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## BEING ELDERLY AND LIVING WITH LEPROSY: AN ANALYSIS OF THE QUALITY OF LIFE

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### ABSTRACT

**Introduction:** When the individual, in addition to the elderly condition, is affected by a stigmatizing disease like leprosy, he can suffer significant interference in his aging process, which reflects on their quality of life.

**Methods:** Descriptive study, using a form of identification and the following instruments: WHOQOL – bref and WHOQOL – OLD. Participants in the study were elderly, affected by leprosy, in outpatient treatment. Data analysis was carried out through the EpiInfo 7 program and Microsoft Excel software.

**Results:** Among the participants of the research (n = 60), most of them have between 60 to 69 years (53.3%) of age, are male (58.3%), with brown skin color (66.6%) and married (45%). The analysis of the General Quality of Life Index (GQLI) of WHOQOL - bref obtained an average score of 60.42%, representing "Satisfaction" with the general quality of life. The domains of this instrument achieved an average score of 58.40%, approximate number to the average reached by facets of WHOQOL - OLD (58.28%).

**Conclusion:** The reformulation of public policies is indispensable to promote health and preventive and therapeutic actions targeted to a better quality of life for this population.

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## INTRODUCTION

Human aging is a complex and multifactorial process, which is influenced by vary biological, psychological, social and cultural factors. Thus, the individual experience can be experienced positively or negatively, in line with the person's life story and old age representation rooted in a given society (Schneider; Irigaray, 2008). The progressive ageing of the population has been going on in several parts of the world in a much higher rate than in the past, due mostly to significant reductions in mortality at younger ages and for infectious diseases, reducing the fertility rate, in addition to the decline of mortality in developed countries (WHO, 2015). Estimates indicate that the Brazilian elderly population will grow at a rate of 3.2% per year for the next 40 years, and it will reach 64 million inhabitants in 2050, which will represent about 30% of the population (IESS, 2013).

On the other hand, although the socio-sanitary and health conditions have evolved in general, these changes do not necessarily impact on improving the health of elderly people. With the increase in life expectancy, the elderly are more affected by chronic diseases, generating new challenges for public policies and health systems, especially when it comes to a disease of stigmatizing character and rooted by prejudice, like leprosy. The diagnosis of leprosy is confirmed when at least one of the cardinal signs is manifested: definite loss of sensation in a hypochromic or reddened skin lesion, presence of a peripheral nerve thickened with loss of sensation and/or weakness of the muscles innervated by it and the presence of acid-fast bacilli in a shaved intradermal area (OMS, 2015). It is valid to point out that, although considered a curable disease through multidrug therapy, leprosy is still an important public health problem in Brazil, for its potential to become chronic, accounting for more than 90% of the number of recorded cases in the Americas (WHO, 2012).

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Because it is an ancient disease that remained without treatment and cure for a long time, the segregation of a person with leprosy in colony hospitals was the only form of prophylaxis of the disease, being the person excluded from his family, friends and the society (Cid *et al.*, 2012). Thus, the population that today is older than 60 years may have gone through this experience, seen the situation through personal compulsory internment or of known people in former colony hospitals, also called "leper colonies", reinforcing even more the stigma and prejudice of this disease. Elderly affected by leprosy feel stigmatized, primarily with respect to disease, treating it as something that mistreats and secretes. But, also, with respect to aging, for standing before a prejudiced society. Such stigmas cause in the elderly an intense feeling of rejection by the family and the society as a whole (Souza; Sena, 2014).

Diseases such as leprosy, in addition to causing social complications, can also trigger long-term deformities and disabilities, in which the quality of life of the elderly can be intensely involved (An *et al.*, 2010). The definition proposed by the World Health Organization is the one that better reflects the scope of the construct of quality of life (QOL), defined as "an individual's perception of his position in life in the context of culture and value system in which he lives and in relation to his goals, expectations, standards and concerns" (The Whoqol Group, 1995, p.1405). The approach of old age on quality of life is extremely important, as this has been a constant concern of the human being from the beginning of his existence and it currently is a personal commitment to continuous pursuit of a healthy life (Reis *et al.*, 2009). Studies on quality of life are relevant to the knowledge of the impact that diseases and treatments can cause, in a multidimensional approach, contributing to a better planning of public policies and promotion of public health. However, searching in the databases of the Virtual Health Library portal, using the keywords "elderly", "leprosy" and "quality of life", only one article was found from Brazil, that gave focus to general quality of life evaluation of elderly people with leprosy, denoting the scarcity of research in this area (Savassiet *al.*, 2014). Given the above, it is considered relevant to understand the specificities involved in the aging process, being in this context the self-perception of the elderly facing a chronic condition that has in its origins historical and cultural issues of suffering in the biopsychosocial and spiritual context. Therefore, it was outlined as objective: to analyze the quality of life of elderly people aging with leprosy.

## MATERIALS AND METHODS

A study of quantitative approach held in a Rehabilitation Center on Leprosy and in a public hospital in São Luís, Maranhão – a state capital of northeastern Brazil, considered references in the care of people affected by leprosy in the region (SES-MA, 2012). The Rehabilitation Centre on Leprosy has six clinics for care and health multidisciplinary team. It provides contact examinations, dermatological and neurological evaluation, management of supervised doses, educational activities, education/training in basic actions and disabilities, special healing and adaptation of shoes, among others. It receives, each day, leprosy patients from all over the State of Maranhão – among them, elderly people. The research setting hospital is configured as a general hospital offering specialized care for patients with / without leprosy, from the capital and the State of Maranhão.

Data was collected from December 2012 to June 2013. The research respondents were elderly people diagnosed with leprosy. In this sense, elderly people were those aged 60 years or more, based on the WHO definition (OMS, 2008). As inclusion criteria, were adopted: elderly, with clinical diagnosis of leprosy and in outpatient treatment, who sought care in research sites at the time of data collection. And as exclusion criteria: the existence of psychiatric, neurological, visual and speech problems, given the possibility of compromising the reliability of the information issued in the course of data collection. These problems were identified from the records in the medical records. To calculate the sample, were used Stat Calc of Epi Info Program, version 7 of Center for Disease Control and Prevention (CDC) of Atlanta, based on 71 cases of leprosy in the elderly (reported in 2012 by the Health Units of the Municipality of São Luís - MA, Brazil), with an expected frequency of 18.1%, confidence level of 95% and a minimum error of 5%. After the calculation, the sample was set in a minimum number of 54 cases. Initially, the elderly were identified in the book of new cases of leprosy and from this information the card containing information on the day of attendance of the elderly was located. On that day, and after the nursing consultation, each elderly person has been clarified as regards the objectives and forms of participation in the research. The signing of an Informed Consent (TFCC) was requested to those who agreed to participate in the research. After signing the TFCC, an Elderly Identification Form was completed and later the questionnaires of World Health Organization Quality of Life - bref (WHOQOL - bref) and World Health Organization Quality of Life - older adults (WHOQOL - OLD) were delivered, both instruments of the World Health Organization (WHO), which were completed in a single meeting.

For the application of the questionnaires, the instructions of *The Whoqol Group* were obeyed (The Whoqol Group, 1998). The WHOQOL-bref consists of 26 questions, being the first two for the General Quality of Life Index (GQLI) and the remaining 24 questions representing each of the 24 facets that make up the original instrument, the WHOQOL - 100. So, unlike the WHOQOL-100, in which each of the 24 facets is evaluated from 4 issues, in the WHOQOL - bref every facet is evaluated by just one questions (The Whoqol Group, 1998). These 24 facets are within the following areas: Physical, Psychological, Social Relation and Environment. WHOQOL-OLD module consists of 24 questions assigned to six facets: "Operation of the Sensory", "Autonomy", "Past, Present and Future Activities", "Social Participation", "Death and Dying" and "Intimacy". Each of the facets has 4 questions (Fleck; Chachamovich; Trentini, 2003). It should be used along with the WHOQOL-100 or WHOQOL-Bref, in order to collect more comprehensive and complementary data that have not been covered previously. Elderly Identification Form analysis was held using the variables: gender, age, race and marital status. The program used for this purpose was the *EpiInfo*, version 7 of the CDC of Atlanta. As it regards descriptive statistics, the results were analyzed in absolute numbers and percentage. Answers by facet of WHOQOL - bref and WHOQOL - OLD are obtained by the *Likert* type scale with five points (1 to 5). These extremes represent 0% and 100%, respectively. For the analysis of responses on Likert scale, frequency distribution is done, and 1 and 2 (between 0% and 40%) represent a negative rating signaling dissatisfaction, 3 (between 41% and 60%) intermediate or neutral, 4 and 5 (between 61% and 100%) a positive evaluation, indicating

satisfaction. Domains are measured in positive direction, i.e., higher scores mean better Quality of Life (QOL). The final score obtained in each domain and in General QOL can transform into two types of scale: one of 4 to 20 and another of 0 to 100. In this research, we used the scale of 0 to 100, as proposed by the WHOQOL (1998). by being easily interpretable, given the associations with the percentages. WHOQOL Group directs that, for this analysis, the statistical program that shall be used is the Statistical Package of the Social Sciences (SPSS). Although the WHOQOL instruments are widely used and disseminated, using the SPSS software for the calculation of the results of these instruments is a limiting factor in its use – as it is software of high cost and that requires specific knowledge to be used. Seeking the removal of that limitation, a group of researchers built tools from the Microsoft Excel software, which were used in this research for the calculation of scores and descriptive statistics of the WHOQOL - bref and WHOQOL - OLD.

### Ethical Considerations

The research was approved by the Research Ethics Committee at the University Hospital of the Federal University of Maranhão, under the title "Quality of life of elderly patients with leprosy", on 17 may 2013, by opinion No. 289.202. Were taken into consideration the ethical observances governing research on humans in force in the country, stressing the guarantee of the confidentiality of identity in research, as well as in the preparation of the report of the survey and the absence of any onus to the respondent. The research did not receive funding for its implementation.

### RESULTS

The research respondents were 60 elderly people diagnosed with leprosy. Of these, 53.3% presented between 60 to 69 years of age, followed by 35% between 70 to 79 years of age, 10% between 80 to 89 years of age, and an elderly over 90 years of age (1.7%). There were more often male (58.3%) compared to female (41.7%). In relation to the race/skin color, brown was prevalent (66.6%); the black and white colors were referred to, respectively, by 26.7% and 6.7% of the participants. In relation to marital status, 45% of seniors were married; others were living in consensual union (15%) or were single (13.3%), separated (11.6%), widowed (11.6%) or did not answer (3.5%).

### Quality of life of elderly people affected by leprosy, according to the WHOQOL – bref instrument

By analyzing the General Quality of Life Index (GQLI) of WHOQOL - bref (Table 1), it was noted that most of the elderly showed "Satisfaction" (61.6%) in the evaluation of their quality of life. But it is also valid to point out that 38.3% of the elderly are dissatisfied or have a neutral posture of satisfaction with their QOL. With respect to the evaluation concerning their health, the most common answer was "Satisfaction" (51.6%) of elderly, although a large part (31.6%) of them is dissatisfied in this dimension. Figure 1 represents the scores of each facet of the WHOQOL-bref instrument. It is valid to remember that each question is represented by a facet, and only the facet of Self-assessment of Quality of Life, also called General Quality of Life Index (GQLI), is related to two questions (Table 1), and it obtained an average score of 60.42%, which represents "Satisfaction" with the quality of life, according to the scale Likert type.

Thus, the instrument has 25 facets and 26 questions to be examined by the investigation of its scores. It was found that between facets, the scores showed variation between 35% to

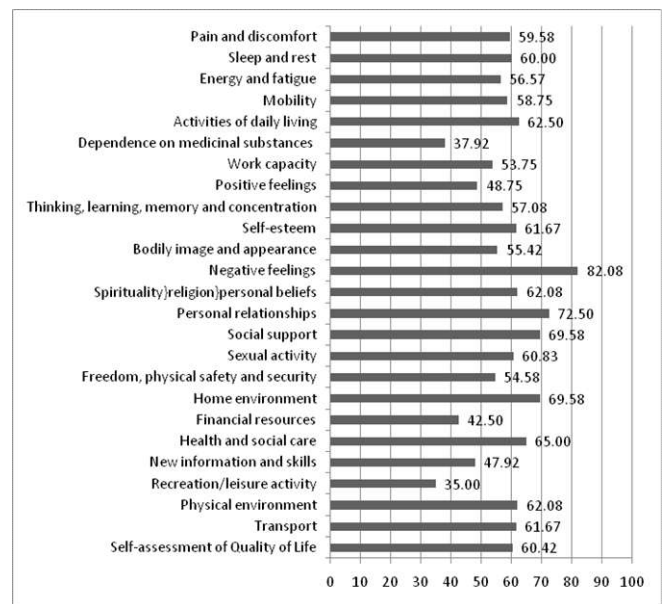


Figure 1. Quality of life of elderly people affected by leprosy, according to the facets of the WHOQOL – bref instrument. São Luís, MA, Brazil, 2013

82.08% on a scale ranging from 0% to 100%. In this way, the facets that have obtained higher results were: "Negative feelings" (82.08%), "Personal relations" (72.5%), "Support and personal support" (69.58%), "Home setting" (69.58%) and "Healthcare" (65.0%), representing the highest levels of quality of life among elderly people affected by leprosy, demonstrating "Satisfaction" with QOL. Facets with the lowest scores were: "Recreation and leisure" (35.0%), "Dependence on medicine or treatments" (37.92%), "Financial Resources" (42.5%), "New information and skills" (47.92%) and "Positive feelings" (48.75%), which may be negatively influencing the QOL of this population. By analysis of Figure 2,

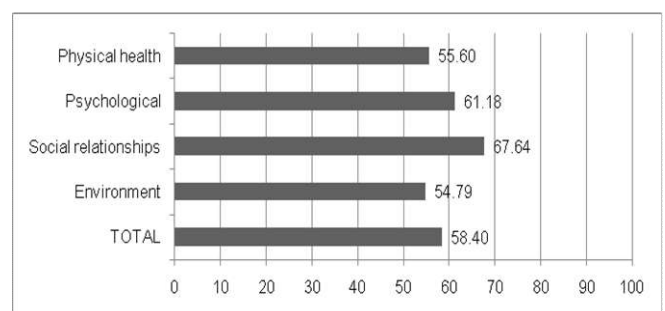


Figure 2. Domains of Quality of life of elderly people affected by leprosy, according to the WHOQOL – bref instrument. São Luís, MA, Brazil, 2013

it was possible to observe that the domain of Social Relations and Psychological domination presented the highest scores, with 67.64% and 61.18%, respectively, which represent "Satisfaction" of QOL in these areas, according to the scale Likerttype. In turn, the Physical and Environmental domains showed the lowest scores, with 55.6% and 54.79%, respectively, representing a "Neutral or Intermediate Posture" of QOL. Total domains analysis brings an average score of 58.4%, what constitutes "Neutral or Intermediate Posture" of

QOL, little different from the Self-evaluation results of Quality of Life (Figure 1), which was 60.42%, considered a *level of "Satisfaction"*.

### Quality of life of elderly people affected by leprosy, according to the WHOQOL – OLD instrument

By analyzing Figure 3, it was observed that the facets of "Past, Present and Future Activities" and "Death and Dying" presented the highest scores with 64.79% both, the facet "Social participation" hit average score of 62.71%, all contributing to *"Satisfaction"* the quality of life of the elderly. The facet "Intimacy" got the lowest score with 44.69%, following the facets of "Sensorimotor functioning" and "Autonomy", obtaining average scores of 58.85% and 53.85%, respectively, which gives them a "Neutral or Intermediate Posture" of QOL. The total analysis of the facets of WHOQOL-OLD (58.28%) brings a result very close to that achieved by WHOQOL-Bref domains, in which the average score is of 58.40% (Figure 2). Reaffirming that, among elderly people with leprosy disease there is a predominance of a *"Neutral or Intermediate Posture"* of quality of life.

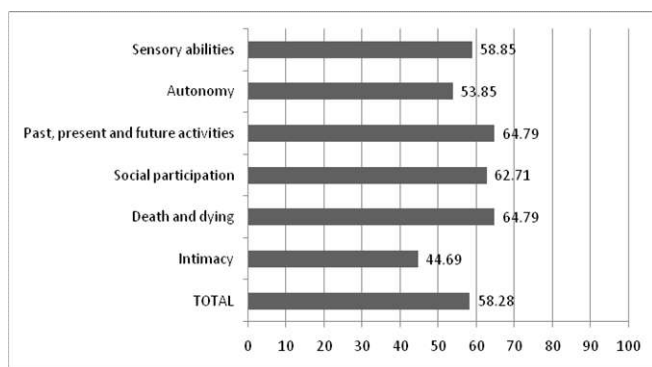


Figure 3. Facets of Quality of life of elderly people affected by leprosy, according to the WHOQOL – OLD instrument. São Luís, MA, Brazil, 2013

## DISCUSSION

The findings corroborate the literature regarding the predominance of males (Palheta *et al.*, 2010; Pelarigo *et al.*, 2014) race/brown skin color (Souza *et al.*, 2014; Barbosa; Almeida; Santos, 2014), average age within the age group of 60-69 years (Pelarigo *et al.*, 2014; Oliveira, 2011) and married/consensual union (Souza *et al.*, 2014). In addition to going through the natural process of aging, the elderly affected by leprosy suffers also with the double prejudice of society that does not value nor stimulates the people over 60, secreting and belittling the person with leprosy (Souza; Silva; Henriques, 2005).

The General Quality of Life Index (GQLI) of WHOQOL - bref found that most seniors evaluate with *"Satisfaction"* their quality of life, despite their condition, affected by leprosy. The reality observed in this research resembled other studies, however the data disagreed with the findings of some authors (Santos Junior; Santos, 2006; Castro *et al.*, 2009) – it certainly occurred due to the subjective dimension of QOL. The good quality of life relates to the level of satisfaction and/or well-being perceived by the individual, being defined, above all, by their state of health and an understanding of the disease (Sousa *et al.*, 2011). It is important to recall the classic health definition of WHO in which it is understood as a complete

state of physical, mental and social well-being, and not merely the absence of disease (WHO, 1946). When we think about health in this way, we can infer that the positive self-perception of health allows greater involvement of individuals in relation to therapy and control of the disease (Miranzi *et al.*, 2008). Still on the WHOQOL-bref instrument, it was observed that among the facets of the Physical domain, the "dependence on medication or treatments" and the "ability to work" were the most damaged, indicating a low level of satisfaction. Despite this, the facet of "activities of everyday life" was the one that obtained greater score, which indicates that the elderly of this study, in spite of the difficulties, presented a good level of activities. Elderly, who have autonomy and can perform their everyday activities in a satisfactory way, continuing their relationships and social activities and exercising their citizenship, can assess their health as good even affected by chronic diseases, because their health parameter is a life without dependency, under which they have control, without the need of another care (Paschoal, 2011).

The Environment domain presented the lowest scores, in line with most national studies that used the WHOQOL, as these have demonstrated that the environment domain is the worst facet of quality of life of the Brazilian population (Gordia; Quadros; Vilela Junior, 2006). Through that domain it was possible to observe that the elderly have little or no "recreation and leisure" and "financial resources" to keep their needs. Being the practice of leisure the one with lowest score among all the facets of the WHOQOL-bref. The result found may be related to physical changes caused by leprosy, which people are forced to live with. However, in the case of the "home environment", there is a high rate of satisfaction. Among seniors, the environment is strongly associated with the QOL due to their relationship to the prevention of falls, social interaction, involvement in daily activities, independence, security, protection and well-being (Ribeiro *et al.*, 2008).

In the Psychological domain, it was observed that elderly experienced negative feelings in considered low frequency, being this the facet with the highest average score. They have "spirituality" and "self-esteem" and, consequently, a good acceptance of their "body image and appearance". The literature points out that the greater the independence in daily activities, the lesser are the chances of the elderly to present depressive symptoms (Pelarigo *et al.*, 2014; Freitas, 2013). That's because the elderly can feel frustrated because of the functional and psychosocial losses incurred both by leprosy disease and the aging process. Social relations were the domain that presented the biggest score. Such a situation can be understood due to the "personal relationships" and "support and personal support" in which most of the elderly are involved. Social support can be understood as the degree to which interpersonal relationships correspond to certain functions (assistance/emotional support, material and/or emotional). Social inclusion decreases the effects of transformations from the aging process and good interpersonal relationship is the determining factor of an individual's satisfaction with his QOL (Viana *et al.*, 2015). Regarding WHOQOL-OLD instrument, it was possible to observe that among its facets, the "intimacy" of elderly people affected by leprosy had the lowest average score, having direct influence with marital status. The total number of social relationships tends to decrease with advancing age, however the emotional support is relatively stable in old age, being offered by the closest relationship contacts (Areosa; Benitez; Wichmann,

2012), which replace the intimate contact with a spouse. The facet "past, present and future activities", along with the process of "death and dying", showed the highest scores, demonstrating high level of satisfaction and acceptance of the aging process, which positively influences the quality of life. The detachment attitude toward death occurs often because of previous experiences (loss of friends, relatives, for example), which results in lower revolt trend (Nicolazi *et al.*, 2009).

## Conclusions

Based on these results, the study showed that while the General Quality of Life Index (GQLI), represented by the first two questions of the WHOQOL - BREF, has a level of "Satisfaction", the quality of life of elderly people against the process age affected by leprosy appeared in as a "Neutral posture or Intermediary" both between the domains of WHOQOL - bref, as in the facets of the WHOQOL - OLD, although they are tending to satisfaction, possibly due to the existing balance between the scores of the various facets of both instruments. These results point to the need for a more specific investigation of how the quality of life of these elderly is affected, especially in domains and facets with low score levels. To identify its origins, a more precise intervention is needed, finding the "key points" from which efforts can be invested in an attempt to change reality. So, there is the need for a reformulation of the existing public policies, mainly in the fields and facets with low scores, which are evidenced with dissatisfaction regarding the quality of life of elderly people affected by leprosy, as well as support programs aimed at health promotion, preventive and therapeutic action, on every level of their life, in order that such measures promote a better quality of life for this population.

## Conflict of Interest

The authors declare that there is no conflict of interest.

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