

SOCIAL RELATIONSHIPS AND INTIMATE DIMENSIONS OF ELDERLY INDIVIDUALS AFFECTED BY HANSEN'S DISEASE*

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ABSTRACT: The aim of this study was to assess social and intimate relationships of elderly individuals with Hansen's disease. This study has a quantitative approach, with 60 elderly individuals from two Hansen's Disease Control Programs in the capital city of a Brazilian Northeastern state, using the Social Relationships domain of the World Health Organization Quality of Life – brief and the Intimacy facet of the World Health Organization Quality of Life – older adults, with descriptive statistical analysis. Data were collected between December 2012 and June 2013. In the Social Relationships domain, satisfaction was found at 85% in personal relationships, 78.3% in social support and 60% in sexual activity. The elderly individuals presented lower satisfaction in the Intimacy facet. The Social Relationships of elderly individuals with Hansen's disease presented a high score due to the social support network, which presented significant satisfaction and reflected on quality of life. In conclusion, it is important that nursing coordinates strategies for educational and care practices for elderly individuals affected by Hansen's disease.

DESCRIPTORS: Interpersonal relations; Aged; Nursing; Leprosy.

RELAÇÕES SOCIAIS E DIMENSÕES ÍNTIMAS DE IDOSOS AFETADOS POR HANSENÍASE

RESUMO: Objetivou-se avaliar relações sociais e íntimas de pessoas idosas com hanseníase. Abordagem quantitativa, com 60 idosos em dois Programas de Controle da Hanseníase, em uma capital do nordeste brasileiro, utilizando o Domínio das Relações Sociais do *World Health Organization Quality of Life – brief* e a faceta Intimidade do *World Health Organization Quality of Life – older adults*, com análise estatística descritiva. A coleta de dados ocorreu entre dezembro de 2012 e junho de 2013. No Domínio das Relações Sociais, a satisfação foi de 85% nas relações pessoais, 78,3% no suporte social e 60% em atividade sexual. Na Faceta Intimidade, os idosos apresentaram menor satisfação. As Relações Sociais dos idosos com hanseníase apresentou alto escore devido à rede de apoio social, trazendo expressiva satisfação e se refletindo na sua qualidade de vida. Conclui-se sobre a importância da Enfermagem articular estratégias de práticas educativas e de cuidados à pessoa idosa e com hanseníase.

DESCRIPTORES: Relações interpessoais; Idoso; Enfermagem; Hanseníase.

RELACIONES SOCIALES Y DIMENSIONES ÍNTIMAS DE ANCIANOS ATINGIDOS POR ENFERMEDAD DE HANSEN

RESUMEN: El objetivo fue evaluar relaciones sociales así como íntimas de personas ancianas con enfermedad de Hansen. Abordaje cuantitativo, con 60 ancianos en dos Programas de Control de la enfermedad de Hansen, en una capital del nordeste brasileño, utilizando el Dominio de las Relaciones Sociales del *World Health Organization Quality of Life – brief* y la categoría Intimidad del *World Health Organization Quality of Life – older adults*, con análisis estadístico descriptivo. Los datos fueron obtenidos entre diciembre de 2012 y junio de 2013. En el Dominio de las Relaciones Sociales, la satisfacción fue de 85% en las relaciones personales, 78,3% en el apoyo social y 60% en actividad sexual. En la categoría Intimidad, los ancianos presentaron menor satisfacción. Las Relaciones Sociales de los ancianos con enfermedad de Hansen presentó alto escore a causa de la red de apoyo social, trayendo expresiva satisfacción y reflejando en su cualidad de vida. Se concluye que es muy importante que la Enfermería articule estrategias de prácticas educativas y de cuidados al anciano con enfermedad de Hansen.

DESCRIPTORES: Relaciones interpersonales; Anciano; Enfermería; Enfermedad de Hansen.

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INTRODUCTION

The aging process is a complex phenomenon that pervades various contexts regarding cultural, economic, political and social factors. At the same time, it also has specific aspects that are particular to elderly individuals in the psychosocial, biological and spiritual spheres⁽¹⁻³⁾. In this sense, thinking about and supporting elderly individuals' health require an understanding of ageing in its multidimensionality. Therefore, this phenomenon is a transdisciplinary challenge⁽³⁾.

The World Health Organization (WHO) defines elderly individuals as those over 65 years of age in developed countries and over 60 in developing countries⁽⁴⁾, such as Brazil. For the Pan American Health Organization, aging consists of a sequential, individual, cumulative, irreversible, universal, natural process⁽⁵⁾. However, it is important to emphasize that the aging process, as a dynamic system, is influenced by intervening factors, as previously mentioned⁽¹⁻³⁾, among which are chronic health conditions and their impacts on social/affective interactions and intimate dimensions of elderly individuals⁽¹⁾.

Chronic health conditions, in their multifaceted varieties, contribute to the impairment of functional capacities in elderly individuals^(3,6-7), reflecting on their degree of dependency for performing self-care; caregiver overload, especially for the main caregiver⁽⁶⁾; family functionality and dynamics, among others. Thus, it has a wide presence in the health-disease process.

Hansen's disease is in the realm of chronic health conditions – a chronic infection and contagious disease caused by *Mycobacterium leprae*, which prefers skin and peripheral nerves. It is one of the oldest diseases in humankind and, although it has a cure through polychemotherapy since 1986, it is still an important public health problem in Brazil⁽⁸⁾, where it ranks first in incidence and second in prevalence in the world, following India. Brazil has 90% of reported cases in the Americas⁽⁹⁾.

The phenomenon at hand is worsened by the stereotyped concept of Hansen's disease as a disease full of taboos, fears and prejudices that are ingrained in historical and cultural factors and lack of knowledge, which stigmatize carriers to the point of influencing their capacity for social interaction, which has an impact, consequently, on their isolation⁽¹⁰⁾.

Thus, it is crucial to know the aspects that

interfere in the capacity of elderly individuals with Hansen's disease to have social interactions. It is necessary to identify the nuances that cause and/or foster the phenomenon to plan and establish intervention strategies, in other words, to understand the aging process in its global and specific dynamics, in association with the presence of chronic pathologies. In this sense, gerontogeriatric nursing^(2-3,11-12) has an important role in the care and prevention of health harms for these individuals, being fundamental in face of the progressive changes in the age structure of the country, which reflect on demographic aging^(1,12-13).

With this in mind, it is pertinent to understand the specific aspects of the aging process, including the capacity for socio-affective interactions, in a perspective that is collective and unique to the individual who experiences a chronic condition in this phase of life. Therefore, the following objective was defined: to assess the social and intimate relationships of elderly people affected by Hansen's disease.

METHOD

This is a study with a quantitative approach, conducted in a Hansen's disease Rehabilitation Center and a public hospital of São Luís, capital city of the state of Maranhão, a Northeastern Brazilian state, which are considered reference institutions in the care for individuals affected by Hansen's disease in the region⁽¹⁴⁾.

The Hansen's disease Rehabilitation Center has six clinics and a multi-professional health team. It offers contact exams, dermato-neurologic assessment, supervised dose administration, educational activities, training for basic actions and incapacities, special bandages and footwear adaptation, among others. It receives patients with Hansen's disease from the entire state of Maranhão every day – among whom, elderly individuals. The hospital, where the research took place, is a general hospital, offering specialized care for patients with and without Hansen's disease from the capital and countryside of Maranhão.

Data were collected in the period between December 2012 and June 2013. The participants were elderly individuals with Hansen's disease diagnoses. In this sense, elderly individuals were considered those aged 60 or over, based on the definition of the WHO⁽⁴⁾. The inclusion criteria were: elderly individuals, with a clinical diagnosis

of Hansen's disease and under clinical treatment, who sought care in the research locations at the time of data collection. Exclusion criteria were: presence of psychiatric, neurologic, audiovisual and speech problems, since they can possibly compromise the reliability of information transmitted during the data collection process. These problems were identified through the patients' medical records.

The sample was calculated using the StatCalc feature of the EpiInfo software, version 7, of the Center for Disease Control and Prevention of Atlanta, based on 71 Hansen's disease cases in elderly individuals (reported in 2012 by the Health Units of the City of São Luís, state of Maranhão, Brazil), with an expected frequency of 18.1%, level of confidence equal to 95% and standard error of 5%. After calculation, the sample was set for a minimum of 54 cases.

Initially, the researchers searched for the elderly participants in the book of records of new cases of Hansen's disease. Using that information, we searched for records on when those patients would return to the clinic. On those days, after the nursing consultation, each individual was informed of the aims and types of participation in the research. Those who accepted to participate in the research were requested to sign a Free and Informed Consent Form. Once they signed the form, the researchers filled out an Elderly Individual Identification Card and gave them the questionnaires World Health Organization Quality of Life – bref (WHOQOL- bref) and World Health Organization Quality of Life – older adults (WHOQOL – OLD), which were filled out in a single meeting. All instructions from The Whoqol Group⁽¹⁵⁾ to the application of the questionnaires were observed.

The WHOQOL-bref has 26 questions, with the first two addressing the Overall Quality of Life Index (OQLI), and the remaining 24 representing each of the 24 facets that comprise the original instrument, the WHOQOL – 100. Thus, in contrast to the WHOQOL – 100, in which each of the 24 facets is assessed through 4 questions, in the WHOQOL – bref each facet is assessed through only one question⁽¹⁵⁾. These 24 facets are inside the following domains: Physical, Psychological, Social Relationships and Environment.

The WHOQOL – OLD has 24 questions distributed into six facets: Sensory Functioning, Autonomy, Past, Present and Future Activities, Social Participation, Death and Dying, and Intimacy. Each facet has four questions⁽¹⁶⁾.

In order reach the aim of this research, the researchers analyzed the Social Relationships domain of the WHOQOL – bref, comprised of three facets: Personal relationships, Social support and Sexual activity, as well as the Intimacy facet of the WHOQOL – OLD instrument.

The Elderly Individual Identification Cards were analyzed using the variables: gender, age, race and marital status. The EpiInfo software, Version 7 of the CDC of Atlanta, was used for that end. Since descriptive statistics were used, the researchers analyzed results in absolute numbers and percentages.

Answers by facets of the WHOQOL – bref and WHOQOL – OLD were obtained through a Likert scale with five points (1 through 5). These extremes correspond to 0% and 100%, respectively. For analysis of the answers in the Likert scale, there is a frequency distribution, with 1 and 2 representing a negative assessment, indicating dissatisfaction, 3 representing intermediary or neutral, and 4 and 5 representing a positive assessment, indicating satisfaction.

Domains are measured in a positive direction, in other words, higher scores correspond to better quality of life (QoL). The final score obtained from each domain and from the overall QoL can transform into two types of scale: one from 4 to 20 and another from 0 to 100. In this research, the 0 to 100 scale was used, as proposed by the WHOQOL⁽¹⁵⁾, since it is easily understood because of its association with percentages.

For this analysis, the WHOQOL Group recommends the statistical software Statistical Package of the Social Sciences (SPSS). Although the WHOQOL instruments are widely known and used, the use of the SPSS software for calculating the results of these instruments is a limiting factor in their adoption, as it is an expensive software that requires specific knowledge for proper use. Aiming to suppress this limitation, a group of researchers built tools using Microsoft Excel. These tools were used in this research for the calculation of scores and descriptive analysis of the WHOQOL – bref and the WHOQOL – OLD⁽¹⁷⁾.

The study proposal was approved by the Research Ethics Committee of the University Hospital of the Federal University of Maranhão, under the title "Quality of Life of elderly individuals affected by Hansen's disease", on May 17, 2013, by resolution no. 289.202.

The current ethical guidelines that rule research involving humans subjects in the

country were observed, with special attention to identity secrecy in the research, as well as during the creation of the research report and the absence of any burden for the interviewees. The development of this study had no funding.

RESULTS

Sixty elderly individuals diagnosed with Hansen's disease participated in the research. Of these, 53.3% were aged between 60 and 69, followed by 35% between 70 and 79, 10% between 80 and 89 and one individual over 90 years of age (1.7%). There was a higher frequency of men (58.3%) in relation to women (41.7%). As for race/ethnicity, mixed ancestry was prevalent (66.6%); white and black ethnicities were reported, respectively, by 26.7% and 6.7% of participants. On marital status, 45% were married, some individuals reported that they lived with a partner (15%) or were single (13.3%), separated (11.6%), widowed (11.6%) or did not respond (3.5%).

When analyzing the facets of the Social Relationships Domain of the WHOQOL – bref, it is observed that among elderly individuals affected by Hansen's disease, 85% were satisfied with their personal relationships and 78.3% believed they

received wide social support. Concerning sexual activity, 60% of elderly individuals were satisfied, although it may be necessary to note that 40% were dissatisfied or had a neutral/intermediate attitude toward it.

In regard to the questions of the Intimacy Facet of the WHOQOL – OLD, opinions were disparate. The elderly individuals considered themselves satisfied or dissatisfied in relation to the feeling of companionship in their lives (40% satisfied and 38.3% dissatisfied), the feeling of love (45% satisfied and 43.3% dissatisfied), and opportunities to love (35% satisfied and 41.6% dissatisfied) and to be loved (36.6% satisfied and 38.3% dissatisfied).

DISCUSSION

When asked about their satisfaction with their personal relationships, 85% reported that they were satisfied. It is well known that family relationships and friendships are the most important social matrixes for elderly individuals and that they help them with daily issues and feelings of loneliness, which are noticeable in old age⁽¹⁸⁾. However, the aging process influences family dynamics and functionality, both in relation

Table 1 – Responses of elderly individuals affected by Hansen's disease, according to the aspects of the Social Relationships domain of the WHOQOL-bref. São Luís, Maranhão, Brazil, 2013.

SOCIAL RELATIONSHIPS DOMAIN						
FACETS	DISSATISFACTION		NEUTRAL OR INTERMEDIATE ATTITUDE		SATISFACTION	
	n	%	n	%	N	%
Personal relationships	3	5	6	10	51	85
Social support	5	8.4	8	13.3	47	78.3
Sexual activity	12	20	12	20	36	60

Table 2 – Responses of elderly individuals affected by Hansen's disease, according to questions from the Intimacy facet of the WHOQOL – OLD. São Luís, Maranhão, Brazil, 2013

INTIMACY						
QUESTIONS	DISSATISFACTION		NEUTRAL OR INTERMEDIATE ATTITUDE		SATISFACTION	
	n	%	N	%	n	%
To which point do you have a feeling of companionship in your life?	23	38.3	13	21.6	24	40
To which point do you feel love in your life?	26	43.3	7	11.6	27	45
To which point do you have the opportunity to love?	25	41.6	14	23.3	21	35
To which point do you have the opportunity to be loved?	23	38.3	15	25	22	36.6

to social interactions or caregiver overload⁽⁶⁾.

Despite the common ideas regarding Hansen's disease, that it is a disease that causes physical disfigurement and tends to drive people away, it was perceived that the disease did not keep other people away and can also deepen relationships and social networks⁽¹⁹⁾. However, not only because of the changes related to the aging process, but also because of current family situations, it is crucial to establish a support network for the elderly, especially for those who live alone. These social networks have the role of promoting interpersonal interactions, which act on many aspects, such as emotional and instrumental support⁽²⁰⁾. Nursing, when managing its care, must contemplate the complexities of these interactions with the aim of identifying potentials and limitations to plan intervention mechanisms.

Still on the support network (friends), the elderly individuals were found to be satisfied, even though 21.7% reported a neutral attitude or were unsatisfied. This reality shows the importance of social living for health maintenance and prevention of diseases or harms^(6-7,13), because in the sphere of Hansen's disease, there are many stigmas and it is very important to break this stereotyped image of an incurable disease⁽¹⁰⁾ that isolates the elderly and compromises their quality of life. In a study carried out in Indonesia with carriers of incapacities related to Hansen's disease, 60.3% had problems participating in social life and 35.5% felt stigmatized⁽²¹⁾. Therefore, formal and health education must become decisive strategies for nursing performance in the aforementioned challenge.

In relation to satisfaction with sex life, 60% reported that they were satisfied. Being satisfied does not mean that they have an active or inactive sexual life, because some elderly individuals consider themselves satisfied with the absence of this parameter in their lives. Elderly sexuality must be understood through the fact that it is composed by the totality of the individual, taking into account its complete sense. Thus, being not only a biological factor, but also biopsychosociocultural⁽²²⁾. Sexuality, when related to aging, brings to mind myths and taboos, which result in the idea that elderly individuals are "asexual"⁽²³⁾, as if aging brought disinterest in life and that sexuality was inherent to young people.

Concerning Hansen's disease, there is an even larger context of myths and taboos. An example of this is that in the beginning of the past century, in sanitary debates around the world, the sexual

behavior of "leprosy" carriers was still viewed as a problem for planning population politics, with recurring doubts regarding how the disease was transmitted, if it was transmitted sexually or by inheritance. Thus, those who lived in colonies lived in pavilions segregated by age and gender and could only visit spaces for their own gender. Stories were even more suggestive when concerning married individuals, since a Hansen's disease diagnosis in one individual of the couple doomed them to an abrupt separation⁽²⁴⁻²⁶⁾.

It is known that a healthy dynamic in a married couple's life in old age is linked to intimacy, companionship and the capacity to express genuine feelings between one another, in an atmosphere of security, affection and reciprocity⁽²⁷⁾. Results obtained in the facet Intimacy showed higher scores among individuals who were married and lived together, which represented 60% of elderly individuals and shows a possible change in the current view of this population, who lived intensely the period of Hansen's disease colony hospitals.

It can be observed that the percentage of elderly individuals that reported "satisfaction" and "dissatisfaction" was close when they were questioned about having feelings of companionship and love in their lives, having opportunities to love and to be loved by someone that shares their intimacy. These responses can be explained by the presence or lack of a partner, respectively. A study conducted with elderly individuals with or without partners⁽²⁷⁾ found lower scores for intimacy among those without partners (66.53%), in comparison to those with partners (73.23%), although the difference was not significant.

It is important to stress, however, that other factors, such as lack of information and prejudice against Hansen's disease carriers, may worsen the level of dissatisfaction in their intimate relationships. During data collection there were individuals who reported having considerably lowered or even stopped intimate relations with their spouses, some for fear of physical and intimate contact, others for lack of knowledge regarding how Hansen's disease is transmitted. There were even doubts if transmission could happen sexually, for example.

Historically, discussions regarding the sexuality of Hansen's disease carriers were neglected, with them being considered "asexual" people due to the higher emphasis put on the disease⁽²⁸⁾. Even in classic works such as "The history of Hansen's

disease in Brazil"⁽²⁹⁾, published in the mid-50s, there is no direct reference to sexuality, dating and marriage in colony hospitals⁽²⁴⁾.

Hence, health education becomes a relevant strategy in the construction of concepts that contemplate the elderly as individuals who are free to experience their sexuality, unburdened by myths and prejudices that were socially solidified, being necessary to consider that these educational actions must involve everyone, not only elderly individuals, since aging is inherent to human beings, and sexuality issues must be discussed during all stages of life. Therefore, sexuality remains under construction throughout the life course of humans. Observing this process, the role of nurses as educators is noteworthy, and they should be inserted in places that involve sexual education⁽³⁰⁾.

CONCLUSION

Social relationships of elderly individuals affected by Hansen's disease was a domain that presented a high score, especially in the facets "Personal relationships" and "Social Support". This situation can be understood due to the social support networks in which most elderly individuals are involved. These personal relationships, of family or friends, cause a noticeable satisfaction to this population, which reflects on their quality of life.

In the light of this, it is important for nursing to coordinate strategies that include interaction with support networks in its care practices directed to elderly individuals, whether in chronic conditions or not. It is also important to consider that in the aging process these interactions can be potentially harmed by cultural stereotypes, such as old age as an unnatural life condition.

For the facet "Sexual Activity", a lower satisfaction among the elderly individuals was observed, as well as in the facet "Intimacy", which seems to be related to their marital status, although other factors, such as lack of information, have probably contributed for this result. In this area, nursing is also of great importance in conducting educational actions focused on demystifying societal prejudices linked to Hansen's disease.

This study was limited by its physical area and the use of descriptive statistical analysis, which made it more difficult to generalize results and possible inferences, as well as by difficulties in finding scientific studies addressing the same theme. As possibilities, the data collection

instruments were effective to provide support for multidimensional interventions in the social, family and intimate spheres; factors that must be taken into account by nursing when caring for elderly individuals with Hansen's disease.

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