

Quality of life of leprosy sequelae patients living in a former leprosarium under home care: univariate analysis

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Abstract

Introduction Quality of life (QoL) is a broad concept that has become more important during the last decades. Despite this fact, few studies have been conducted to evaluate leprosy patients, none of which has specifically addressed patients with leprosy sequels submitted to home care.

Purpose To evaluate the QoL of leprosy sequel bearers and the factors that may affect their perception of their condition.

Methods WHOQoL-BREF, a questionnaire developed by the World Health Organization, was administered to 32 people living in the coverage area of a former leprosarium. Patient socio-demographic and care-related caregiver data were collected. Activities of daily living and Instrumental Activities of Daily Living Scales were used to evaluate autonomy. Mini-Mental Status Examination was used to

evaluate cognitive status. Simple linear regression analyses were conducted using SPSS Statistical Software and the non-standardized beta values were presented.

Results The patients were mainly female, widowed, elderly, with bone sequels; all had impairment of at least one Instrumental Daily Living Activity. QoL scores were 12.35 in a 4–20 scale (52.18 %) in the physical domain, 12.95 (55.94 %) in the psychological health domain, 13.18 (57.40 %) in the environment domain, and 16.09 (75.56 %) in the social domain. Univariate analysis suggests that instrumental daily activity “capacity of shopping,” marital status, and caregiver age were associated with self-perceived QoL. Data were also compared to those from other studies.

Conclusion Individuals affected by leprosy had low QoL scores in the physical and psychological health domains and high scores in the social domain. The factors that impact their QoL seem to be related to specific conditions found in the leprosarium and the previous isolation practices.

Keywords Leprosy · Quality of life · Leprosarium

Introduction

Quality of life (QoL) concept includes physical health, psychological health, level of independence, social relationships, personal beliefs, and relationship with the environment [1].

Leprosy is caused by *Mycobacterium leprae* bacillus, which lodges at the Schwann cell inside the myelin membrane of peripheral nerves. Leprosy may be manifested by skin lesions and loss of sensations associated with neurological changes. Patients not treated with a course of

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multidrug therapy present neurological and mainly motor sequels [2].

Leprosy remains a public health problem in Brazil. The prevalence was 1.54 cases per 10,000 inhabitants, corresponding to 33,995 new cases in 2011. From 130 countries reporting cases of leprosy, Brazil remains in second place in the absolute number of new cases (WHO 2011) [3].

The broad concept of QoL in leprosy is important to 3 social representations: prejudice, marginalization, and stigma. The disease is not limited to the skin or neurological sites, as it also affects osteomuscular sites and the eyes, interfering with quality of life in social and psychological health domains [4]. Unlike traditional clinical evaluation, there is a few evidence of QoL studies concerning leprosy.

Although leprosy involves more than dermatologic issues, evaluation using the Dermatology Life Quality Index in Brazil revealed that leprosy (but not its sequels) had the lowest score when compared to skin diseases [5–7]. Some researchers have also evaluated leprosy using Short Forms 36, a questionnaire that focuses on biomedical symptoms and does not tap into social, spiritual, or religion issues. These researchers found that low scores on the SF-36 were associated with late diagnosis, multibacillary leprosy, grade II disability in the diagnosis, and prejudice factors [8, 9].

A few studies used WHOQoL-BREF to evaluate individuals affected by leprosy sequels [10], leprosy acute infection [11, 12] and in reactional outbreaks [13]. Leprosy disabilities have also been evaluated in Nepal, but without conversion of the scores to the 4–20 or centesimal scales, making comparisons impossible [14].

For decades, Brazilian patients were isolated from society and their families, which led to psychological and social consequences. In addition, educational establishments isolated children of leprosy patients [15–19]. Brazilian compulsory isolation was extinguished in 1967. Nowadays, people treated in leprosariums have rebuilt their lives with the support of friends or started new families with other patients. These people are the target of this study [20–22].

Methods

Study design

A cross-sectional study was carried out at the *Santa Isabel Health House* (CSSI), a Brazilian former leprosarium. The home-care service is responsible for patients living at home and provides multiprofessional care.

Inclusion criteria

All home-care patients with a caregiver (required for home care by Brazilian Legislation) were included [23, 24].

Participants

Thirty ($n = 30$) patients met the inclusion criteria and completed the WHOQoL-BREF questionnaire.

Assessment

Clinical, social, and demographic data were collected from the patients and caregivers who participated in the study.

Autonomy was evaluated through Mini-Mental Status Examination (MMSE) (Folstein 1975) [25] that has been validated in Brazilian Portuguese (kappa coefficient, 0.79; Cronbach's alpha, 0.71) [26], Activities of Daily Living Scale (ADLS, Katz 1969; Cronbach's alpha, 0.72) [27, 28], and Instrumental Activities of Daily Living scale (IADL, Lawton, 1970; Cronbach's alpha = 0.093) [28, 29]. Out of a total score of 30 on the Mini-Mental Status Examination (MMSE), 24 is accepted as a cutoff indicative of cognitive impairment. ADLS final score allows for a general assessment ranging from completely dependent (0–2), partially dependent (3–4) to completely independent (5–6). While the IADL has no cutoff point, this provides evaluation of eight activities for complete dependence (0), requirement of assistance (1), and complete independence (2).

The WHOQoL brief version questionnaire (WHOQoL-BREF) compares persons or groups through the assessment of four main domains: physical health, psychological health, social relationships, and environment [4], in which higher scores indicate better QoL. We chose WHOQoL-BREF because it is a generic and multidimensional tool that assesses other QoL aspects in addition to biomedical issues. This measure has been validated in Brazilian Portuguese language [[30]; Cronbach's alpha >0.69 for the four domains], used in cross-cultural evaluation research, and is widely used in the literature.

Statistical analysis

WHO's syntax for SPSS software package was used to calculate the four WHOQoL-BREF domain scores. Final scores were converted to a 4–20 scale, and domain scores were converted to a 0–100 scale according to the WHOQoL-group guidelines. Univariate linear regression model was used to assess the relationship between the patient independent variables and the WHOQoL-BREF domains. In this model, we calculated the statistical significance for

Table 1 Domains and scores of WHOQoL-BREF of 30 Santa Isabel patients (Brazil, 2009) compared to those of other studies concerning leprosy in a centesimal scale

Study	Location	<i>n</i>	Clinical condition	Environment [#]	Physical [#]	Psychological [#]	Social [#]
Santa Isabel (2009)	Brazil	30	Leprosy sequels	57.4 (15.1)	52.2 (17.6)	55.9 (17.5)	75.6 (21.8)
Quaggio [10]	Brazil	35	Leprosy sequels	62.7 (9.9)	54.9 (17.1)	62.5 (12.9)	71.5 (17.4)
Mankar et al. [11]	India	51	Acute leprosy	58.1 (11.5)	65.4 (11.5)	62.3 (13.9)	61.4 (28.1)
Tsutsumi et al. [12]	Bangladesh	154	Males in treatment	53.3 (10.9)	46.4 (16.7)	49.1 (16.2)	61.6 (15.4)
Costa et al. [13]	Brazil	120	Leprosy reactional outbreak	53.0 (10.8)	48.2 (15.5)	58.6 (14.3)	61.7 (16.4)

[#] Results in a centesimal scale (and standard deviation between brackets)

the relationship between each independent variable and each domain of the WHOQoL-BREF (dependent variable). Thus, we studied the associations by calculating the value and significance of non-standardized beta values using the *F* test. Beta values indicate the direct relationship between two continuous variables: For nominal variables, beta is exactly the difference between the mean score of the comparison group and the reference group, and for continuous variables, beta represents the increase in the score for each variation in a covariate unit (for instance, increase of 1 year in age).

Results

The majority of patients was female ($n = 23$, 76.7 %). The mean age was 78.2 years (range 62–89 years). There was no gender difference for age (male = 79.0, female = 78.0). The mean for schooling was 2 years (median = 0.5). Half (50 %) of the sample had no schooling at all.

The most prevalent leprosy sequels were in bone and joint sites: amputation ($n = 11$, 36.7 %), bone reabsorption ($n = 23$, 76.7 %), and bone deformity ($n = 26$, 86.7 %), mainly clawhand, clawfoot, and joint ankylosis. Ciliary

Table 2 Descriptive and univariate analysis of Santa Isabel patient's data—Brazil, 2009

General sample characterization		Patients' WHOQoL—domain beta values ^{a,b}			
Sample characteristics	Patients <i>N</i> = 30	Environment domain	Physical domain	Psychological domain	Social domain
Demographic data					
Patient mean age (SD)	78.22 (7.12)	0.27 ^b	−0.14 ^b	−0.34 ^b	0.39 ^b
Patient gender					
Male	7 (23.3 %)				
Female	23 (76.7 %)	−5.08 ^b	11.94 ^b	−7.00 ^b	5.38 ^b
Marital status					
Without companion	23 (76.7 %)				
With companion	7 (23.3 %)	−11.98 ^b	−14.82 ($p = 0.048$) ^{b*}	−13.97 ^b	0.83 ^b
Mean patient schooling (SD)	2.13 (2.78)	−0.51 ^b	−1.93 ^b	−0.99 ^b	0.18 ^b
Relationship with caregiver					
None	11 (36.7 %)				
Relative	19 (63.3 %)	−0.89 ^b	5.50 ^b	−7.96 ^b	−1.51 ^b
Clinic and independence data					
Use of assistive devices					
Wheelchair	14 (46.7 %)				
Cane/crutch	6 (20.0 %)	3.47 ^b	−0.85 ^b	3.03 ^b	12.70 ^b
None	10 (33.3 %)	−0.75 ^b	−4.42 ^b	−12.38 ^b	−9.52 ^b
MEEM					
Changed	18 (60.0 %)				
Normal	12 (40.0 %)	1.07 ^b	6.28 ^b	−2.50 ^b	−3.24 ^b

^a Linear regression performed with *F* test significance < 0.05

^b Beta values. For categorical variables, beta in relation to reference categories (first row of each category)

* Significance at $p < 0.05$

Table 3 Descriptive and univariate analysis of Santa Isabel patient's instrumental daily living activities—Brazil, 2009

General characterization of sample		Patients' WHOQoL—domain's beta values ^b			
Sample characteristics	Patients <i>N</i> = 30	Environment domain	Physical domain	Psychological domain	Social domain
Basic daily living activities					
Dependent	10 (33.3 %)				
Independent	20 (66.7 %)	3.86 ^b	1.67 ^b	0.17 ^b	0.83 ^b
Instrumental daily living activities					
1. Using the telephone					
Incapable	10 (33.3 %)				
With help	5 (16.7 %)	-0.71 ^b	3.21 ^b	-8.67 ^b	-7.50 ^b
Without help	15 (50.0 %)	-8.90 ^b	-4.57 ^b	0.78 ^b	-1.39 ^b
2. Shopping					
Incapable	16 (53.3 %)	(<i>p</i> = 0.022)			
With help	9 (30.0 %)	-15.70 ^{b*}	2.18 ^b	-9.99 ^b	0.17 ^b
Without help	5 (16.7 %)	-10.56 ^{b*}	-8.96 ^b	-5.73 ^b	-12.60 ^b
3. Preparing food					
Incapable	19 (63.3 %)				
With help	3 (10.0 %)	-12.03 ^b	-0.75 ^b	-20.06 ^b	-2.78 ^b
Without help	8 (26.7 %)	-1.147 ^b	1.18 ^b	-3.74 ^b	3.12 ^b
4. Housekeeping					
Incapable	15 (50.0 %)				
With help	10 (33.3 %)	1.28 ^b	1.71 ^b	-3.55 ^b	-7.22 ^{bb}
Without help	5 (16.7 %)	-4.61 ^b	0.63 ^b	-5.56 ^b	-5.56 ^b
5. Doing laundry					
Incapable	22 (73.3 %)				
With help	6 (20.0 %)	5.21 ^b	-0.33 ^b	-7.92 ^b	7.83 ^b
Without help	2 (6.7 %)	1.56 ^b	10.98 ^b	-5.84 ^b	18.94 ^b
6. Using transportation					
Incapable	14 (46.7 %)				
With help	15 (50.0 %)	-4.24 ^b	-7.69 ^b	-0.01 ^b	5.08 ^b
Without help	1 (3.3 %)	-13.70 ^b	-28.40 ^b	-14.82 ^b	-23.81 ^b
7. Handling medications					
Incapable	6 (20.0 %)				
With help	6 (20.0 %)	-17.71 ^b	-6.55 ^b	-11.11 ^b	5.55 ^b
Without help	18 (60.0 %)	-10.42 ^b	-6.09 ^b	0.88 ^b	-0.93 ^b
8. Handling finances					
Incapable	12 (40.0 %)				
With help	14 (46.7 %)	-4.05 ^b	-0.35 ^b	7.04 ^b	10.02 ^b
Without help	4 (13.3 %)	-14.32 ^b	-9.92 ^b	1.74 ^b	-4.86 ^b

^a Linear regression performed with *F* test significance < 0.05

^b Beta values. For categorical variables, beta in relation to reference categories (first row of each category)

* Significance at *p* < 0.05

madarosis, saddle nose, and blindness were non-orthopedic complications. Comorbidities were mainly hypertension (*n* = 16, 53.7 %), diabetes (*n* = 3, 10 %), osteoporosis (*n* = 3, 10 %), and lower limb ulcers (*n* = 18, 60 %).

Eleven participants (36.7 %) had some degree of dependence for ADLs; two of whom (6.7 %) were totally dependent (scores of 2 or less). All 30 patients were

dependent for performing at least one IADL. Fifteen patients (50 %) were totally dependent for five or more activities. A descriptive analysis is given in the first two columns of Tables 2 and 3.

The physical health mean domain score was 12.35 in a 4–20 scale, and the psychological health mean domain score was 13.0. The environment mean domain score was

Table 4 Descriptive and univariate analysis of Santa Izabel caregiver's data, Brazil, 2009

General characterization of sample		Patients' WHOQoL—domain beta values ^b			
Sample characteristics	Patients <i>N</i> = 30	Environment domain	Physical domain	Psychological domain	Social domain
Data regarding to caregiver					
Caregiver age (SD)	52.14 (14.69)	-0.20 ^b	-0.41 (<i>p</i> = 0.043)^{b*}	-0.23 ^{bb}	0.13 ^b
Caregiver gender					
Male	7 (23.3 %)				
Female	23 (76.7 %)	7.32 ^b	-2.48 ^b	4.65 ^b	-0.83 ^b
Time with caregiver assistance (in months) (SD)	94.3 (90.04)	-0.02 ^b	-0.038	-0.02	-0.04
Daytime care					
Part time	4 (13.3 %)				
Half period	9 (30.0 %)	2.85 ^b	-15.276 ^b	-10.30 ^b	-2.78 ^b
Full time	17 (56.7 %)	4.84 ^b	-3.815 ^b	-7.955 ^b	2.45 ^b

^a Linear regression performed with *F* test significance < 0.05

^b Beta values. For categorical variables, beta in relation to reference categories (first row of each category)

* Significance at *p* < 0.05

13.2, and the social relationship mean domain score was 16.1. The QoL centesimal scores for the patients are summarized in the second row of Table 1.

Tables 2, 3, and 4 (last four columns) provide observations for three associations: (1) the environment domain with the Instrumental DLA “capable of shopping,” (2) the physical domain with the marital status, and (3) caregiver age (Tables 2, 3, 4, last four columns).

Discussion

The high number of IADL-impaired patients shows the importance of caregiver support. Although 63.4 % (*n* = 19) of the patients were autonomous to ADLs, all had some IADL impairment.

Lower score on IADL *capable of shopping* domain is associated with low perceived QoL in the environment domain. Patients who required assistance to shop had the worst QoL scores. Since other IADL domains did not present the same trend, the significance of the environment domain score may be a chance event. Other possibilities are the external exposure of sequels and lost autonomy or the transition to the autonomy loss, with a worse QoL perception than incapable person who has already adapted to his/her limitations [31].

The marital status “with companion,” in comparison with “without companion” status, is related to a negative B value of -14.82 (*p* = 0.048). In other words, widowed individuals have an average physical score of 14.8 points higher than individuals with partners. The same association for the physical score also emerged for the environment

domain (beta = -11.98) and psychological subscale (beta = -13.97), with borderline significance (*p* values of 0.056 and 0.060, respectively). Almost 77 % of patients were older females who were living in vulnerable situations with restricted access to the labor market. Latin American studies show that widows may feel released from partner submission and gain financial independence afforded by death pension [31, 32].

Although the WHOQoL-BREF does not have a cutoff point, the results can be compared to other scenarios. Compared with other Brazilian studies, CSSI patients have worse scores in the physical and psychological domains and better scores in the social domains [32–36]. This appears to be related to the clinical condition of disability and the segregation by imposed isolation.

Better scores in the social domain can be related to the building of a social network that provides social support and the achievement of resilience or a constructed empowerment. This is mediated by the Movement of People Affected by *Hanseniasis* (MORHAN), a non-profit national organization. Moreover, we point out that since we observed that the community is formed by strong friendship ties, there is a wider social network and a more active social life. These results are very similar to those found in a former *leprosarium*, where strong ties of friendship were also observed [10], and in a minor scale to studies that enrolled people with acute leprosy or reactional outbreaks (Table 1) [12, 13].

Environment domain scores in CSI were low, but not as low as those in the psychological and physical domains, yet higher than those of studies conducted in large urban centers. This is likely to be explained by the rural

characteristics of the neighborhood [33, 35]. The psychological domain score was the lowest when compared to other Brazilian studies [32–36].

It seems that a low QoL may be related to the disease itself and to segregation. Since the study was cross-sectional, no causal attributions can be made. Longitudinal or (quasi)-experimental studies are required to clarify these issues. Because we worked with non-normally distributed small sample, even including all eligible ones, generalizations cannot be made.

Ethical standards This study was approved by the Brazilian Ethics and Research Committee (CONEP), protocol number CAAE—0022.0.245.000-08.

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