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Original Article

SOCIAL AND HEALTH ASPECTS OF PATIENTS CO-INFECTED WITH HIV/TUBERCULOSIS

ASPECTOS SOCIAIS E DE SAÚDE DE PORTADORES DA COINFECÇÃO HIV/TUBERCULOSE

ASPECTOS SOCIALES Y DE SALUD DE PORTADORES DE LA COINFECCIÓN VIH/TUBERCULOSIS

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The aim was to assess the social and health aspects and perception about the diagnosis of individuals co-infected with HIV/tuberculosis. This descriptive study, with quantitative-qualitative approach was accomplished at a referral hospital in Fortaleza, Ceará, Brazil, between January and April 2009, using semistructured interviews held in a private environment. Data were analyzed descriptively and through content analysis. Participants were 16 patients co-infected with HIV/tuberculosis, 56.25% male. The predominant age range was between 31 and 39 years (43.75%), education levels were low and the monthly family income was approximately one minimum wage. Pulmonary tuberculosis was the predominant form (62.50%). Patients' perception about the discovery of the co-infection was demonstrated through two categories: Fear and anguish in view of the diagnosis and Changes in health habits and lifestyle. In view of the findings, there is an urgent need to promote these patients' psychological and physical wellbeing through political and health actions.
Descriptors: Coinfection; HIV; Tuberculosis.

Objetivou-se avaliar os aspectos sociais e de saúde e a percepção diante do diagnóstico de indivíduos com a coinfecção HIV/tuberculose. Estudo descritivo, com abordagem quantiqualitativa, realizado em hospital de referência em Fortaleza, Ceará, de janeiro a abril de 2009, utilizando-se entrevista semiestruturada em ambiente privativo. Os dados foram analisados de modo descritivo e por análise de conteúdo. Participaram 16 pacientes com coinfecção HIV/tuberculose, 56,25% do sexo masculino, com faixa etária predominante entre 31 a 39 anos (43,75%), com pouca escolaridade e renda familiar mensal de aproximadamente um salário mínimo. A forma predominante da apresentação da tuberculose foi a pulmonar (62,50%). A percepção sobre a descoberta da coinfecção foi demonstrada por duas categorias: Medo e angústia face ao diagnóstico e Mudanças nos hábitos de saúde e no estilo de vida. Urge, diante dos achados, a promoção do bem-estar psicológico e físico desses pacientes, por meio de ações políticas e de saúde.
Descritores: Coinfecção; HIV; Tuberculose.

La finalidad fue evaluar los aspectos sociales y de salud y la percepción ante diagnóstico de individuos coinfectados con VIH/tuberculosis. Estudio descriptivo con enfoque cuantitativo-cualitativo en hospital de referencia en Fortaleza, Ceará, Brasil, desarrollado entre enero y abril del 2009, mediante entrevista semiestructurada en ambiente privativo. Los datos fueron analizados de manera descriptiva y por análisis de contenido. Participaron 16 pacientes con coinfección VIH/tuberculosis, 56,25% masculino, en el rango de edad predominante entre 31 y 39 años (43,75%), con poca escolaridad y renta familiar mensual de aproximadamente un salario mínimo. La forma predominante de la tuberculosis fue la pulmonar (62,50%). La percepción sobre la descubierta de la coinfección fue demostrada por dos categorías: Miedo y angustia ante el diagnóstico y Cambios en los hábitos de salud y estilo de vida. Urge, ante los hallazgos, la promoción del bienestar psicológico y físico de esos pacientes, mediante acciones políticas y de salud.
Descriptores: Coinfección; VIH; Tuberculosis.

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INTRODUCTION

Tuberculosis (TB) is one of the most common complications associated to the human immunodeficiency virus (HIV) worldwide and in particular, in developing countries. The connection between the two diseases, denominated HIV/TB co-infection is provoked by the easy transmission and development of the active disease in conditions of malnutrition, poverty, crowded environments and in immunosuppressed patients [1].

In agreement with data released by the Health Ministry, the situations that negatively affect successful tuberculosis control are: the precariousness of health services to assist sick patients or individuals suspected of contracting TB; the difficulty for the lower classes to access transportation means to reach public health services and the lack of resources to grant adequate nutrition and follow treatment. Consequently, such conditions compromise early diagnosis and treatment continuity, resulting in disastrous consequences for the coinfected patient and thus enabling tuberculosis containment [2].

The TB problem in Brazil is reflected in the national and social development situation, as poverty conditions, precarious sanitary services and organizational deficiencies in the public health system limit the achievement of tuberculosis control goals, and consequently, inhibit the disappearance of diseases marked by the social context [3]. The Northeastern region has the worst socioeconomic development levels, thus making disease prevention and control initiatives more difficult [4].

With regards to the different aspects described to control the HIV/TB coinfection outbreak, a wide global effort is necessary, linking early case detection and treatment strategies for patients, communicating agents and individuals with latent infection [5]. This also implies that professionals should be aware of the need to implement health promotion initiatives and managers should generate and facilitate public policies aimed at reducing HIV/TB coinfection rates and improving quality of life for this population sector.

However, although the health system and health professionals are sensitive about this problem, coinfection control goes beyond living conditions and lifestyles of infected patients, as tuberculosis is a disease that is strongly related to bad living conditions [6]. Therefore, vulnerable individuals with poor living standards are more likely to get infected and develop the disease as a consequence of their precarious living conditions and the poverty they have to endure.

Consequently, with these ideas in mind, the goal of the present study is to evaluate social and health issues, as well as the perceptions of HIV/tuberculosis diagnosed patients treated at reference health services in the State of Ceará.

METHODS

This is a descriptive study with a quantitative-qualitative approach. A quantitative research was applied to evaluate data on some aspects of the social and health conditions of HIV/TB coinfected patients. To better understand the influence of such aspects in the living conditions of these individuals, we intended to learn about their perceptions when confronted to the HIV/TB diagnosis.

The investigation was carried out at the specialized ambulatory service for HIV/TB coinfection of the São José Infectious Diseases Hospital (HSJ), which is a reference hospital for HIV/Aids and Tuberculosis treatment in the state of Ceará. The study took place between January and April, 2009.

16 patients of legal age and of both sexes took part in the study, all with confirmed diagnosis of tuberculosis and HIV as detailed in their clinical records. As inclusion criteria we considered patients with new TB cases, that is to say, those who had never received TB

treatment for a month or longer period and were in their first month of treatment.

Patients were invited to participate in the study, being informed on the study purpose. There were no objections so all new cases being accompanied during that time took part in the study. The interviews were conducted in a private environment in the premises of the referred ambulatory service after routine medical consultation. It is worth highlighting that assistance to HIV/TB coinfected patients would only take place on Friday mornings, being this period used to recruit patients that met inclusion criteria.

For data collection purposes, a semi-structured form divided into two sections was used. In the first section, sociodemographic and clinical data was entered according to the following variables: sex, age, schooling, family income, occupational situation, nutritional habits, living habits (physical and leisure activities) smoking, drinking, use of illegal drugs, sleep and rest, complaints related to health problems (signs and symptoms) and tuberculosis type. The second section included two guiding questions to study the patients' perceptions on the HIV/TB coinfection diagnosis, described as follows: "tell me how you felt when you learned about your HIV/TB coinfection diagnosis" and "are there any changes related to the HIV/TB coinfection in your daily routine?

In order to organize data, responses were analyzed through descriptive statistics through absolute and relative frequency. As for the open questions, statements were studied according to contents analysis [7] composed of three phases: 1. Organization and systematization of ideas; 2. Analysis of material corresponding to the systematic transformation of raw text data through clipping, aggregation and enumeration, seeking to reach contents meanings and consequently, optimal text comprehension and; 3. Treatment of results, inference and interpretation. Statements were analyzed and similar contents were grouped together, creating two thematic subcategories: fear and anguish when confronting the diagnosis and changes in health habits and lifestyle.

The study was approved by the Research Ethics Committee of the São José Infectious Diseases Hospital under protocol nº 025/2008. Interviewees' participation was formalized through the signature of an Informed Consent Agreement. Seeking to keep patients' anonymity, each patient was identified with a letter P followed by a number that corresponds to the order in which they appear in the study.

RESULTS

Out of the 16 patients included in the study, 56.25% were males. The age distribution shows that 31.25% were between 21 and 29 years of age, 43.75% were between 31 and 39 and 43.75% were between 41 and 49. Pulmonary tuberculosis was the predominant type with 62.50% of cases.

As for schooling, only 37.50% had more than eight years of education, out of which two had completed higher education, all others had little formal education. With regards to their employment status, 18.75% were unemployed and 18.75% did the housework. As for their financial situation, 75% reported an income of one minimum monthly salary (the amount at that time was R$ 415.00) and the rest (n=4) did not have a steady income.

With regards to nutrition facts, none of them were following any nutritional advice and were not concerned about keeping a balanced diet. 68.75% were drinking two or more liters of water per day.

Among described symptoms, 62.50% mentioned coughing with or without expectoration; dyspnea was present in 50.00% of patients; 18.75% showed other respiratory symptoms resulting from allergy, sinusitis or pharyngitis. As for sleep and rest, 6.25% were sleeping less than six hours a day. Although most of them reported enough rest hours for adequate sleep

standards, 18.75% said they needed to use medication to sleep.

When talking about living habits, there was a predominance of individuals who did not practice physical activity (93.75%); the search for leisure activities was present in 75.00% of all patients. It was also verified that most of them were non-smokers (93.75%) whereas 12.50% were drinking alcohol or using other drugs.

The predominant HIV contamination way was sexual intercourse (87.50%). 37.50% of patients had learned about their HIV positive condition between one and eight months ago, confirming that the TB diagnosis suggests a possible HIV infection. Therefore, it is clear that all new TB cases should be HIV tested. As for the disease state, they were all in the symptomatic infection stage. Opportunistic diseases such as pneumocystosis, neurotoxoplasmosis and herpes zoster attacked nearly 37.50% of patients. 56.25% of patients were hospitalized after their HIV infection notification. They were all under antiretroviral therapy and antituberculosis medication treatment.

In the context to of their perceptions on their coinfection diagnosis, statements related to patients' feelings were carefully read and grouped in thematic categories according to the proposed goal, demonstrating significant changes in their daily routines due to their new health situation.

Fear and anguish when confronting the diagnosis

Feelings of sadness, fear and anguish prevailed when facing the new situation, as well as thoughts about death and the impossibility to live life like before learning about their disease. The desire to die pervades the feelings experienced after the positive result, evidenced when the coinfection diagnosis is concomitantly obtained. Besides, knowing that Aids, and especially the HIV/TB coinfection has a bad prognosis and a clinical evolution of rapid deterioration scares patients even more, as the following statements express it: *I feel almost dead, but I have hopes that I can be cured* (P4). *I am so sad; the shock was even higher when I discovered HIV* (P7). *I was so afraid, anguished; I wanted to die* (P9). *I am so sad because of my condition, I cannot work and I don't have friends* (P10).

Therefore, the diagnosis discovery unleashes a crisis situation with different feelings and negative reactions because the patient understands that Aids and tuberculosis represent a health risk. However, as therapeutic possibilities for both conditions are clarified, as well as the favorable tuberculosis prognosis, as it is a curable disease, such feelings diminish: *I felt terribly but now I am better, as long as I have medicines to take* (P7). *I live well with the disease, I take the remedies and I don't feel anything.* (P11).

Sometimes, these feelings disappear after the first impact of learning about their HIV positive status, mainly when patients receive support from health professionals and in particular, from friends and family.

Changes in health habits and lifestyle

Despite the disturbance experienced by individuals when discovering their infection, some proved to be indifferent to the diagnosis, especially in those cases in which they suspected that they might have contracted the virus due to having indulged in high-risk behavior. In spite of the referred indifference, however, most interviewees reported life habits changes aimed at feeling healthier, such as quitting drinking and smoking and increasing water intake and sleep and rest hours, also motivated by the impossibility to work. Such changes are described as follows: *A lot has changed, I isolated myself from friends, I don't go to parties anymore and I stopped drinking.* (P2). *I used to drink almost everyday* (P5). *Today I am a more quiet person, I stopped going out (to parties) I prefer to stay at home with my family* (P13). *I am doing well, I take treatment and I treat myself well. At first I felt badly, I would throw up when I started treatment but now I am fine* (P16).

As it has been described, the main lifestyle changes noticed after diagnosis are related to the reduction of health-risky behavior, as well as a dramatic

decrease or interruption of nightlife activities, considered by most as inadequate for disease sufferers.

It was verified that even when they are aware of the coinfection, the diagnosis that affects and changes lifestyles the most is HIV, which remarks the need for a personalized accompaniment to reestablish the patient's emotional and psychological wellbeing, as revealed in the next statements: *I have never accepted this (HIV), I follow treatment because I have to* (P4). *I still don't take it, I spend most of the time at home, and I don't want to do anything.* (P2).

DISCUSSION

The occurrence of HIV/TB coinfection is more frequent among men, although the HIV outbreak is also growing among women [8]. In this study, we verified a similar situation, as there were more male cases. The male population is therefore more vulnerable to the HIV/TB coinfection.

As for the age range, most studied patients were young adults, who represent a significant part of the economically active population. Consequently, the majority of HIV/TB coinfected patients are in the most productive stage of their professional lives, which has social consequences to the HIV positive patient, his/her family and the society as a whole, such as financial hardship as a result of unemployment, prejudice and stigmatization and affected interpersonal relations, among others. Similar data was found in other studies, suggesting that young adults are frequently the victims of the HIV and TB infections [8-9].

The insufficient schooling levels of most patients are reflected in their restricted professional opportunities, relegating them to low-paying jobs, thus perpetuating their poverty condition. It is in the lower classes that the HIV infection rate is higher, thus favoring precarious living conditions and facilitating tuberculosis infections [9].

As it is a weakening disease, tuberculosis is an obstacle for patients to keep their jobs, provoking everyday life changes and affecting the patients' personal and professional lives. Coinfected patients have their health condition severely compromised, dramatically affecting their lifestyles due to the abandonment of work and social life [10]. Moreover, the lack of information on tuberculosis is also a factor that facilitates the appearance of complications and often triggers non-adherence to treatment [11].

As for health-protection related matters, financial, social and cultural issues are fundamental, besides the disease knowledge level and the capacity to understand both the condition and its treatment [12]. This interactions are corroborated in this study, in which low income, insufficient schooling and high percentage of alcoholics, illegal drug users and smokers are ever-present. However, most patients in this study said to have abandoned such habits, as drinking and drugs abuse have been mentioned as the main factors that contributed to an HIV/TB infection worsening.

As current clinical aspects demonstrate, there is a need for strict patient follow-up, as the study reveals that the HIV infection may be considered as one of the main risk factors for the development of active TB from a latent infection [13]. At the same time, TB may accelerate the development of the HIV infection, so the diagnosis is often difficult. Besides, the HIV infection also alters the TB infection, its clinical manifestations, treatment duration and antituberculostatics tolerance levels [14].

The initial fear resulting from the diagnosis discovery is probably due to the fact that both Aids and its treatment are still not very well known by the general population. Consequently, incomplete, incorrect or contradictory information sent by the media may provoke confusion and difficulty to understand the disease progress [15].

Learning about being HIV positive is in some cases an unexpected situation in someone's life and it may imply a threat to the physical, emotional and social balance. These circumstances are almost always surrounded by anxiety, anguish, tension, questionings and doubts. When facing these events, individuals often have their social relations severely compromised, resulting in changes in their behavior and lifestyles. Therefore, finding out about their diagnosis and the coexistence with this situation can generate new behavior patterns and feelings such as guilt for having been infected, which is translated into self-stigma and rejection feelings [16].

This aspect is corroborated by the study findings, although an indifferent posture with regards to their diagnosis has been described by some participants. Sometimes, the patient is not even aware of the seriousness of the disease, mainly due to lack of education. For some, the first concern is related to the likely financial implications and possible consequences of their treatment [15].

Aids generates by itself different feelings such as fear of prejudice and abandonment, causing much anxiety and suffering to these patients. Such negative feelings also reveal the possibility of treatment abandonment or difficulty to comply with it. They may affect the patients' living conditions, thus reducing their survival chances [17].

Diagnosis and treatment progress have turned HIV into a chronic disease. This proves the importance of long-term patient accompaniment, as new therapies have a great impact on the lives of HIV patients, reducing fears related to the imminence of death and enabling them to continue with their social, affective, professional and leisure activities. Therefore, it is important to recognize that there are assistance possibilities that may bring improvements to the patients' health conditions, even being aware that it is an incurable disease. [18].

CONCLUSION

The study allowed us to identify social and health aspects of HIV/TB coinfected patients; mainly demonstrating their unfavorable financial conditions provoked by unemployment and low schooling levels. As for health conditions, there were reports of respiratory symptoms, as well as eating and sleeping disorders.

With regards to the coinfection perceptions, patients reported fear, sadness and aguish when facing the diagnosis. It was also corroborated that coinfected patients, when confronted with the difficulties imposed by the disease, try to abandon bad health habits such as smoking and drinking.

When analyzing the patients' perceptions on the coinfection, it is worth remarking the importance to boost and reestablish their social and emotional wellbeing through political and health initiatives that can contribute to a positive disease evolution. Therefore, we can conclude that the HIV/TB coinfection control is closely related to a planned nursing assistance based on health promotion in a multidisciplinary context, seeking to improve social and health conditions that involve a behavioral change that can ensure a reduction in tuberculosis and HIV infections, thus lowering morbimortality rates provoked by this coinfection.

Therefore, it is mandatory to develop new studies that encourage the creation of new strategies to fight this coinfection. Initiatives aimed at TB control are fundamental for the effectiveness of programmatic initiatives aimed at controlling the HIV infection.

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