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Therapeutic workshops and psychosocial rehabilitation for institutionalised leprosy patients

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Abstract *Leprosy is still a major public health problem and psychosocial rehabilitation services for patients suffering from the disease remain insufficient. This study aimed to assess the impact of therapeutic workshops on quality of life and symptoms of depression among institutionalised leprosy patients. The Beck Depression Inventory (BDI) and generic World Health Organization Quality of Life questionnaire (WHOQOL-BREF) were used before and after the implementation of a series of therapeutic workshops over a period of six months. Sixty-two patients participated in the study. Almost all of the sample were elderly and had a low level of education. There was a significant reduction in the symptoms of depression scores after the intervention (p < 0,001) and a positive impact was shown for the psychological (p = 0,001), physical (p = 0,03) and environment (p < 0,001) domains, but not for the social relationships (p = 0,124) domain. Therapeutic workshops appear to a useful tool for psychosocial rehabilitation work with leprosy patients.*

Key words *Leprosy, Symptoms of depression, Quality of life*

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Introduction

Leprosy is a disease that has been known since biblical times. Apart from strongly affecting social, family and emotional ties, it is a highly incapacitating disease and is capable of affecting the "functional dimensions of the body"[1]. Although leprosy is curable, it remains a major public health problem[2], especially in countries like Brazil where the prevalence of the disease is second only to India[3]. Brazil is yet to achieve the World Health Organization (WHO) goal of reducing the number of cases to less than 1/10,000 population, and therefore the fight against this disease remains a key public health concern.

Leprosy is one of the neglected tropical diseases which, according to the WHO[4], are related to poverty and precarious living conditions, and thus mainly afflict poor, marginalised and underprivileged segments of society. The negligence associated with this disease transcends the medical and care aspect, and is strongly associated with the prejudice and stigmas that have been present in society's collective imaginary ever since ancient times[5]. Leprosy was governed by religion up to the threshold of the twentieth century, when it became the concern of the growing field of social medicine. The prevention of leprosy at the time consisted of assuming control of the body of the individual afflicted by the disease. As such, patients were isolated in leper colonies and subject to forced confinement to prevent the spread of illness in the "world of the healthy"[5,6]. This exclusion policy generated both physical and psychological scars and sequelae in isolated patients[7,8].

The patient isolation strategy for leprosy was officially extinguished by law in 1962. However, many patients remained hospitalised and isolated up to 1986, when the practice was effectively ended and recommendations were made to transform certain leper hospitals into general hospitals[9]. Although the gates of the old asylum-colonies were opened after the end of confinement, many patients continued to live in these places since they had lost their family and social ties and either saw no prospect whatsoever of living in the outside world or encountered difficulties during the social reintegration process[9]. Of the 101 leper colony hospitals built in Brazil, 33 were maintained to house patients without family ties, or those who had no job and nowhere to go. One of these institutions is the *Casa de Saúde Santa Fé* (CSSFé) in Três Corações, State of Minas Gerais[10], where patients receive care provided by a multidisciplinary team maintained by the state. According to the organisation which runs the CSSFé, *Fundação Hospitalar de Minas Gerais* (FHEMIG), the institution has 93 beds, 70 of which are occupied. Patients receive medical, nursing, psychological, nutritional and dental care, physiotherapy and occupational therapy. It may be assumed that, despite receiving multiprofessional care, these patients have a low quality of life and suffer from depression. Studies have shown that the use of therapeutic workshops in mental health care is a useful tool for promoting resocialisation and individual integration into groups, through activities that stimulate collective experiences and thinking based on a psychosocial approach and respect for individuality, alterity and subjectivity[11].

This study aimed to evaluate the impact of a series of therapeutic workshops specially developed for this target audience by calculating and analysing depression and quality of life scores among a group of patients in the CSSFé before and after the implementation of activities.

Methods

This investigation consists of an open quantitative intervention study with leprosy patients that remain housed at the CSSFé and who agreed to participate in activities. Patients with a major neurological disorder which impeded them from participating in the workshops and responding the questionnaires and those that did not give their consent to participate in the study were excluded from the sample. The same assessment questionnaires were conducted with the patients before carrying out the workshops (March 2011) and six months after the completion of activities (October 2011).

The World Health Organization Quality of Life questionnaire (WHOQOL-BREF), validated for use in Brazil, was utilised to assess quality of life. This questionnaire has 26 questions categorised into the following domains: physical, psychological, social relationships, and environment[12]. Both the domain and general quality of life scores are scaled in a positive direction with higher scores indicating better quality of life.

The 21-item Beck Depression Inventory (BDI)[13,14] was used to assess the cognitive, behavioural, affective and somatic symptoms of depression based on the following scoring system: absence of symptoms of depression (zero to nine), mild depression (10 to 16), moderate depression (17 to 29), and severe depression (30 to 63).

The questionnaires and workshops were conducted by a psychologist with experience in treating institutionalised patients with chronic disorders. Three types of therapeutic workshops (arts, music, and recreational activities/games) were conducted prospectively on a weekly basis, each lasting approximately two hours. The workshops were held in the male and female wards and also in the community (itinerant workshops for patients who tend not leave their home). The workshops were intended to collectively create an environment in which participants had space to express themselves and socialise, thus enabling patients to broaden their scope of life experiences. To this end, activities sought to boost self-esteem and help patients cope with stigma and negative self-image, and to promote the resignification of life stories. To achieve these objectives, participants were encouraged to talk about difficulties related to the disease and the coping strategies they used, share experiences, and assist other members of the groups in their difficulties. The effective participation of the patients – the achievement of which is one of the main challenges of therapeutic workshops – was stimulated by providing participants with the opportunity of collectively enjoying pleasurable moments interacting with other patients and part of the staff from the CSSFé.

The Wilcoxon test for paired samples ("before" and "after") was used to compare medians, while the chi-square test was used to compare proportions. The WHOQOL-BREF scores were computed using the software SPSS.

The study complied with all ethical standards and was conducted with the previous approval of the managers of the CSSFé. All patients signed an informed consent form and the project was approved by the research ethics committees of the State University of Montes Claros and the *Fundação Hospitalar do Estado de Minas Gerais* – FHEMIG.

Results

A total of 62 patients participated in the study. The main characteristics of this group are shown in Table 1: 51.6% of the group were male; 32.3% were aged between 66 and 75 years; 45.2% were widowed; and 91.9% were retired or pensioners. With respect to level of education, 45.3% (28) of the patients were illiterate and 43.5% (27) had only completed the first phase of primary school. The main form of the disease among patients was lepromatous leprosy (67.7%). The most prevalent (32.3%) disability grading among this group – according to the Screening of Activity Limitation and Safety Awareness (SALSA) scale and Participation Scale – was grade 2 disability (moderate degree of limitations in activities)[15].

Table 2 presents the symptoms of depression scores before and after the intervention. It can be noted that before the workshops 21% of the patients did not have symptoms of depression and that this proportion increased to 53.2% after the intervention. Similarly, the proportion of patients with scores indicating moderate depression decreased from 54.8% to 17.7%.

Table 3 shows the quality of life scores before and after the therapeutic workshops. Significant changes were noticed for all domains except social relationships.

Discussion

The results show that there were positive changes in depression and quality of life scores after the implementation of the therapeutic workshops. This is an important finding given that various studies highlight the negative effects of leprosy on the quality of life of people afflicted with this disease[16-19].

A study conducted in the State of Piauí showed a direct relationship between the impacts of severe and debilitating forms of leprosy and poor quality of life, even in leprosy patients who had been cured. The study showed that the factors most associated with poor quality of life were late diagnosis, having multibacillary leprosy, grade 2 disability, and reactions and prejudice surrounding the disease perceived by patients[16].

A study of the treatment of reactive states of leprosy showed that the disease has a significant impact on the quality of life of patients. The authors concluded that the suffering caused by this disease goes beyond the pain and illness strictly related to physical deterioration to include major social and psychological imapcts[17]. In line with the findings of the present study, the authors also found significant changes in the physical, psychological and social relationships domains. Furthermore, a study of the quality of life of leprosy patients by Martins et al.[18] concluded that the suffering caused by the disease extends beyond the physical consequences, negatively affecting the social relationships and psychological status of patients, thus justifying a multidisciplinary approach to the treatment of the disease.

In contrast to the context of the patients assessed by the present study, which suggests that leprosy has a significant impact on quality of life, Bottenne and Reis found that the impact of the disease on the quality of life of patients with paucibacillary leprosy was minimal, leading the authors to conclude that early diagnosis and treatment minimises the impact of the disease on quality of life of these patients[19]. Other studies highlight that institutionalised leprosy patients suffer considerably due to the stigma and prejudice surrounding the disease[20,21]. In certain cases, patients' life stories reveal a veritable, and inacceptable, exclusion of these individuals from society, thus deepening the psychological sequelae of the disease[22]. Hence, the present study not only seeks to emphasise a situation already highlighted by the literature, but also underlines the need for objective interventions which target patients that are forced to live with the consequences of a highly stigmatised disease. Unfortunately, the literature does not include studies which address interventions designed to improve the mental health status of these patients.

Therapeutic workshops designed for psychosocial rehabilitation work with patients that live with the stigma of leprosy, such as those carried out during this study, have the potential to make a significant contribution to improving quality of life and the facets that make up the following domains: physical health (mobility, energy and fatigue, working capacity), psychological health (self-esteem, positive feelings), and environmental quality of life (financial resources, home environment, health and social care).

The workshops were not effective in improving the social relationships domain, i.e., they were not able to promote resocialisation or social inclusion. This important finding may be linked to the effects of chronic institutionalization, underlining the need for other intervention strategies which ideally encompass society as a whole

Table 1. Characteristics of the leprosy patients housed at the Casa de Saúde Santa Fé (Minas Gerais), 2011.

Variable	(n)	(%)
Sex		
Male	32	51.6
Female	30	48.4
Marital status		
Single	11	17.7
Married; Stable union	18	29.0
Separated	5	8.1
Widowed	28	45.2
Level of Education		0.0
Illiterate	28	45.2
1-4 years	27	43.5
5-8 years	6	9.7
≥ 9 years	1	1.6
Functional situation		
Retired/pensioner	57	91.9
Active	2	3.2
No income	3	4.8
Age		
46-55 years	9	14.5
56-65 years	15	24.2
66-75 years	20	32.3
≥ 76 years	18	29.0
Type of leprosy*		
Undetermined	05	8.1
Lepromatous	42	67.7
Tuberculoid	11	17.7
Dimorfous	04	6.5
Disability grading*		
Grade zero	04	6.5
Grade 1	06	9.7
Grade 2	20	32.3
Grade 3	11	17.7
Information not available	21	33.9

* Information regarding "type of leprosy" and "disability grading" was taken from the patients' medical records.

Table 2. Beck Depression Inventory scores before and after therapy workshops (Minas Gerais), 2011.

Symptoms of depression scores	Before intervention		After intervention		
	n	%	n	%	p-value*
≤ 9 (absence of symptoms)	13	21.0	3	53.2	< 0.001
10-16 (mild depression)	7	11.3	13	21.0	0.222
17-29 (moderate depression)	34	54.8	11	17.7	<0.001
≥ 30 (severe depression)	8	12.9	5	8.1	0.557
Total	62	100.0	62	100.0	

* Chi-square test.

Table 3. WHOQOL-BREF scores before and after therapy workshops, 2011.

Domain	Before intervention				After intervention				
	Average	DP	Median	Value	Average	DP	Median	Value	p-value*
Physical	47.2	19.2	46.4	11-79	58.8	20.5	60.7	4-93	0.003
Psychological	49.9	16.8	54.2	8-83	61.3	19.4	66.7	8-92	0.001
Social relationships	61.7	17.6	66.7	8-92	66.7	15.5	66.7	33-100	0.124
Environment	44.9	11.6	43.7	25-75	57.8	10.3	59.4	31-81	< 0.001

* Wilcoxon test for paired samples.

and promote the social inclusion of institutionalised leprosy patients.

Therapeutic workshops are recognised and recommended by the Health Ministry as a useful tool for promoting socialisation and social integration[23,24]. This type of workshop is one of the forms of treatment currently promoted by the National Mental Health Policy as an intervention into citizenship in the form of psychosocial rehabilitation to foster the construction and valorisation of an individual's subjectivity in relation to their living environment. These workshops have been shown to be an effective tool in the care and treatment of patients with psychiatric disorders that have to live with the stigma of mental illness[23,24]. This form of treatment promotes expressiveness, socialisation, creativity, intellectual development and contributes towards restoring citizenship and reestablishing identity and other aspects directly linked to patient experience and autonomy. Azevedo and Miranda emphasise that therapeutic workshops are an important form of treatment for promoting resocialisation and individual integration into groups[11].

Therapeutic workshops emerged during the Brazilian psychiatric reform movement as one of the main types of therapy used in Psychosocial Care Centres (CAPS, acronym in Portuguese) and have become a major type of treatment for clinical depression[25]. The present study used the therapeutic workshops' potential to transform as a way of promoting psychosocial rehabilitation.

Given their situation, it may be assumed that institutionalised leprosy patients are likely to have symptoms of depression. Although some international studies have addressed this issue[26-28], no studies on this topic were found in the national literature. The general consensus between international authors is that stigma and self-segregation are intimately linked with symptoms of depression.

In the present study, although symptoms of depression were observed both before and after the intervention, it should be noted that there was a significant reduction in the symptoms after conducting the workshops. The process of institutionalisation experienced by the patients who participated in this study may well have contributed to an increase in symptoms of depression and a decline in quality of life, reinforcing the need for psychosocial rehabilitation. It is important to highlight that the categories of symptoms and attitudes assessed by the Beck Depression Inventory include mood, pessimism, lack of satisfaction, feelings of guilt, self-esteem, crying, irritability, social withdrawal, changes in body image, insomnia, anorexia, loss of weight and somatic complaints[13,14]. Many of these categories are empirically associated with chronic diseases, including leprosy and all its related stigmas[28,29].

The therapeutic workshops undertaken in this study were unable to promote significant improvements among the group of patients with severe depression. It is reasonable to believe that patients with severe depression are not responsive to psychotherapeutic interventions, and in such situations the use of antidepressant medications is essential. According to the basic ethical principles for conducting research of this nature, the researchers took special care with respect to the referral of patients with symptoms of severe depression.

The approach to care for hospitalised patients and the chronically ill should be creative and flexible, rather than set in stone and rigid, so that an ever greater number of patients may benefit from treatment. The creation process is important, since it helps patients to reestablish relationships with the outside world, making them players in their own their own discourse and everyday development[30]. In this sense, therapeutic workshops promote the valorisation of the subjective dimension of the patient and stimulate empowerment and citizenship, and are therefore an essential element of mental health care[31,32]. This form of treatment may contribute towards improved psychosocial integrity, reduce self-stigma, and help patients to cope with stigma and prejudice, and, as a consequence, lead to a process of resocialisation and resignification of individual and collective histories. The concept of psychosocial rehabilitation can be viewed as a search for greater individual autonomy and the restoration of community functioning of an individual[11].

Naturally, this study is subject to certain limitations. First, the study was carried out in only one health facility and with a relatively small sample of participants. Furthermore, the therapeutic workshops were given by the same person who conducted the assessment questionnaires. Therefore, during the second assessment (post intervention) participants may have tended to provide responses which they believed would be pleasing to the interviewer as an expression of gratitude for the activities.

Other limitations include the lack of a control group and the fact that the improvements observed after the intervention may be partially secondary to other concomitant interventions not investigated by the study, such as the use of antidepressant medication. However, the results of this study are important, particularly given the lack of studies on interventions targeting this group. The implementation of a therapeutic workshop program at the CSSFé is recommended to complement the range of care interventions open to the facility. Despite physical and psychological limitations, these workshops provided each of the patients housed in the CSSFé with the opportunity to resignify their life history and create a more positive outlook.

Collaborators

SCC Leite and AP Caldeira contributed equally to project conception and elaboration, data analysis and drafting the final version of this article. SCC Leite collected the data and conducted the interventions.

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