

Aids and tuberculosis: coinfection from the perspective of the quality of life of patients*

AIDS E TUBERCULOSE: A COINFECÇÃO VISTA PELA PERSPECTIVA DA QUALIDADE DE VIDA DOS INDIVÍDUOS

SIDA Y TUBERCULOSIS: LA COINFECCIÓN VISTA SEGÚN LA PERSPECTIVA DE LA CALIDAD DE VIDA DE LOS INDIVIDUOS.

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ABSTRACT

Tuberculosis (TB) and HIV coinfection adversely affects the lives of individuals in both the biological and psychosocial aspects. Aiming to describe the quality of life of individuals with HIV/TB coinfection, this descriptive cross-sectional study was conducted in Ribeirão Preto-SP. Participants were HIV-seropositive individuals with and without TB, using the WHOQOL HIV BREF. 115 individuals who were HIV-positive participated: 57 were coinfecting and 58 were not; most were male heterosexuals, predominantly aged 40-49 years. Of those coinfecting, most had lower education and income. In assessing the quality of life the coinfecting individuals showed lower results in all areas, with significant differences in the Physical, Psychological, Level of Independence and Social Relations areas. TB and HIV / AIDS are stigmatized diseases, and overlap of the two may have severe consequences on the physical and psychosocial health of the individual.

DESCRIPTORS

Tuberculosis
Acquired Immunodeficiency Syndrome
HIV
Quality of life

RESUMO

A coinfeção tuberculose (TB) e HIV afeta negativamente a vida dos indivíduos, tanto nos aspectos biológicos como nos psicossociais. Com o objetivo de descrever a qualidade de vida de indivíduos com coinfeção HIV/TB, foi realizado este estudo descritivo, de corte transversal, no município de Ribeirão Preto-SP. Foram entrevistados indivíduos soropositivos para o HIV, com e sem TB, por meio do instrumento WHOQOL-HIV bref. Participaram 115 indivíduos soropositivos para o HIV – 57 coinfectados e 58 não coinfectados; a maioria do sexo masculino, heterossexuais, faixa etária predominante de 40-49 anos, com os coinfectados apresentando baixas escolaridade e renda; na avaliação da qualidade de vida os coinfectados apresentaram resultados mais baixos em todos os domínios, com diferença importante no Físico, Psicológico, Nível de Independência e Relações Sociais. TB e HIV/aids são doenças estigmatizadas historicamente e a sobreposição das duas pode ter consequências graves na saúde física e psicossocial do indivíduo.

DESCRITORES

Tuberculose
Síndrome de Imunodeficiência Adquirida
HIV
Qualidade de vida

RESUMEN

La coinfección tuberculosis (TB) y HIV afecta negativamente la vida del individuo, tanto en los aspectos biológicos como en los psicosociales. Objetivando describir la calidad de vida de individuos con coinfección HIV/TB se realizó este estudio descriptivo, de corte transversal, en el municipio de Ribeirão Preto-SP. Fueron entrevistados individuos seropositivos para HIV, con o sin TB, mediante instrumento WHOQOL-HIV bref. Participaron 115 individuos seropositivos para HIV, 57 coinfectados y 58 no coinfectados, la mayoría de sexo masculino, heterossexuales, faja etaria predominante de 40-49 años, los coinfectados presentando escolaridad e ingresos inferiores; en la evaluación de calidad de vida los coinfectados presentaron resultados más bajos en todos los dominios, con diferencias importantes en el Físico, Psicológico, Nivel de Independencia y Relaciones Sociales. TB y HIV/SIDA son enfermedades históricamente estigmatizadas, la superposición de ambas puede tener graves consecuencias en la salud física y psicosocial del individuo.

DESCRIPTORES

Tuberculosis
Síndrome de Inmunodeficiencia Adquirida
VIH
Calidad de vida

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INTRODUCTION

Infection with HIV significantly increases the risk of developing active tuberculosis (TB): an individual infected with HIV is 25 times more vulnerable to TB in contrast to non-infected individuals, and the risk of death in patients who are coinfecting with HIV and *Koch's bacillus* is twice as high than in an HIV-seropositive individual without TB⁽¹⁾.

The association of this coinfection is synergetic, interactive and reciprocal, with significant impact on the course of the two pathologies. Coinfection is responsible for the increase in mortality rates, becoming a challenge for public health⁽²⁾.

Prior to the 1990's, there were poor therapeutic solutions to reduce the effects of HIV on the individual. The arrival of antiretroviral therapy (ART) for the treatment of individuals with HIV/Aids led to an increase in survival time; however, infection with HIV assumed chronic-degenerative characteristics, with effects related to the long-term experience of living with the virus, its comorbidities and the adverse effects of the treatment⁽³⁾.

The clinical improvement of patients infected with HIV under ART was assessed several times through the reduction in mortality, opportunistic infection rates and/or severe symptoms related to Aids. The assessment of the quality of life (QoL) may be used to monitor the impact of the disease, and may be clinically useful to identify which aspects are more greatly affected by direct interventions, in addition to measuring treatment results⁽⁴⁾.

The growing interest in the assessment of the quality of life (QoL) also includes patients with TB. Although TB is a curable disease, it presents the need for long-term therapy, with great impact on the life of the patients infected with the disease⁽⁵⁾, and lower results in terms of QoL than in the general population⁽⁶⁾.

In order to assess QoL, two types of instruments are used: the generic types, which comprise common and important aspects of health and may be used to assess and compare QoL in individuals suffering from different health conditions and sub-populations; or the specific types, which are designed to assess QoL in certain chronic diseases⁽⁵⁾.

Several specific instruments for individuals with HIV were found in the international literature, but only HAT-QoL and WHOQOL HIV were validated for use in Brazil. As for TB, the international studies found by the authors used generic instruments, such as SF-36 and MOS, and a specific instrument created and used only in India, the DR-12⁽⁵⁾.

The present study used the instrument of the World Health Organization (WHO), in its brief version –*WHO-QOL-HIV BREF*, and adopted the concept of quality of life defined by the Quality of Life Group of the WHO:

an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns⁽⁷⁾.

It is worth highlighting that, despite the epidemiological importance of TB in Brazil, there were no national studies found regarding QoL in patients with TB and in patients coinfecting with HIV/Aids. There is still a need for studies to identify the variables related to QoL in local populations, aimed not only at proposing interventions in the physical and mental healthcare areas, but also at contributing to public health policies that will lead to the betterment of the quality of life of these patients.

OBJECTIVE

The present study aimed at describing the quality of life of individuals with HIV/TB coinfection and at comparing it to the quality of life of HIV-seropositive individuals without TB.

METHOD

This is a descriptive cross-sectional study, developed through individual interviews with HIV-seropositive individuals with and without TB.

The study population comprised all of the HIV/TB coinfecting patients of both genders enrolled in follow-up at the outpatient clinic of specialized units in Ribeirão Preto-SP, who agreed to participate in the study and complied with the inclusion criteria: having a positive reagent serological test for HIV; attending follow-up at an outpatient clinic for the treatment of HIV/Aids; aged 18 years or older; having a confirmed diagnosis of TB; and having the physical, mental and psychological stamina to participate in the interview.

The exclusion criterion included those individuals under confinement (prisoners).

In order to identify coinfecting individuals, the authors requested monthly that the coordinator of the TB program of the Municipal Health Department send a list of the patients notified in the municipality, according to the results of the HIV exam, as well as the outpatient clinic that notified the patient. Interviews were then scheduled and performed according to the availability of the patient.

For the composition of the group of non-coinfecting HIV-seropositive individuals, the authors selected indi-

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viduals who attended the follow-up appointments at the outpatient clinic during the period of data collection, considering the same inclusion and exclusion criteria, in a proportion of 1:1 to the group of coinfecting patients. A pairing of these groups was performed according to gender in order to reduce the possibility of gender bias.

A questionnaire was used to gather the socioeconomic, epidemiologic and clinical characterizations, as well as the instrument WHOQOL-HIVBREF. WHOQOL-HIV BREF presents 31 questions, divided into six categories: physical, psychological, level of independence, social relations, environment and spirituality⁽⁷⁾.

The physical area includes the items: pain and discomfort, energy and fatigue, sleep and rest and symptoms; the psychological area involves positive and negative feelings, cognition, self-esteem and body image and appearance; the area of level of independence relates to mobility, activities of daily living, treatment dependence and ability to work; the social relations area includes personal relationships, social support, sexual activity and social inclusion; the environmental area involves physical security, housing, finances, health and social care, information, leisure, physical environment and transportation; and the area of spirituality includes the items spirituality, religion, forgiveness and guilt, concerns regarding the future and death.

The global calculation of each area, which varies between four and 20, was performed with the equation suggested by WHO⁽⁷⁾. Data were described in means and standard deviations. The Kolmogorov-Smirnov test was used to assess the normality of the distributions. Student's

t-test was used to analyze possible differences between the mean scores of quality of life. The level of statistical significance adopted was 5% ($\alpha = 0.05$).

Data were collected in the period from February of 2008 to February of 2010. All coinfecting patients were under supervised treatment.

The study was approved by the Committee of Ethics in Research of the Nursing School of Ribeirão Preto – USP, protocol 0858/2007. Interviews were performed after the clarification and agreement of the subjects, and only after the Free and Clarified Consent Forms were signed.

RESULTS

In the years 2008 and 2009, in the municipality of Ribeirão Preto, 391 patients with TB were notified, 84 (21.5%) of whom presented positive serology for HIV. Interviews were performed with 57 HIV/TB coinfecting patients who met the inclusion criteria and 58 HIV-seropositive individuals without TB who were being followed up by the outpatient clinic, totaling 115 participants in the study.

Among all participants, 86 (74.8%) were male, with an average age of 40 years, varying between 18 and 62 years; the prevalent age range fell between 40 and 49 years (40.9%).

The socioeconomic and epidemiological characteristics of the study population are presented in Table 1.

Table 2 presents the clinical characteristics of the interviewees.

Table 1 – Distribution of individuals with HIV/Aids, according to tuberculosis coinfection, socioeconomic variables and values of probabilities associated with the statistics tests – Ribeirão Preto, SP - 2008/2009

Variables	With TB		Without TB		Total		P
	N	%	N	%	N	%	
Gender^(a)							
Male	43	75.4	43	74.1	86	74.8	1.000 ^(ns)
Female	14	24.6	15	25.9	29	25.2	
Age (years)^(b)							
18 to 29	9	15.8	5	8.6	14	12.2	0.260 ^(ns)
30 to 39	18	31.6	23	39.7	41	35.7	
40 to 49	24	42.1	23	39.7	47	40.8	
≥50	6	10.5	7	12.1	13	11.3	
Education^(a)							
Illiterate	5	8.8	3	5.2	8	7.0	0.001**
Incomplete elementary education	34	59.6	31	53.4	65	56.5	
Complete elementary education	16	28.1	7	12.1	23	20.0	
Higher education or greater	2	3.5	17	29.3	20	16.5	
Income (minimum wage)^(b)							
Up to 1	23	40.4	12	20.7	35	30.4	0.001**
1.1 to 3	29	50.9	38	65.5	67	58.3	
>3	5	8.8	8	13.8	13	11.3	
Sexual orientation^(a)							
Homosexual	8	14.0	12	20.7	20	17.4	0.487 ^(ns)
Heterosexual	49	86.0	46	79.3	95	82.6	
Exposure category^{NR}							
Sexual	49	86.0	54	93.0	103	89.6	---
Use of injectable drugs	5	8.8	2	3.5	7	6.1	
Unknown	3	5.2	2	3.5	5	4.3	

current minimum wage at the time of study: R\$ 415.00 in 2008 and R\$ 465.00 in 2009; (a) chi-square test; (b) Student's t-test; *0.01 < p < 0.05; **p < 0.01; ns: not significant.

Table 2 – Distribution of the individuals with HIV/Aids, according to tuberculosis coinfection, clinical variables and values of probabilities associated with the statistics tests – Ribeirão Preto, SP – 2008/2009

Variables	With TB		Without TB		Total		p
	N	%	N	%	N	%	
Time since HIV diagnosis(months)^(a)							
≤ 6	17	29.8	5	8.6	22	19.1	0.009**
7 to 60	13	22.8	22	38.0	35	30.4	
61 to 120	16	28.1	12	20.7	28	24.3	
≥ 121	11	19.3	19	32.7	30	26.1	
Lymphocytes T CD4 (cells/ mm³ of blood)^(b)							
≤ 200	42	73.7	25	43.1	67	58.3	0.000**
201 to 350	10	17.5	16	27.6	26	22.6	
≥ 351	5	8.8	17	29.3	22	19.1	
Viral load (copies RNA viral/ml)^(b)							
Undetectable	4	7.0	33	56.9	37	32.2	0.000**
51 to 20.000	9	15.8	10	17.2	7	6.1	
20.001 to 100.000	26	45.6	9	15.5	47	40.8	
≥ 100.000	18	31.6	6	10.4	24	20.9	
Use de ART^(a)							
Yes	37	64.9	56	96.6	93	80.9	0.000**
No	20	35.1	2	3.4	22	19.1	
TB clinical form							
Pulmonary	34	59.6	-	-	34	59.6	
Extra-pulmonary	23	40.4	-	-	23	40.4	
Time of TB treatment							
≤ 60	13	22.8	-	-	13	22.8	
61 to 180	38	66.7	-	-	38	66.7	
≥ 181	6	10.5	-	-	6	10.5	

(a) chi-square test; (b): Student's t-test; *: 0.01 < p < 0.05; **p < 0.01; ns: not significant

WHOQOL-HIV BREF was submitted to the assessment of reliability through Cronbach's coefficient alpha, presenting values that varied from 0.69 to 0.74, which demonstrates good internal consistency of the instrument.

Regarding the QoL, the results obtained are presented in Table 3.

Table 3 – Mean scores, respective standard deviations and values of probabilities associated with Student's t-test for each of the areas of WHOQOL-HIV BREF of the individuals with HIV/Aids, according to tuberculosis coinfection – Ribeirão Preto, SP – 2008/2009

Areas	Mean	SD	p*
Physical			
With TB	12.07	3.67	0.000**
Without TB	14.82	3.34	
Psychological			
With TB	13.57	2.99	0.027*
Without TB	14.80	2.86	
Level of Independence			
With TB	11.42	2.96	0.000**
Without TB	13.60	2.64	
Social Relations			
With TB	13.14	2.79	0.028*
Without TB	14.39	3.22	
Environment			
With TB	13.05	1.91	0.189
Without TB	13.65	2.87	
Spirituality			
With TB	14.80	3.51	0.585
Without TB	15.17	3.64	

* 0.01 < p < 0.05; *p < 0.01; ns: not significant; Values of WHOQOL: from 4 to 20

A statistically significant difference was identified between the two groups in the physical (p < 0.01), psychological (p = 0.027), level of independence (p < 0.01) and social relations (p = 0.028) areas, with the group of coinfecting patients presenting lower mean scores than the group without coinfection. The area of level of independence presented the lowest mean for both groups and spirituality had the highest mean in both.

DISCUSSION

Among the participants in the coinfection group, 75.4% were male. The prevalence of the male gender, both in TB and in Aids, has also been described by other studies in different locations from Brazil since the early 1990's, confirming the male population as more vulnerable and having a higher prevalence rate for coinfection with *Mtb* and HIV⁽⁸⁾.

As for education and income, data agree with the social profile of the epidemic of Aids and TB, which in Brazil strike mainly the less economically favored classes of the population^(3, 9-10). Even so, in the group of coinfecting individuals, these indicators were even lower than the others. Lower levels of education lead to social vulnerability, since it influences the individuals regarding their ability to obtain information in general, and more specifically for the particular disease⁽¹¹⁾.

Nearly a third of the coinfecting patients became aware of their seropositivity almost at the same time that TB was diagnosed, which emphasizes the importance of performing HIV testing in these patients⁽¹²⁾. On the other hand, the fact that 27 (47.4%) individuals knew they were HIV-seropositive for more than five years reinforces the need to study and prevent TB among patients with HIV/Aids.

In the individuals of the present study, it was observed that the coinfecting patients presented lower levels of CD4T-cell counts and higher viral loads than those with HIV/Aids alone, which agrees with the literature and indicates that TB is an opportunistic infection highly associated with the deterioration of the immune system^(8,13).

Regarding the use of ART, the higher percentage of non-coinfecting individuals using this drug therapy could be justified by the fact that the individuals had only recently become aware of their HIV diagnosis and had yet to begin taking AR drugs; another factor to be considered is that the coinfecting patients who were aware of their serologic condition for a longer period of time did not have good compliance with the treatment, increasing their risk of developing TB.

The QoL areas with statistically significant differences between the individuals with and without coinfection were the physical, psychological, independence level and social relations areas.

Regarding the *physical* area, individuals with TB have both their physical and emotional well-being affected, since they experience symptoms of discomfort, using medications that may cause adverse reactions during the entire period of treatment⁽¹⁴⁾.

The clinical variables of CD4T-cell counts, viral load and use of ART, which did not show homogeneity between the groups, were factors associated with the worst scores in the physical area⁽¹⁵⁾. Immunosuppression causes aggravation of clinical conditions, intensifying the symptoms and increasing the possibility of hospitalization. Therefore, the low scores of QoL in the physical area of individuals with HIV/TB coinfection may be associated with the TB symptomatology, immunosuppression and the non-use of AR drugs.

The *psychological* area also presented a statistically significant difference in the QoL means of the groups. The therapeutic advances obtained with ART resulted in an important impact on the physical and psychological health of people who live with HIV/Aids, considering the increase in survival, reduction of mortality and decrease in the number of hospitalizations. However, at the onset of diagnosis and during the initial period of treatment, the patients' fear is constant, since the association between Aids and imminent death still persists in popular representations.

In addition to the suffering it causes, in terms of social living Aids is emphasized by stigma and prejudice, contributing to the *social death* of the person and triggering

states of emotional instability, depressive episodes and psychic suffering⁽¹⁶⁾, which often occur immediately after the individual becomes aware of his/her diagnosis.

On the other hand, the social stigma associated with the diagnosis of TB is significant in some cultures. Individuals with TB may feel isolated from their family and friends and experience fear and anxiety regarding the disclosure of their diagnosis to others⁽⁵⁾.

Currently, the importance of non-biological factors determining morbidity and mortality in some diseases is emphasized, for instance in TB. The simple presence of *Koch's bacillus* is not enough to cause the disease. Frequently, social, economic and cultural factors come into play so that the disease develops⁽¹⁷⁾.

A review performed on studies of QoL in patients with TB showed that tuberculostatic drugs had a positive effect on the improvement of QoL of the patients, inferring that physical health was quite affected by the disease, but improved quickly during treatment, whereas the compromised state of psychological well-being tended to persist for longer periods, even after the treatment had ended⁽⁵⁾.

The area of *social relations* also presented a statistically significant difference between the two groups. In general terms, the processes of stigma and discrimination associated with the revelation of diagnosis in social areas such as work, family and friends, both of HIV and TB, may negatively affect this area.

Health stigmatization may be defined as a social process characterized by exclusion, rejection and guilt, or the devaluation resulting from the experience of unfavorable social judgment due to a particular health condition⁽¹⁸⁾.

Regarding TB, a study developed in Santa Catarina⁽¹⁹⁾ observed that prejudice contributed to social isolation, even within close relationships, such as spouses and children. Prejudice does not come only from others towards in their attitudes towards the person with TB, but also from the patient, rooted in his/her (mis)conception of the disease.

Patients with TB are afraid of transmitting the disease, mainly to their partner. Feeling guilty, they distance themselves from everyone, including their family and partners, which leads to isolation and, consequently, to loneliness. In the case of a stigmatizing disease, fraught with prejudice as TB is, it is observed that the negative reactions may overlap the close feelings and bonds involving family and friends.

Nevertheless, a study developed in Thailand observed that the greatest stigma towards Aids in the community was associated with a shorter period of time spent on the search for treatment for TB symptoms, which suggests that these patients sought medical treatment in the hope that their symptoms would be attributed to TB, rather than Aids⁽²⁰⁾.

In the context of double infection with HIV/TB, the TB stigma is considered less significant than that of Aids, since at the beginning of the HIV/Aids epidemic the disease was associated with specific population groups, identified as engaging in *transgressing* behaviors. The trajectory of the epidemic shows that there have been many changes, mainly in the way AIDS is viewed by society; however, a great number of HIV-seropositive individuals hide the fact that they are infected for as long as they can, entering into a pact of secrecy, which may lead to social isolation, restriction of social relationships and difficulties in the emotional-sexual field.

The results of this study show that TB may be related to the worst QoL in the area of social relations among the coinfecting individuals, both due to the stigma and prejudice associated with the disease and its clinical manifestations, which results in social isolation.

The area of *level of independence* presented a statistically significant difference between the individuals with and without coinfection. The authors searched the literature and found studies that relate low education and income to lower QoL means in this area in individuals with HIV⁽³⁾ and HIV/TB coinfection⁽¹³⁾. Income relates to material and nutritional resources, and its lack results in poor nutrition and, subsequently, poor immune function.

Better QoL means in the level of independence area were also highly associated with treatment with ART⁽⁹⁾. Drug therapy provided the perception of global improvement in energy, ability to walk, physical appearance, self-esteem, personal relations and sexual life, reflecting higher QoL means⁽⁹⁾. TB demands the regular ingestion of drugs, significantly improving clinical symptoms after treatment has begun.

Although the areas of environment and spirituality presented lower mean scores in the coinfecting group than in the individuals with TB, no statistically significant difference was found between the groups.

However, in the *environment* area, studies relate better socioeconomic and educational levels to higher QoL means^(3,13), and this association also occurs with patients who have other diseases or chronic conditions⁽²¹⁾.

Education and income may be related to emotional and material aspects, as individuals present better life conditions to cope with the disease, and greater intellectual resources for the emotional adaptation required as a consequence of the disease⁽²²⁾.

The QoL means found in the environment area emphasize the character of poverty associated with the HIV/Aids epidemic and relate QoL to socioeconomic questions. Although there was a statistically significant difference between the groups in the variables of education and

income, the same difference was not verified in the QoL means of this area between individuals with and without active TB, even though they were slightly lower in the group of coinfecting individuals.

In the assessment of the QoL areas, it was observed that the *spirituality* area presented the highest mean score among all individuals; however, there was no statistically significant difference between the groups.

Spirituality has a definite relationship to the improvement of QoL of patients with chronic diseases. Studies indicate that religiosity and spirituality in people with HIV/Aids may help in the psychological adjustment and in coping with the disease⁽²²⁾.

Living with a serious disease leads to readjustments in the daily life, as well as to the redefinition of the self and relationships with others. The threat of death may generate the need to find a meaning in one's life, which is often found in association with spirituality⁽¹⁵⁾. Spiritual well-being may be highlighted as one of the variables present in resiliency and health protection⁽¹⁵⁾; it may help people who live with HIV/Aids to reduce symptoms in the health-disease process, contributing to the betterment of the QoL.

The reality of the people who live in less favored situations, which is the case of most of the individuals in this study, is characterized by constant struggle for survival, often mobilizing feelings of affiliation towards a religious belief. Moreover, spirituality may provide great help in coping with HIV, assisting in the adaptation to the new reality and in coping with the deprivations and anxieties imposed by the disease.

CONCLUSION

Several biopsychosocial factors may be altered in HIV/TB coinfection. Among them, it is important to mention physical-organic, psychoemotional and behavioral consequences. These consequences, which are quite evident in the case of stigmatized diseases such as TB and Aids, change the different dimensions of QoL significantly.

In the assessment of the quality of life (QoL), the coinfecting individuals presented lower mean scores than non-coinfecting individuals in all areas, with important differences in the physical, psychological, level of independence and social relations areas.

It becomes evident that there is a need to develop strategies of policies aimed at reducing the epidemiological impact of one disease over another, for instance the early detection of HIV and TB, the implementation of ART, the investigation of TB in HIV-seropositive individuals, the treatment of latent TB, and the expansion of supervised treatment and qualification of professionals.

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