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Original Article

TREATMENT OF TUBERCULOSIS UNDER THE VIEW OF THE USER*

TRATAMENTO DA TUBERCULOSE NA VISÃO DO USUÁRIO

TRATAMIENTO DE LA TUBERCULOSIS EN LA VISION DEL USUARIO

Ana Angélica Lima Dias[1], Daniela Maria Falcão de Oliveira[2], Ellen Cristine Ramdohr Sobrinho[3], Pedro Fredemir Palha[4], Rosely Moralez de Figueiredo[5]

Clinical-qualitative study aimed at analyzing the experiences of users who completed treatment for tuberculosis in the county of São Carlos-São Paulo, Brazil. Data were collected from February to September 2011, through semi-structured interviews, with 15 users. These were organized according to the content analysis technique, thematic modality. The patients face difficulties in being diagnosed and use different health services; they suffer with the reactions resulting from the treatment, and the supervision of drug intake is seen both as a facilitator for the formation of the link and also as a deterrent to adherence. Assessment researches related to difficulty in establishing the diagnosis and the monitoring of the supervised treatment should be made to minimize the barriers to control the disease.
Descriptors: Tuberculosis; Medication Adherence; Directly Observed Therapy; Treatment Outcome; Nursing.

Estudo clínico-qualitativo que objetivou analisar experiências de usuários que concluíram o tratamento de tuberculose no Município de São Carlos-São Paulo, Brasil. Os dados foram coletados de fevereiro a setembro de 2011, por meio de entrevistas semiestruturadas, com 15 usuários. Estes foram organizados conforme a Técnica de Análise de Conteúdo, modalidade temática. Os doentes enfrentam dificuldades para o diagnóstico e peregrinam pelos serviços de saúde; sofrem com reações decorrentes do tratamento e a supervisão da ingesta do medicamento é vista como facilitador para formação de vínculo e como dificultador na adesão. Pesquisas avaliativas relacionadas à dificuldade no estabelecimento do diagnóstico e seguimento do tratamento supervisionado devem ser realizadas para minimizar as barreiras no controle da doença.
Descritores: Tuberculose; Adesão à Medicação; Terapia Diretamente Observada; Resultado de Tratamento; Enfermagem.

Estudio clínico-cualitativo cuyo objetivo fue analizar experiencias de usuarios que concluyeron el tratamiento de la tuberculosis en São Carlos-São Paulo, Brasil. Los datos fueron recolectados de febrero a septiembre de 2011, a través de entrevistas semiestructuradas, con 15 usuarios. Estos fueron organizados de acuerdo a la técnica de análisis de contenido, modalidad temática. Los enfermos tuvieron dificultades para el diagnóstico y circulaban por servicios de salud; sufrieron con reacciones decurrentes del tratamiento, y el control de la ingesta de drogas era visto tanto con facilitador para la formación del vínculo y como impedimento para la adhesión. Investigaciones de evaluación relacionadas con la dificultad para establecer el diagnóstico y seguimiento del tratamiento supervisado deben ser llevadas a cabo para reducir al mínimo las barreras para controlar la enfermedad.
Descriptores: Tuberculosis; Cumplimiento de la Medicación; Terapia por Observación Directa; Resultado del Tratamiento; Enfermería.

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[1]RN, Master´s Degree, Programa de Pós Graduação em Enfermagem, Universidade Federal de São Carlos. São Carlos, SP, Brazil. E-mail: anaangelica2@yahoo.com.br
[2]RN, Master´s Degree, Programa de Pós Graduação em Enfermagem, Universidade Federal de São Carlos. São Carlos, SP, Brazil. E-mail: dmfolive@gmail.com
[3]RN, Master´s Degree Student, Programa de Pós-Graduação em Enfermagem, Universidade Federal de São Carlos. São Carlos, SP, Brazil. E-mail: ellen_ramdohr@yahoo.com.br
[4]RN, Doctor, Associate Professor, Escola de Enfermagem de Ribeirão Preto, Universidade de São Paulo. Ribeirão Preto, SP, Brazil. E-mail: palha@eerp.usp.br
[5]RN, Doctor, Associate Professor, Universidade Federal de São Carlos. São Carlos, SP, Brazil. E-mail: rosely@ufscar.br

Corresponding Author: Rosely Moralez de Figueiredo
Rodovia Washington Luís, km 235. Caixa Postal 676. CEP: 13565-905. São Carlos, SP, Brazil. E-mail: rosely@ufscar.br

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INTRODUCTION

Tuberculosis (TB), despite being declared a world emergency concern in 1993, by the World Health Organization (WHO), is still far from being considered under control in the world[1]. In 2011, the WHO estimated the occurrence of 8.7 million new cases of TB in the world, corresponding to 125 cases/100,000 inhabitants. In that same year 1.4 million deaths by TB were registered, equivalent to 14 deaths/100,000 inhabitants. Brazil occupies the 17th position in the ranking among 22 countries that are responsible for 82% of all the incidences of the disease in the world. In that same year more than 84 thousand cases of the disease were notified in Brazil[1]. In the state of São Paulo 16,290 new cases of the disease were notified in 2010, representing an incidence of 39.5/100,000[2].

To minimize this problem, the WHO launched the *Directly Observed Treatment Short-Course* (DOTS) strategy, with the objective to reduce the morbidity and mortality of the disease, to establish targets for the detection of new cases and to increase the cure resulting from the treatment implemented[1].

The Directly Observed Treatment (DOT) is a key element of the DOTS strategy. However, for the DOT to obtain the expected success it is necessary that it is seen beyond the supervision of medicine intake. The complexity involved in the treatment of TB requires that the health services know the needs of these people, allowing the health team to re-orientate its practices, facing the improvement of the assistance rendered[3]. Therefore, it is indispensible that a link between the patient and the health service is established, besides the strategies of social rehabilitation, improvement of self-esteem and professional qualification[3].

However, there are still many obstacles to reach such targets, such as the difficulty to the access to health services and the inadequacy of their physical structure and organization of the process of work[3]. Furthermore, the preconized therapeutic plan itself, although effective,

can cause undesirable side effects[4]. Based on the above considerations, getting to know the view of the patient, who managed to overcome all the stages of the treatment of TB and resumed his routine of daily life, is extremely important to identify the specific needs of health and possible actions that minimize the obstacles for the cure of the disease. Therefore, this study had as objective to analyze the experiences of these users, identifying their opinion regarding the treatment.

METHOD

It is a clinical-qualitative study, which aims at interpreting the meanings of the experiences, consciously and unconsciously attributed by the subjects, facing specific problems in the relation health-disease[5].

The study was made in the county of São Carlos, SP, Brazil. It has 220,000 inhabitants, where the actions of control of TB are centralized and taken by the Program of Control of Tuberculosis (PCT) of the county. When the DOT is appointed to the user, the supervision is shared, that is, the medical supervision made is centralized and the supervision of the medicine intake, in the nearest health unit.

The subjects of the research were found in the register book of patients with TB, of the PCT of the county. They were called on the phone and invited to participate in the research. The objects of the research were clarified and, once agreed upon, the interview was booked at a venue and time which was more adequate for the subject. Therefore, the sample of the study was selected by convenience and its size (No. = 15) defined by the saturation of the data. The saturation occurs when no other relevant and new datum for the research is found to subsidize the aimed theorization, so it is not considered relevant to persist in the data collection[5].

The following criteria of inclusion were considered: having treated TB for the first time and in the predicted time (six months), not presenting HIV/AIDS and been above 16 years. The semi-structured interviews were made in the homes of the subjects from February to September 2011, recorded in digital media and later on transcript. For the qualitative analysis of the material, of the Content Analysis Technique, thematic modality was used, which allowed to organize the speeches of the interviewed subjects and unveil the nuclei of the sense, for a later codification of the speeches[6]. This technique is unfolded into three stages: Pre-analysis; Exploration of the Material and Treatment of the Results Obtained and Interpretation[6].

The study was approved by the Committee of Ethics and Research with Human Beings of the Universidade Federal de São Carlos (Legal Opinion No. 413/2010), according to Resolution 196/96 of Conselho Nacional de Saúde (National Council of Health). All the participants signed the Informed Consent Form (ICF). In order to guarantee the anonymity of the subjects, the sections of the interviews were coded with the letter E, followed by Arabic numbers in a crescent order of its making (E1, E2,...E15).

RESULTS

Subjects of the male sex predominated (80%), with the lung type of the disease (80%) and average of 48 years of age, ranging from 16 to 80 years. Twelve (80%) had seven or more years of study, nine (60%) reported to be married and 13(86%) lived with family. As to the occupation six were working, two were away from work due to other problems of health, four were retired, two students and one unemployed.

From the analysis of the speeches three categories emerged: difficulty for the diagnosis, difficulty with the medicine and ambivalence of the supervised treatment.

In the first category (Difficulty for diagnosis), the difficulty was caused by the delay in the suspicion of the disease and not by the difficult of access to the health services. The patients sought the health services more than once, presenting signs and symptoms characteristics of the diseases, but they were treated and diagnosed as if they had other pathologies. … *At the beginning the thing was diagnosed first as sinusitis...I took medicine for pneumonia, two weeks of antibiotics and i don't know what, it went away and after one week the pneumonia was back* (E15). *He said I had cancer, he told my daughter everything* (E10)*….I had twice (radiography), a pain they didn't think much of. Ah, you don't have anything, its muscular, emotional* (E11).

In the second category, (Difficulty with the medicine), most of the interviewed subjects considered that the medicine treatment was the main obstacle in the adhesion to the treatment, due to adverse reactions and to the quantity of pills taken. *The greatest difficulty was to take this medicine every day. They have some strong medicine that was the greatest difficulty* (E4). *To take six drugs every day, every day, is not easy* (E7).

The reactions occurred from the medicine were so intense that some of the interviewed subjects reported them as worse than the attitudes of prejudice experienced. *For me that is torture….the fact that the people kept away I didn´t care so much, because for me it really was the reaction to the medicine* (E12).

The minor adverse reactions are articular pains, headache, asthenia and gastrointestinal disorders, and those were the most frequently mentioned. Some reports stated that these reactions persisted after the conclusion of the treatment: *… it makes us feel bad, breathless, you become rather weird, you know? Yes, I was tired, pain in the stomach. …. It made me loose appetite, I didn't have time for anything else, only to take medicine. It´s strong, It makes me feel bad inside* (E14). *Until today I have digestive problems…I thought the treatment was terrible, It did harm to me* (E8).

Although the interventions of the health professionals with the minor adverse reactions were not mentioned, for the major ones it was inferred that the health professionals intervened minimizing such reaction making the conclusion of the treatment possible. *… When*

I started the treatment I had…A type like hepatitis, the liver couldn´t stand water, then I started with the shots…it was the best way, because I didn´t accept oral medicine (E11). *... the medicine they prescribed didn´t get along with my body… the medicine was offending the kidneys and that´s when they took part of the medicine away that they thought was making me feel bad* (E3).

In the third category (Ambivalence of the supervised treatment), the supervision of the medicine intake was perceived by the user both as potentiality as limit. When the medication was perceived as potentiality, the interviewed subject recognizes that the medicine intake supervised by the health professional stimulates the conclusion of the treatment. *The head nurse kept watching me take in front of her…, if I didn´t have conditions to come here, they would go to my house* (E14). *When I used to drink, they worried about me… the girl would come all the times I had to take the medicine, the nurses came to our house* (E3).

However, they considered that the treatment required a lot of effort to be concluded, once they have difficulties to move to the health unit daily due to their weak health. They also mentioned that the commitment with the treatment required alterations in their daily life routines, made them stay away from work, from school, from the family activities and from leisure. *To tell the truth it was difficult to take there (at the health unit) everyday, but I managed it* (E4). *Tiring, very tiring. I had to leave school to go there, some days you get it, and some days you have to go back there! …Then it is a little tiring having to go there every day, but I managed to treat* (E13*). It was difficult to take me there* (E5)…. *I stopped going out, at the time I was taking, I just stayed home, I didn´t go to family parties* (E11). *...I really wasn´t well to attend school, I was thin and the medicine provoked pain and I didn´t go anymore, understand?* (E9).

The way the service is organized for the medical assistance was mentioned as a limit once the appointments are booked following the order of arrival of the patients and the schedules are not respected, also influencing in their daily routine. Just the assistance for medicine intake was mentioned as agile. *Then, some delay, like in this kind of place, there is delay, there is a lot of things…and you can´t think that if you go there it´s going to be quick, because there it does not exist….but it happens that it was like this there, from the moment you had already been medicated, that you only get to go and get the medicine it was fast* (E2). *I had to be there at seven, some fifteen minutes before the doctor arrived. Sometimes I was the first or the second and there were a lot of people there, there were people lying down on the chairs in the waiting room* (E5).

They reported that they felt embarrassed when they were in the health unit, once the medical assistance is provided in the same place of the program of SDT/AIDS. *I had to go there also to take the medicine and the people kept looking at me, kept waiting. Sick but not hospitalized, but free…I didn´t feel very well no…I noticed they stopped interrupting the treatment because they had to go there. The people were kind of kept away, there are two, three with TB, another one with AIDS, all together. Then, it gets a little weird* (E14).

DISCUSSION

The difficulty to establish the diagnosis of TB is similar to findings in other studies which at first the patients were diagnosed and treated with pneumonia, sinusitis and cancer, and the diagnosis was only established during the secondary or tertiary attention to health[7].

The late diagnosis of TB can increase morbidity and mortality and still increases the incidence of the disease due to the greater probability of transmission among the contacts. The maximum time accepted for the diagnosis of lung TB is three weeks[8].

The delay in establishing the diagnosis can also be related to the lack of planning in the actions of control of the disease turned to the identification of respiratory symptoms, which is confirmed in the study in which the speech of the managers of health regarding the control of TB was assessed[9].

The way the patients perceive, identify and express their disease may have interfered in the time of diagnosis and provoked a late diagnosis confirming the literature[10]. An international study observed that the bad interpretation of the signs and symptoms and financial limitation was the most common reason for the delay in the diagnosis[11].

Adding to that, the interviewed subjects had a different social economical profile, from the typical profile of the population vulnerable to the disease[12].

This conception, the one in which TB is associated to poverty, can be seen in a study made in the greater São Paulo, where the interviewed health professionals mentioned the low social condition of the patient as one of the greatest difficulties on the confrontation of TB[3]. This restricted view may have delayed the suspicion of the disease in the population of this study.

The health professionals should carry out strategies of early identification of the symptomatic respiratory (SR)[8] , and recognize the variations in the classic picture of the disease, once three of the interviewed subjects had extra-lung TB and all of them had difficulties in having their diagnosis established.

A research made in Rio Grande do Sul, Brazil, showed that the widening of the active search of symptomatic respiratory, surpassing the expected target of 1% of the population, contributed for the decrease in the of new cases of the disease. This makes clear that the maintenance of preventive actions and control of TB are efficient[13]. But, in order to have a fast process of diagnosis, the health services must be prepared for the reception of the suspect of TB, with able health professionals, with political transit in the management and conduction in the county, besides having the syntony and involvement of all the health team[14].

In a research made in same region of this study, the health professionals reported as unfavorable points in the control of TB: the lack of professional training of the team, the absence of adequate place for the reception of SR, a delay of the laboratory results, the lack of specialized doctors and of exclusive nurses[7]. So, the health professionals in this study reinforce a centralized and fragmented view of the actions of control of TB considering them exclusive of the center of reference[7]. Besides that, in a similar study, it was noticed that the nursing assistants had important attributions in the control of TB, but their actions were damaged by the low knowledge, jeopardizing the treatment, the orientation given on the disease and the identification of the symptomatic respiratory[15].

As to the report of the high number of pills to be taken daily, even in the current therapeutically schedule, for an adult subject, the amount of pills was not reduced significantly[1]. So, the urgent need of the development of shorter, simpler procedures, with better tolerance, effective against TB; the procedures are susceptible to association with antiretroviral agents and to adequacy of the children dosage[16].

The side effects were mentioned by many of the interviewed subjects, although the literature reports that most of the patients finish the treatment without presenting them in a relevant way[4].

A research made in the county of São Paulo states that in the routine of the health services, the patients are not always asked about the possible side effects and that they might not report them for considering them irrelevant[4]. A study shows that, although the health professionals know the adverse effects caused by the medicine, they tend to have difficulty in valuing the complaints of the patients once they consider those effects inevitable[17].

The health team valued the adverse reactions which brought more damage for the health of the interviewed patient. This valuing tends to happen more frequently with the patients with more serious adverse effects, once this provokes an increase in the rate of abandoning, longer period of treatment, hospitalization, ambulatory appointments and home visits[4]. However, the interventions and the information on the side effects need to the enhanced to all the patients.

The conclusion of the treatment within the predicted time despite the adverse reactions, occurred because the users believed in the treatment and overcame the adversities, believing in the cure, a datum confirmed by the literature[18].

The ambivalence in the assessment of the supervision of medicine intake is also mentioned by

other authors [19]. One of the potentialities of DOT is the link, which according to the view of the health professionals and users, can be understood as a relation of friendship and trust between the health professional and the user, resulting from the daily contact along all the treatment in which the health professional perceives the needs of the user, in order to make him strong in the face of the disease[3,19]. The supervised treatment provides more commitment in the continuity of the treatment by the patients once the link formed with the health professionals encourages them in the decision to finish the treatment[18].

However, it can cause changes in the daily activities of the people, once it imposes a routine of obligations such as the daily or weekly presence in the health services for the medicine intake and such situation is not always conciliated with their routine activities[17]. Besides that, the debilitating aspects of the disease[17] interferes in their willingness to go to the health service.

Despite these difficulties, for the patient the treatment is a real possibility of cure, facing an altered daily life[17]. So, the recommendations are adopted even if they imply in the non performance of the routine activities.

The informal flexibility in the supervision of the treatment allows the reduction of the barriers found in this stage of the disease[20]. The establishment of a therapeutic plan which considers the specificities of each patient would make the treatment easier.

An international study shows that some patients experiment barriers during the intensive period of the treatment and that they could be easily overcome if the approaches were more flexible, such as the adequacy of the schedule for the assistance and the decentralization of the supervised treatment. The patients were orientated to be present all at the same time and they waited for more than one hour to receive the medicine, and this was considered humiliating by some[21].

The interviewed subjects understand that the supervision makes moments of exchange, sharing and formation of link possible, but for some, the supervision leads them to embarrassment which is confirmed by the literature[10,19].

This perception can be overcome if the health professional shares the justifications of supervising the treatment with the user, pointing out the importance of the supervision in the individual and collective protection, besides the individual assessment and flexibility of this supervision. The health professional must also listen to their restlessness, needs and difficulties with the treatment[20,22].

FINAL CONSIDERATIONS

The work of the health professionals as to the suspicion of TB can be restrained only to the typical social picture of the disease, making the diagnosis in other conditions difficult.

Despite having finished the treatment, these users consider the reaction to the medicine the greatest difficulty experienced. The concretization of the development of more efficient medicine, with fewer side effects and less time of treatment is fundamental, as well as the valuing of the complaints and the early identification of the reactions to the medicine.

The DOT still has frailties and generates obstacles for the user, such as alteration in the daily routine and embarrassment, which seem to be enhanced by a greater exposure of the patient when the supervision happens in the health unit. The establishment of a therapeutic plan with more flexibility and adequacy of the supervised medicine intake to the needs of the subject are fundamental to generate fewer alterations in their daily lives.

The complexity of the disease requires sensibility, knowledge and qualification from the health professional in order to provide a kind of approach which contemplates biological and social questions resulting

from the disease. Besides that, there is the need to implement actions of management of care which must be taken preferably by the nurse, during the assistance to the users with this disease.

It is considered that assessment researches related to the difficulty in establishing diagnosis of TB must be developed, as well as the investigation of the difficulties in following the supervised treatment, both in the supervised intake as well as in the reactions resulting from the medicine.

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Dias AAL and Figueiredo RM contributed for the conception, data collection, qualitative analysis of the study and elaboration of the draft of the manuscript. Oliveira DMF contributed in the field work and interpretation of the data. Sobrinho ECR contributed in the interpretation of the data and in the final version to be published. Palha PF contributed for the methodology of the study and in the interpretation of the data. All the authors stated that they had contributed in the writing, critical revision of the article and final approval of the version to be published.

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