



## ORIGINALES

### Social support and quality of life of people with tuberculosis/HIV

Suporte social e qualidade de vida de indivíduos com coinfeção tuberculose/HIV

Apoyo social y calidad de vida de las personas con coinfección de tuberculosis/VIH

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#### ABSTRACT:

**Objective:** To analyze the association of quality of life with social support in people with tuberculosis/HIV.

**Methods:** Descriptive study whose sample consisted of outpatients coinfecting with tuberculosis and HIV from Ribeirão Preto, state of São Paulo, Brazil. Data was collected using three instruments: the WHOQOL-HIV BREF Scale; the Social Support Scale for People Living with HIV/AIDS; and a questionnaire to gather clinical and sociodemographic information. Descriptive and inferential statistics were used in data analysis. All ethical requirements were met.

**Results:** Among the 57 people interviewed, males predominated, as did those who were heterosexual, those with few years of education, and those with low income. Average scores for quality of life and social support were intermediate; associations were identified for instrumental support and the domains physical and social relationships. Emotional support was correlated to all domains except spirituality.

**Conclusion:** Positive associations were found between social support and quality of life. Social support can mitigate the negative consequences of both diseases, directly affecting the quality of life of patients.

**Keywords:** HIV/AIDS; tuberculosis; social support; quality of life

#### RESUMO:

**Objetivo:** Analisar a associação entre qualidade de vida e suporte social dos indivíduos com a coinfeção tuberculose/HIV.

**Métodos:** Estudo descritivo, transversal, envolvendo indivíduos coinfectados com tuberculose/HIV, em acompanhamento ambulatorial em Ribeirão Preto-SP, Brasil. Foi aplicado um questionário para caracterização sociodemográfica, a Escala WHOQOL-HIV Bref e a Escala de Suporte Social para

Pessoas Vivendo com HIV/aids. Na análise dos dados utilizou-se estatística descritiva e inferencial. Foram contemplados todos os aspectos éticos.

**Resultados:** Dos 57 indivíduos entrevistados, a maioria do sexo masculino, heterossexual, com baixa escolaridade e renda. A média dos escores de qualidade de vida e do suporte social foi intermediária; foram identificadas associações entre Apoio Instrumental e os domínios Físico e Relações Sociais. O apoio emocional correlacionou-se com todos os domínios, exceto Espiritualidade.

**Conclui-se** que foram evidenciadas associações positivas entre suporte social e qualidade de vida. O suporte social pode amenizar consequências negativas de ambas as enfermidade, afetando diretamente a qualidade de vida do indivíduo.

**Palavras chave:** HIV/AIDS; tuberculose; apoio social; qualidade de vida

## RESUMEN:

**Objetivo:** Analizar la asociación entre calidad de vida y el apoyo social de las personas con coinfección TB / VIH.

**Métodos:** Estudio descriptivo transversal, con individuos coinfectados TB / VIH, presentes en Ribeirão Preto-SP, Brasil. Se aplicó un cuestionario de caracterización sociodemográfica, la Escala de WHOQOL-HIV-BREF y la Escala de Apoyo Social para las personas que viven con el VIH / SIDA. En el análisis de los datos se utilizó la estadística descriptiva e inferencial. Se contemplaron todos los aspectos éticos.

**Resultados:** De 57 personas entrevistadas, la mayoría eran varones, heterossexuales, con bajo nivel de educación e ingresos. Las puntuaciones medias de la calidad de vida y el apoyo social fue intermedia; Se identificaron asociaciones entre el apoyo instrumental y los dominios físicos y las relaciones sociales. El apoyo emocional se correlacionó con todos los dominios excepto Espiritualidad.

**Se concluye** que se observaron asociaciones positivas entre calidad de vida y apoyo social. El apoyo social puede mitigar las consecuencias negativas de ambas enfermedades, lo que afecta directamente a la calidad de vida del individuo.

**Palabras clave:** VIH/SIDA; tuberculosis; apoyo social; calidad de vida

## INTRODUCTION

Evaluations in the health field are usually based on the effects of interventions to promote health and prevent death. Advances in medical science and increases in life expectancy have made evaluation of quality of life (QL) an important measure whose results help in the design of suitable interventions for people with chronic diseases<sup>(1)</sup>.

Quality of life is defined by the World Health Organization (WHO) as "individuals' 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"<sup>(2)</sup>.

Evaluation of QL in people with tuberculosis (TB) aims to reveal how these people face the disease and the impact of treatment in their lives<sup>(3)</sup>.

Social support (SS) is one of the aspects addressed in the evaluation of QL, mainly in people with HIV/AIDS, because of prejudice in social reactions to seropositivity<sup>(4)</sup>. It is a concept that involves the structure of social relationship networks, the adequacy of their function, and the level of satisfaction with them<sup>(4)</sup>. It is possible to say that SS encompasses support policies and networks, such as families, friends and communities that contribute to the well-being of people, especially those who are excluded.

This type of support and other confrontation strategies directly influence the willingness to encouragement, positive reinforcement, motivation for self-care and adherence to the treatment in people with HIV/AIDS and TB. In this scenario, investigating the impact of SS on the QL of coinfecting people can help nurses provide more qualified care that takes into account the integrality of patients.

Despite the epidemiological importance of TB, no Brazilian studies were found about QL and SS describing patients who have TB or are coinfecting with HIV. The objective of the present study was to fill this gap by analyzing a coinfecting population.

## MATERIALS AND METHODS

The present study was descriptive and cross-sectional; it took place in Ribeirão Preto, state of São Paulo, Brazil, from February 2008 to February 2010.

The sample consisted of all outpatients with a diagnosis of coinfection with TB/HIV who received care in specialized clinics in the city and agreed to participate in the study. Inclusion criteria were being more than 18 years old; having regular follow-ups in the clinics to treat HIV/AIDS; having been diagnosed with TB; and having the physical, mental and psychological condition to allow them to be interviewed. The exclusion criterion was being incarcerated. All the patients were under supervised treatment.

Three instruments were used to collect the data: a questionnaire for socioeconomic and clinical characterization; the WHO Quality of Life-HIV BREF (WHOQOL-HIV BREF) in its Portuguese version; and the Social Support Scale for People Living with HIV/AIDS.

The WHOQOL-HIV BREF consists of 31 questions organized in six domains: physical, psychological, level of independence, social relationships, environment and spirituality<sup>(2)</sup>. The physical question subset contains items about pain and discomfort, energy and fatigue, sleep and rest, and symptoms; the psychological facet encompasses positive and negative feelings, cognition, self-esteem, bodily image and appearance; the level of independence domain is related to mobility, activities of daily living, dependence on treatment, and work capacity; the social relationships domain refers to personal relationships, social support, sexual activity and social inclusion; the environment section includes physical safety, home environment, financial resources, health and social care, information, leisure activities, physical environment, and transport; and the spirituality domain includes religion, forgiveness and blame, concerns about the future, and death.

For a global calculation of the score in each domain, which varies from 4 to 20, an equation suggested by WHO<sup>(2)</sup> was used, and the Kolmogorov-Smirnov test was performed to evaluate the normality of the distributions.

The Social Support Scale for People Living with HIV/AIDS, an instrument adapted and validated in Brazil by Seidl and Trócoli<sup>(4)</sup>, is based on the Social Support Inventory for People Who are Positive or Have AIDS<sup>(5)</sup>, which was developed in Canada. The Brazilian version has 22 items grouped under two factors: instrumental and emotional support. The first is related to perceptions about and satisfaction with the availability of support for handling or solving operational matters of treatment and care, activities of daily living, and material and/or financial assistance. The second is associated with the availability of listening, attention, information, esteem and company. The score is calculated by averaging the values obtained for the factors, which vary from 1 to 5<sup>(4)</sup>. The correlations between the scores from the QL domains and the SS factors were assessed through the calculation of Pearson's linear correlation coefficients. The data were presented as means followed by standard deviations.

The study was approved by the Research Ethics Committee of the Ribeirão Preto College of Nursing under protocol 0858/2007. The interviews were carried out after the signature of free and informed consent forms.

## RESULTS

During data collection, 391 patients were notified about the TB infection and 84 (21.5%) presented positive serology for HIV. It is important to emphasize that one of the limitations of the present study was the fact that many coinfecting patients were significantly weakened and could not be interviewed, or even died during their hospital stay. Consequently, the final sample consisted of 57 coinfecting people who met the inclusion criteria, as shown in Table 1.

**Table 1** – Socioeconomic and clinical characteristics of people with TB/HIV coinfection, Ribeirão Preto, São Paulo, Brazil, 2010. (N = 57)

<b>Variables</b>	<b>n</b>	<b>%</b>
<b>Gender</b>		
Male	43	75.4
Female	14	24.6
<b>Level of education</b>		
Illiterate	5	8.8
Incomplete primary school	34	59.6
Complete primary school	16	28.1
High school or more	2	3.5
<b>Income (in minimum wages)</b>		
≤ 1	23	40.4
1.1 to 3	29	50.9
> 3	5	8.8
<b>Time of awareness of HIV infection (in months)</b>		
≤ 6	17	29.8
7 to 60	13	22.8
61 to 120	16	28.1
≥ 121	11	19.3
<b>Number of TCD4+ lymphocytes (cells/mm<sup>3</sup>)</b>		
≤ 200	42	73.7
201 to 350	10	17.5
≥ 351	5	8.8
<b>Viral load (copies of viral RNA/ml)</b>		
Undetectable	4	7.0
51 to 20,000	9	15.8
20,001 to 100,000	26	45.6
> 100,000	18	31.6

Source: Elaborated by the authors.

The reliability of the instruments used in the investigation was tested using Cronbach's alpha. The calculated values varied from 0.69 to 0.74 for WHOQOL-HIV BREF and 0.88 to 0.92 for the Social Support Scale, revealing satisfactory internal consistency. These results can be seen in Table 2.

**Table 2** – Values obtained through Cronbach's alpha for the WHOQOL-HIV brief domains and factors of the Social Support Scale, Ribeirão Preto, São Paulo, Brazil, 2010. (N = 57)

Variables	Cronbach's alpha Mean
<i>WHOQOL-HIV BREF</i>	
Physical	0.69
Psychological	0.74
Level of independence	0.72
Social relationships	0.71
Environment	0.62
Spirituality	0.54
<i>SS Scale factors</i>	
Instrumental support	0.88
Emotional support	0.92

Source: elaborated by the authors.

The variable instrumental support on the Social Support Scale showed statistically significant linear correlations with the domains physical and social relationships; as for emotional support, correlations were identified with all domains, except spirituality. Table 3 exhibits these data.

**Table 3** – Values of Pearson's linear correlation coefficients calculated to investigate the relationship between WHOQOL-HIV BREF domains and the factors of the Social Support Scale, Ribeirão Preto, São Paulo, Brazil, 2010.

	Social Support Scale	
	Instrumental Support	Emotional Support
<b>WHOQOL-HIV BREF domains</b>		
Physical	0.661*	0.617**
Psychological	0.255	0.778**
Level of independence	0.115	0.620**
Social relationships	0.710*	0.680**
Environment	0.256	0.584**
Spirituality	0.030	0.210

Source: elaborated by the authors.

\*0.01 < p < 0.05; \*\*p < 0.01

## DISCUSSION

The results of the present study showed that the socioeconomic characteristics of the participants matched the social profile observed in other studies of populations with AIDS and TB, which are diseases that affect people with low levels of education and low income<sup>(6-8)</sup>.

Most of the patients interviewed were males. The higher rate of TB infection in men may be explained by behavioral characteristics, such as higher exposure to the bacterium and difficulty adhering to treatment<sup>(9)</sup>.

One-third of the people with coinfection had known about their serological condition less than six months before the interview, a finding that reveals the importance of testing for HIV in this type of population. Twenty-seven participants, or 47.4% of the sample, had learned about the viral infection more than five years before the interview, illustrating the need to prevent infection by the TB bacillus in people with HIV/AIDS. The clinical outcomes, such as low levels of TCD4+ lymphocytes and high viral load, were evidence that TB is an opportunistic infection associated with significant mortality rates<sup>(10,11)</sup>. A study carried out in Goiânia reported that most people with TB/HIV had a cell count lower than 350 cells/mm<sup>3</sup><sup>(9)</sup>.

The average scores for the QL domains were intermediate. The literature shows that some aspects of the quality of life of people with HIV/AIDS are affected when the infection results in a chronic condition<sup>(1)</sup>. A survey in Fortaleza found that patients coinfecting with TB/HIV presented lower QL scores in comparison to those who only had HIV<sup>(12)</sup>.

Other authors have found lower QL for patients with HIV/AIDS than for the population in general<sup>(13)</sup>. This was also observed for patients with TB in a study that took place in China<sup>(14)</sup>.

Taking into account that social support is a relevant factor in the evaluation of QL, and that people coinfecting with TB/HIV are more vulnerable because of the double infection, some authors have pointed to the importance of adherence and confrontation in people with HIV/AIDS<sup>(15)</sup>. As for TB, no reports were found, but given its incidence in adverse socioeconomic scenarios, SS is cited as a significant component of treatment. The literature indicates that SS is a predictive factor for improvement of QL dimensions<sup>(16,17)</sup>.

The correlation analysis revealed an association between instrumental support and the physical and social relationship domains. Emotional support was related to all domains, except spirituality.

The physical domain, in which SS is important to help keep patients functioning<sup>(18)</sup>, presented a correlation with instrumental and emotional support. Physical manifestations, such as cough and weight loss, together with prejudice, contribute to changes in self-image and make patients see themselves as sick and fragile people<sup>(19)</sup>, a situation that can be improved through the support of family and friends. Social support also impacts adherence to treatment: One study demonstrated that people with AIDS who can count on family support showed better adherence to antiretroviral therapy<sup>(20)</sup>.

The other domain that showed a correlation with both types of support was social relationships, in which the structuring of the support network is more evident and takes into consideration the possibility of social isolation and restriction of relationships due to fear of prejudice. This discrimination causes patients to feel guilty when faced with what they cannot change, a feeling that can be strengthened by family, friends and society through demands and isolation<sup>(21)</sup>.

Contrary to what happens in other chronic conditions, usually people with AIDS decide to keep the diagnosis secret, which may lead to detachment from people who could provide support.

The suffering described by people with TB refers not only to the physical disease, but also to a condition that impacts different aspects of life, especially social relationships<sup>(19)</sup>. They move towards isolation, which can result from the discrimination that patients experience from people around them or from prejudice against the condition itself, which causes infected people to see themselves as a risk to the community.

The only QL domains that showed a correlation with emotional support were psychological, environment and level of independence.

The correlation of the psychological domain with emotional support was predictable, as reported by other authors<sup>(22)</sup>, given that it refers to feelings, self-esteem and cognition. A study in India<sup>(23)</sup> showed that lack of family support was one of the predictive factors for low QL in coinfecting people. In addition, support from family and friends is positively associated with emotional well-being and helps support changes in lifestyle<sup>(17)</sup>.

A family structure that understands the disease and adapts to it allows patients to feel stronger as a result of affection and help<sup>(24)</sup>.

The environment domain encompasses items related to financial safety, access to health services, information, and leisure activities. The low scores found in this domain stress the poverty nature of both epidemics<sup>(25)</sup>. The difficulties caused by socioeconomic factors, together with those associated with the disease itself, result in a larger number of stressful factors, which negatively impacts psychological well-being and QL<sup>(15)</sup>.

Supervised treatment can be perceived as a type of support provided by health services. The right therapy results in quick improvement in symptoms, and the bond established between professionals and patients promotes better perceptions of the care received<sup>(25,26)</sup>.

The association between emotional support and independence stresses the importance of feeling functional in carrying out the activities of daily living and not being a burden on the family. Aptitude for work is a relevant factor for confronting disease and characterizes individuals as productive before society. Having a job increases self-esteem and favors the development of a sense of identity<sup>(27)</sup>.

The experience of having the TB/HIV coinfection can cause suffering and changes in daily life and the way patients interact with themselves and others; this population

presents characteristics inherent to its usually unfavorable social context, which increases its dependence on support.

## CONCLUSION

The the low to moderate QL outcomes in the present study are fed by clinical manifestations and the fear of the stigma attached to both diseases, which implies changes in social relationships.

Social support can have positive or negative effects on QL, affecting physical and emotional aspects. Support from family, friends and healthcare professionals promotes an increase in self-esteem and adherence to treatment and eases the negative consequences of stressful events, directly impacting QL.

Support received from the family and members of social networks reduces prejudice against both conditions and positively affects the QL of coinfecting people.

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