Original Article

Tuberculosis/HIV coinfection focused on care and quality of life

A coinfecção tuberculose/HIV com enfoque no cuidado e na qualidade de vida

Coinfección tuberculosis/VIH con enfoque en el cuidado y en la calidad de vida

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Abstract

Objective: To describe and analyze the perceptions of people who experience tuberculosis/human immunodeficiency virus coinfection in relation to quality of life and health care.

Methods: An exploratory, descriptive, qualitative study conducted with ten people experiencing coinfection who received care at a reference center in the city of São Paulo. A semi-structured questionnaire composed of closed questions and guiding questions was used for data collection. The analysis of testimonies was based on the Theory of Social Determination of the Health-Disease Process.

Results: Participants mentioned that precarious conditions of life interfered in the quality of life and reported satisfaction with the care provided and the health care network. Experiencing tuberculosis/human immunodeficiency virus coinfection caused suffering, social isolation and stigma, which can contribute to suicidal ideation and lower quality of life. In the perception of participants, health professionals contribute to maintain the quality of life by developing bonds and humanized care.

Conclusion: Interventions aimed at reducing social inequalities that support the reduction of stigma and prejudice and increase humanized interaction in health services in order to meet users' health needs can exert positive impact on the perception of quality of life and health care of those experiencing tuberculosis/human immunodeficiency virus coinfection.

Resumo

Objetivo: Descrever e analisar as percepções de pessoas que vivenciam a coinfecção tuberculose/ vírus da imunodeficiência humana, quanto à qualidade de vida e ao cuidado em saúde.

Métodos: Estudo exploratório, descritivo, com abordagem qualitativa, realizado com dez pessoas que vivenciavam a coinfecção e que recebiam atendimento em um centro de referência do município de São Paulo. Para a coleta de dados, foi utilizado um questionário semiestruturado, composto por questões fechadas e questões norteadoras. A análise dos depoimentos baseou-se na teoria da determinação social do processo saúde-doença.

Resultados: Os participantes apontaram que as condições precárias de vida interferiam na qualidade de vida e referiram satisfação em relação ao cuidado ofertado e com a rede de atenção à saúde. Vivenciar a coinfecção tuberculose/vírus da imunodeficiência humana acarretou sofrimento, isolamento social e estigma, o que pode contribuir para ideação suicida e diminuição da qualidade de vida. Na percepção dos participantes, os profissionais de saúde contribuem para a manutenção da qualidade de vida, por meio do estabelecimento de vínculo e atenção humanizada.

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Conflicts of interest: Although Taminato M and Hino P are Associate Editors of the Acta Paulista de Enfermagem, they did not participate in the peer-review process of this article.

Conclusão: Intervenções voltadas à redução das desigualdades sociais, que apoiem a diminuição de estigma e do preconceito e que incrementem a interação humanizada nos serviços de saúde, de forma a atender às necessidades de saúde dos usuários podem repercutir positivamente na percepção sobre a qualidade de vida e o cuidado em saúde daqueles que vivenciam a coinfecção tuberculose/vírus da imunodeficiência humana.

Resumen

Objetivo: Describir y analizar las percepciones de personas que presentan la coinfección tuberculosis/virus de la inmunodeficiencia humana con relación a la calidad de vida y al cuidado de la salud.

Métodos: Estudio exploratorio, descriptivo, con enfoque cualitativo realizado con diez personas que presentaron la coinfección y que recibían atención en un centro de referencia del municipio de São Paulo. Para la recopilación de datos se utilizó un cuestionario semiestructurado, compuesto por preguntas cerradas y preguntas orientadoras. El análisis de los relatos se basó en la teoría de la determinación social del proceso salud-enfermedad.

Resultados: Los participantes señalaron que las condiciones precarias de vida interferían en la calidad de vida y relataron satisfacción con relación al cuidado ofrecido y a la red de atención en salud. Tener la coinfección tuberculosis/virus de la inmunodeficiencia humana conlleva sufrimiento, aislamiento social y estigma, lo que puede contribuir con ideación suicida y reducción de la calidad de vida. Bajo la percepción de los participantes, los profesionales de la salud contribuyen para mantener la calidad de vida, mediante el establecimiento de vínculos y atención humanizada.

Conclusión: Intervenciones orientadas a la reducción de las desigualdades sociales, que apoyen la disminución del estigma y los prejuicios y que aumenten la interacción humanizada en los servicios de salud, a fin de atender las necesidades de salud de los usuarios, pueden repercutir positivamente en la percepción sobre la calidad de vida y el cuidado de la salud de aquellas personas que padecen la coinfección tuberculosis/virus de la inmunodeficiencia humana.

Introduction

Infection with the human immunodeficiency virus (HIV) is one of the main risk factors for the development of tuberculosis (TB), which remains one of the main health problems and causes of death worldwide.(1,2) According to the Global Tuberculosis Control Report, the risk of an HIV-infected individual developing the disease is 28 times greater, compared to the general population.(2)

In 2019, 10 million people became ill with TB worldwide, of which 8.2% living with HIV/AIDS (PLWHA).(1) In Brazil, 73,864 new TB cases were reported in 2019, which represents a coefficient of incidence of 35 cases/100,000 inhabitants. Of the total number of cases, 76.1% underwent HIV serology and 8.4% tested positive. Among people with TB/HIV coinfection, only 47.5% underwent antiretroviral therapy (ART).(3)

With the introduction of the policy of universal and free access to ART, from 1996 onwards, AIDS started to be characterized as a chronic disease. In this sense, the assessment of quality of life (QoL) is considered an essential measure to propose the necessary actions to assist these people.(4,5)

A study of 57 people experiencing TB/HIV coinfection conducted in the countryside of São Paulo showed that they perceived themselves as fragile due to the clinical manifestations related to the association of diseases, among which, weight loss and cough, with repercussions on routine and social relationships. Note that the lack of financial support together with health difficulties had a negative impact on QoL. Quality of life was the result of the interaction between possible social supports such as financial aid, source of income, support from friends and family, and signs and symptoms resulting from coinfection, which may result in better or worse perception of QoL.(6)

Research developed in India with the aim to evaluate and compare QoL between HIV patients with and without TB showed that people with TB/HIV coinfection had a lower QoL score and a greater chance of manifesting mood disorders, compared to PLWHA who did not have TB. People living with TB/HIV coinfection obtained scores suggestive of mild mood disorders, and those with HIV but without TB were mostly classified as healthy from the mental health point of view.(7)

Like HIV/AIDS, TB generates stigma and prejudice, therefore, the person who experiences coinfection faces not only physical consequences of diseases, but also emotionally stressful and less favorable social situations that may impact on QoL.(4,8,9) In fact, both diseases can cause internal conflicts, since accepting a new state of compromise in the health-disease process can be full of difficulties.(5,6,9)

The World Health Organization (WHO) defines QoL as: “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”.(10)

The literature review on the subject in question points out that most research is related to PLWHA, and not specifically to TB/HIV coinfection.(11-14) The justification for studies addressing this theme is to fill this knowledge gap and provide elements that contribute to rethink health actions aimed at improving QoL and health care.

In addition, the relevance of the study refers mainly to the need to unveil meanings and perceptions from the point of view of people experiencing TB/HIV coinfection, which can be achieved by making this group's vocalization possible. The fact that only three qualitative studies on the subject were found is noteworthy.(5,15,16)

In view of the above, the aim of the present study was to describe and analyze the perceptions of people experiencing TB/HIV coinfection with regard to the QoL and health care.

Methods

This is a descriptive, qualitative study on QoL and health care according to perceptions of people experiencing TB/HIV coinfection. The study scenario was an AIDS Reference and Training Center in the city of São Paulo. Inclusion criteria were people aged 18 or over, regardless of sex, with HIV-positive serology (having developed the syndrome or not), who had been undergoing TB and ART treatment for at least a month and with physical and cognitive conditions to answer the questionnaire. The exclusion criterion was being deprived of liberty at the time of data collection.

A semi-structured instrument was used for data collection. It was developed exclusively for this study and composed of questions on the sociodemographic and health profile, as well as the following guiding questions: "1) Report a remarkable situation that you lived since you had the TB and HIV diagnosis; 2) Has the treatment of TB and ART brought needs to that you did not have before?; 3) How do you assess your quality of life?; 4) Does the health service help you to cope with your needs?". The questions allowed interviewees to freely discuss the topic in question. A pilot study was conducted with four people experiencing TB/HIV coinfection, who were not included in the study with the aim to assess the clarity of questions and make the necessary adjustments.

People experiencing TB/HIV coinfection were invited to participate in the study when they came for a medical consultation or to collect their medication. The interviews were conducted between April and August 2019 by one of the authors of the article, who was previously trained to do so. Data collection took place in a reserved room of the institution to guarantee the privacy and quality of information. Interviews lasted an average of 25 minutes and were recorded using a digital audio recorder to provide greater authenticity in understanding participants' perceptions. Subsequently, its content was transcribed by the interviewer himself.

The testimonies were identified by a letter (I), followed by an Arabic number to guarantee the anonymity of participants. The next step involved reading the testimonies in depth, with a view to apprehend meanings about QoL and the health care provided to people experiencing TB/HIV coinfection.

The discourse analysis technique was used in the analysis of empirical material. It allowed the comprehension of real life expressions, containing people's world views regarding the elements of objective reality that materialize in representations.(17) The analysis of testimonies was performed in the light of the Theory of Social Determination of the Health-Disease Process.

As this research involves human beings, the project meets the standards of Resolution number 466/2012 and was approved by the Ethics Committee (opinion number: 2.906.733) and by the Research Ethics Committee of the aforementioned health service where interviews were held (opinion number: 3.267.922) (CAAE: 91820618.0.3001.5375).

Results

The interviews followed the criterion of information saturation with participation of ten people who experienced TB/HIV co-infection. Tables 1 and 2 show some sociodemographic and health characteristics of interviewees.

Table 1. Sociodemographic profile of study participants. AIDS Reference and Training Center

Variables	Absolute frequency
Sex	
Male	7
Female	1
Transsexual	2
Sexual orientation	
Homosexual	5
Heterosexual	4
Bisexual	1
Age group (years)	
18 to 29	3
30 to 39	2
40 to 49	3
50 to 59	2
Skin color	
White	5
Mixed race	5
Religion	
Does not have	4
Buddhist	1
Catholic	4
Evangelical	1
Education (years)	
1 to 4	1
5 to 8	1
9 to 12	7
13 to 16	1
Marital status	
Single	8
Married/common law marriage	2
Occupation	
Retired	3
Unemployed	5
Sex worker	1
Trade	1
Family income (reais)	
No income	2
≤ 1 MW*	1
2 to 3 MW	3
> 3 MW	4

MW – minimum wage

Most participants were male biological sex (n=9) and of these, two declared themselves as trans women. Half of interviewees reported they were looking for a job, two declared to be away from their work activities due to TB and other opportunistic diseases, and three were retired for disability as a result of some incurable HIV-related disability. Regarding HIV, most believed they had contracted the virus through sexual intercourse (n=9) and had known of their serological status for more than ten years (n=7), six reported a viral load below 50 copies/ml and half of participants had been on ART for more than 360 days. As for TB, the pulmonary form was predominant and seven were being treated for a period of 31 to 90 days. The themes emerging during the analysis of testimonies were grouped into four categories (Figure 1).

Table 2. Health-disease profile of study participants. AIDS Reference and Training Center

Variables	Absolute frequency
Form of exposure	
Sexual	9
Does not know	1
HIV diagnosis time (years)	
< 1	2
6 to 9	1
> 10	7
Viral load (copies/ml)	
< 50/undetectable	6
50 to 20.000	4
TCD4 cells	
< 200	5
200 to 350	3
> 350	2
ART use (days)	
31 to 90	1
91 to 360	4
> 360	5
Clinical form of TB	
Pulmonary	8
Pulmonary + Extrapulmonary	2
TB treatment (days)	
31 to 90	7
91 to 360	3

The impact of coinfection	Life after coinfection	Quality of life	Care in the health service
Discovery of diagnoses; suicidal ideation; demotivation; denial of diagnoses	Secrecy; social isolation/suffering; self-stigma; responsibility for disease transmission; relationship difficulties; physical weakness	Side effects of treatments; social determinants of health; support from family and friends	Service organization; professional attitude; vulnerability to treatment abandonment; social support

Figure 1. Categories of analysis and their constituent elements

The in-depth analysis of testimonies made it possible to know the perception of people who had TB/HIV coinfection with regard to QoL and health care. Regarding the category “The impact of coinfection”, most interviewees referred to suicidal ideation as a result of HIV. One of the interviewees reported more than one suicide attempt due to the suffering caused by his HIV status. The illness caused by TB was mentioned as a demotivating situation, as some interviewees did not believe in the success of treatment. According to interviewees, demotivation and constant suicidal ideation have a negative influence on QoL.

> *"At first, I had a lot (depressed mood), I wanted to, of course, I ended up trying to commit suicide, it wasn't just once...". I8*

Most respondents (n=6) were diagnosed with positive HIV serology during a stable relationship, with some experiencing a long period of monogamy, which contributed to a negative perception of the health-disease process, as, according to them, the routine imposed by treatments led to the constant recall of their former partners' betrayals, with a negative impact on QoL. Experiencing the death of partners and friends resulting from HIV complications also interfered in the negative conception of the disease, with repercussions on QoL given the restriction of their social support networks. It is noteworthy, that the non-acceptance of the HIV diagnosis for a long period was common, which included the continuation of casual sexual relations without using condoms. Although paradoxical, according to interviewees, denying the diagnoses made it possible to improve the perception of QoL, as they believed they would suffer less with the reality they experienced.

The "Life after Coinfection" category included representations of the embarrassment and disappointment they felt towards themselves for having both TB and HIV, and fear of discrimination and prejudice, which determined the social isolation imposed by themselves for self-protection. In this line, reports of negative developments on QoL were observed. The confidentiality of the diagnosis was expressed as a coping strategy for this situation, allowing a better perception of QoL.

Another relevant aspect refers to the responsibility for transmitting HIV, since most were concerned with the protection of the partner and had the tendency to adopt the sexual behavior of abstinence, while on the other hand, others continued to have unprotected sexual relations. Those who chose to take responsibility for transmitting the virus reported difficulty in establishing love relationships, which resulted in a feeling of loneliness and impacted negatively on the QoL. Situations of social isolation, self-discrimination and difficulty in establishing love relationships resulted in suffering and a possible decrease in QoL, requiring psychological support to be able to live with such anguish.

> *"...I isolated myself for a year, I didn't see anyone, I didn't want to look anyone in the eye, either because of my prejudice against the disease or because of the prejudice of others, I guess the most difficult thing is: - Why has a married guy caught this? Did you go to the club? No, I caught it at home". I9*

There were testimonies reporting the significant physical weakness caused by the HIV/TB association to the point of preventing daily activities, also with a negative impact on QoL.

The category referring to the "Quality of Life" brought together representations that showed the knowledge of positive serology in adulthood and difficulty in adherence to treatments given the side effects, with an impact on the perception of QoL. On the other hand, participants who discovered their serological status during adolescence reported they did not remember what their QoL was like before HIV, as they only remembered their lives after diagnosis, which seems to reveal the impact of the disease on their lives.

Experiencing TB together with HIV may have contributed to the decrease in QoL. Other elements that may have contributed to the decrease in QoL were unhealthy housing, situation of physical and/or sexual violence, religious and family repression because of sexual orientation, exposure and humiliation, treatment of Kaposi's Sarcoma, deprivation of freedom, prejudice for being transsexual or for sexual orientation. Dependence on alcohol and other drugs, such as cocaine and crack, and discovery of the partner's serological status have also been reported.

Study participants reported that it is impossible to dissociate social and individual factors to analyze how TB and HIV may have influenced QoL. According to them, the interaction between social conditions of the most varied orders, in addition to the representation about them, that is, the way people express their subjectivity, influences the experience of TB/HIV infection and impacts on the perception of QoL, as seen in the following excerpt:

> *"Having HIV is not just a chronic disease, it goes beyond that, I have religious repression, no family protection, I am exposed to the public, sexually overdeveloped as a consequence of abuse, victim of beatings so, I bring these issues with myself every time I take a pill". I2*

The neglect of health mentioned by some of interviewees was associated with traumatic experiences that, according to them, caused suffering, anguish and low self-esteem, which made the search for health care more difficult, and reflected on the QoL.

On the other hand, interviewees mentioned that support from family and friends was fundamental for the acceptance of TB and HIV diagnoses, as well as to feel motivated in the continuity of treatments, with a positive impact on QoL.

The "Care in the Health Service" category included representations showing that interviewees emphasized the importance of the proper organization of the work process to meet the health needs and demands of this population segment, which generated satisfaction and, according to them, was fundamental for maintaining the QoL. The interviewees highlighted as positive the way they were attended by the service's health professionals.

> *"I have already been to several places, the AIDS Reference and Training Center is a paradise ... you see the attention of the nursing staff, always happy, they hug you, a lot of human warmth, everything works here ... if you have a problem, everyone is focused on you and will find a way to solve it, you don't see this anywhere, not even in private services". I4*

Note that cases of abandonment of treatment for both TB and HIV have occurred, and some refused to accept the new health status. In the case of abandonment of TB treatment, it was associated with hopelessness in relation to treatment. There were also reports of the presence of opportunistic diseases and TB recurrence.

Some participants reported not having the financial conditions to continue the treatments thus, the offer of social support measures, not only through financial help, but also the support from family and friends simultaneously with humanized care in the health service are essential.

Discussion

Knowledge of the perception of QoL and health care from the perspective of people experiencing TB/HIV coinfection may help in proposing and implementing health actions aimed at this specific group and understanding their health needs.

Most interviewees were transsexual women and men who had sex with other men (MSM), reported the HIV infection through sexual intercourse and the discovery of their serological status while in a steady relationship, which highlights the need for public policies aimed at this group. The reason is that despite the efforts made towards raising awareness about the forms of transmission and the potential for HIV transmission, there is still vulnerability, especially when considering the meanings of this issue for the general population. This interpretation configures the individual dimension of the concept of vulnerability.(18)

Scientific evidence does not address the relationship between sexual orientation and gender identity of people experiencing TB/HIV coinfection. A Systematic Review on the sociodemographic profile of this population indicated an association with heterosexuality, even though the authors questioned this finding and explained that most research used data from the Notifiable Diseases Information System (*Sistema de Informação de Agravos de Notificação* - SINAN), which has no specific field for such information.(19)

The sociodemographic profile of interviewees demonstrated social conditions of social vulnerability, which requires public policies to reduce social inequalities and provide better living and working conditions. It is also necessary that health services act towards monitoring this population, since most of them have been aware of the diagnosis for more than ten years, reported low viral load, but developed TB, and in some cases, the manifestation of opportunistic infection was related to non-acceptance of HIV infection. This fact demonstrates the need for stronger actions of active search for respiratory symptoms performed by the nursing team in order to avoid the emergence of opportunistic diseases and recurrence of TB in this segment, with impact on QoL.

A study conducted in a municipality in the countryside of São Paulo on adherence to ART demonstrated that people of older age, longer time of HIV diagnosis, lower viral load and greater number of CD4 cells showed better adherence to therapy.(20) These findings corroborate with the present study, in which even with these conditions, the QoL was low. Another study conducted in São Paulo on the difficulties in managing HIV demonstrated that QoL goes beyond the disease, as it involves social aspects that prevent personal, professional and affective development, with emphasis on the prejudice experienced by those who have the infection.(21)

It was also relevant that all respondents reported that their work activities were affected by the experience of one of the infections, either TB or HIV, demonstrating how illness can interfere with the income of these people and families and consequently, compromise their QoL. No studies assessing the impact of TB/HIV coinfection on insertion in the labor market were found in the literature.

Respondents reported they felt the health team's embracement, reporting that professionals cared about their life stories and the care they promoted was often unexpected, which was essential for maintaining QoL. These findings corroborate studies developed in Minas Gerais and in the municipality of Ribeirão Preto.(20,22)

The aim of the National Humanization Policy is to reinforce the importance of ambience in health care, understanding that follow-up treatment in services should result in user satisfaction.(23) A study on adherence to ART conducted in the countryside of São Paulo reinforces the importance of strengthening multidisciplinary, integral and multidimensional strategies in order to promote people's involvement in their treatments.(20)

In the present investigation, reports that self-stigma and fear of discrimination were responsible for social isolation were frequent. This corroborates the results of a study conducted in a city in the state of São Paulo, in which higher QoL scores were related to greater social and emotional support.(6)

In this sense, nurses' participation is indicated, since they can help to bring the support network made up of family and friends closer to the person experiencing the diseases. These people were considered essential by interviewees, and this can contribute to improve the achievement and perception of QoL.

Respondents understood that living and working conditions were related to their health situation, whether due to the greater or lesser susceptibility to falling ill. When asked about QoL, issues related to poverty, violence, prejudice, isolation and relationship difficulties were mentioned, which is in line with the results of a study conducted in a city in the countryside of São Paulo. In such as study, was found an association between unemployment, lack of social support, social isolation and side effects of medications for TB and HIV and the difficulty of adherence to treatment and lower QoL.(20)

The testimonies showed some repeated experiences, namely the denial of diagnosis, social isolation and sum of the side effects of TB treatment and ART. Experiencing TB/HIV coinfection revealed suffering that many pointed out to be the result of situations of violence and exclusion to which they had been exposed throughout their lives and resulted in a negative perception of the quality of their lives.

It was also reported that experiencing TB/HIV coinfection was not the central issue that caused the decrease in QoL, but the social determinants of health that add to that moment.

In fact, according to interviewees, the QoL resulting of the experience of TB/HIV coinfection was derived from a combination involving several social and health factors that impact on the perception of QoL. According to participants, the following individual elements impacted on the QoL: symptomatology, side effects of medications, the social prejudice resulting from both diseases, at the same time that aspects related to living and working conditions, such as homelessness, unemployment, and others, which can be pointed out as a consequence of the organization of society that produces inequalities and affects the health-disease process, such as chemical dependency, or even elements showing mistaken ideological conceptions, such as the prejudice arising from sexual orientation or gender identity.

The testimonies corresponded to the WHO definition of QoL that transcends physical health by integrating emotional and social aspects as well.(10) Studies conducted in Ethiopia, Brazil and Nigeria have shown that QoL has suffered negative consequences due to the association between both infections.(4,8,9,24) In fact, poverty and suffering resulting from facing precarious living and working conditions, and the consequent low self-esteem resulted in lower QoL in people who experience TB/HIV coinfection, according to reports of the present study and of studies performed in Ethiopia, Thailand and South Africa.(4,8,25,26) Other studies also confirmed interviewees' perceptions by indicating that having a source of income, a higher level of education, and family and social support contribute to the maintenance of QoL.(6,8,25,26)

It is important to state that the variables related to social conditions and recognized by the WHO as social determinants are inherently related to QoL, as they constitute the conditions for improvement, coping or strain in the course of life. However, we highlight that the analysis of the object of the present study in the light of the Social Determination of the Health-Disease Process requires the understanding that the structuring of society and its way of organization determine specific processes of social reproduction, i.e., specific possibilities to experience health-disease given the different belonging to social groups. Thus, coping with the health-disease process and the strain suffered by people who experience coinfection are mediated by the specificity in social insertion.

We consider that the findings of the present research contribute to understand how people experiencing the TB/HIV association perceive their QoL. A limitation of the study was the complexity of the QoL concept, which involves aspects related to the experience of the disease, subjectivity, living and working conditions, in addition to the possibilities of access to health services. Such complexity may not have been expressed in its entirety, since the study learns a part of the totality of participants' experience.

Conclusion

From the analysis of testimonies, it was observed that the organization of the health service by offering user embracement to people with TB/HIV coinfection, in addition to support for treatment, which is not restricted to care, but also refers to the provision of free medication and support for follow-up treatment, influence the QoL. Health interventions that consider living and working conditions, the resulting vulnerabilities and the experience of the health-disease process are fundamental for improving the QoL, in addition to social protection actions and interventions aimed at reducing social inequalities.

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Collaborations

Carvalho MVF, Silva ARS, Taminato M, Bertolozzi MR, Fernandes H and Hino P collaborated with the analysis and interpretation of data, writing of the article, relevant critical review of the intellectual content and approval of the final version to be published.

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