their support is crucial.

Most respondents reported to be receiving great support from their families, such as reminding them about the time to take the medication, the incentive to continue the treatment and confidence regarding the cure of the disease. One respondent said that without this support, he would despair. This information is contained in the category [Social support].

> *From my wife, isn't it? [...] By talking, telling me that's the way it is. That... That it'll go away, right? [...] I'm going there, the other University Hospital (the support group at UH Santa Catarina) [...] Ah, it's important, isn't it? People speak, another one speaks, and… then...you always learn. [sic]* – R-08.

Participation in a support group was reported only by a few respondents; however, there was an emphasis on the importance of this participation, even by those who were not participating in any support group. They stated that it would be necessary to join a group like this to receive clarification on the process of illness and healing, about the periods of reactions and the consequences of possible sequelae. Some have reported that it would be necessary to know the disease better to be able to disclose the information to other people, in order to assist in the diagnostic process. Ayres et al. (2012) also argue that when people are more clarified about the disease, they are keen to convey information about their illness to others, and through this behavior they realize that they are accepted and people to not shy away from them, and become more understanding and solidary.

Those who participated in support groups reported benefits from the exchange of experiences between the participants, from the learning process regarding important issues related to health and to the disease in general, and from the guidance provided by the health team concerning self-care. Minuzzo

(2008) states that participating in groups of patients has demonstrated to modify the perceptions and experiences of the disease.

Queiroz and Carrasco (1995) also realized the importance of the health service for individuals with Hansen's disease, who positively evaluate it for the quality of the services and for its gratuity. As mentioned earlier, respondents in this study pointed out the health team as a source of important social support during treatment.

Gonçalves, Pawlowski, Bandeira and Piccinini (2011), after a survey of Brazilian scientific publications that assessed social support, emphasized the importance of social relations, of the social network and/or of social support for the physical and mental health of people. These aspects were considered as protective factors and health promoters, providing assistance in face of specific situations as chronic or acute diseases, times of stress, development crisis and social or physical vulnerability. In this study, social support was also noted as a protective factor to the patient.

Many studies show the importance of health education as support to individuals with Hansen's disease. Adhikari et al. (2014) reported the need for intervention of educational health programs to rectify erroneous conceptions and increase knowledge about Hansen's disease, encouraging the empowerment of affected individuals. Cid et al. (2012) point out health education with patients, in schools and in the community, as an alternative for minimizing the stigma.

However, a review study aimed at identifying interventions to reduce stigma and assess their effectiveness (Sermrittirong et al., 2014) stated that advisory groups would assist people with physical and psychological alterations caused by the disease in learning how to deal with their deficits, but would not affect in reducing the stigma. This study points out that health education groups can be considered as a strategy to share experiences among the individuals affected and a way of empowerment of these individuals from greater knowledge about the disease, the treatment, and possibilities in the society.

Another point that deserves to be highlighted in the interviews is the fact that few reports were obtained regarding the restriction in social participation. In this category [Bond and social participation], the respondents affirmed that there were no changes in their social bonds: *"My life hasn't changed at all. I kept the same way [sic]."* – R-11.

Femina et al. (2007) also found no changes in social bonds, since a large proportion of their respondents reported they have not perceived other people being afraid of getting close. However, these information come into contradiction with the majority of the studies referred to in the literature. The theoretical reference pointed that there would be a reduction in social participation of people with Hansen's disease, and the presence of visible signs, such as spots, would represent a major obstacle to their social participation (Groot, Van Brakel, & Vries, 2011; Nicholls et al., 2005).

Nicholls et al. (2005) performed a study to explore the risk factors related to restrictions in the participation of people affected by Hansen's disease. This study was conducted in six centers in India and Brazil. The regression analysis performed has identified as risk factors the fear of abandonment by the family and hospitalization at the moment of diagnosis. The authors recommend four consolidated items for simple screening to identify individuals at risk of restriction in participation, which would be the physical impact caused by Hansen's disease, the emotional response during the diagnosis, being female and low educational level.

Considering these factors, it is noticed that some of them were positive in the present study, such as the emotional responses to the diagnosis and the low educational level, though they were not enough to be associated to restriction in participation. This absence of restriction may be justified largely by the high level of concealment among the respondents, reason why it was not necessary to move away from any activity performed by them. Few of them reported moving away from other people at first for fear of transmission to other people; however, they soon returned to their normal activities, reassured by the information that the use of specific medication would prevent transmission.

The literature review by Sermrittirong et al. (2014), on the effectiveness of interventions to reduce the stigma of Hansen's disease reports that the main interventions would be the integration of programs to fight Hansen's disease and the health services; the triad information, education and communication; the encouragement of the people involved, besides social-economic rehabilitation programs in order to increase self-esteem, financial independence and acquisition of new skills; and the access to public services. Thus, all these interventions would also be influencing social integration. Since the causes of stigma are associated with the cultural context, which differ according to the society involved, it is important to know the causes of stigma to devise the best strategies to face it (Sermrittirong & Van Brakel, 2014).

Regarding the negative reaction to Hansen's disease, Palmeiras et al. (2013) understand that its carriers are not affected by the disease, but by an avalanche of psychological variables, such as fear, anxiety, loneliness and depression, which negatively influence the quality of life and the evolution of the disease. Therefore, based on the literature about social support (Gonçalves et al., 2011; Minuzzo, 2008), it is possible to understand the benefits offered by this support. However, Ayres et al. (2012) argue that disinformation, stigma and prejudice undermine the relationships, preventing or hindering the establishment of emotional ties.

In the process of completing the analysis of the interviews, it was noticed that the respondents do not understand the consequences of the disease, precisely due to the lack of knowledge about it and its history. Significant reports were not observed regarding "Hansen's disease" itself, showing no knowledge of these individuals about the history represented by this "expression". However, even without this knowledge, the majority of respondents was afraid to talk to others about their illness, for fear of being shunt or excluded from their social environment, for believing that this is a disease that raises discrimination. When they were asked about discrimination against individuals with Hansen's disease, in general, almost all reported that these people are actually discriminated. They believe in this association, though they have never been through situations of prejudice themselves.

Hence, in addition to the suggestions of approaches to Hansen's disease in the structure of health services described in the course of the present discussion, Palmeira et al. (2013) add that, among these strategies, it is necessary to consider the problems arising from human subjectivity and the psychosocial repercussions that the diagnosis and the existence with Hansen's disease bring to its carriers, being essential to cover society itself.

Final considerations

The present study demonstrated that the social representation of Hansen's disease as a stigmatizing condition still implies a fear of revealing this diagnosis to others, showing the concealment as a protective factor that prevents individuals with Hansen's disease of experiencing moments of discrimination and restriction in social participation, thus allowing the coexistence with the disease without causing major social repercussions. There is an emphasis on social support, another factor of protection, which serves as assistance in the process of illness and healing, pointing to the family and the health team as sources of this support. In this support is included the need for empowerment of individuals with Hansen's disease, since they are inserted in a context of discrimination and social exclusion, with consequent social vulnerability.

It was possible to realize how much the ignorance about the disease interferes in the patients' ability to confront the situation. There is an urgency in the various forms of dissemination of clarifications about Hansen's disease, primarily for the population throughout the country and to its carriers, pointing out the need for more assertive campaigns focused on the disease, in addition to assistance in the process of early diagnosis to start the treatment and, consequently, to achieve full healing, allowing the prevention of disabilities and possible psychosocial repercussions.

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