
TUBERCULOSIS TREATMENT ABANDONMENT AND COMPREHENSIVE HEALTH CARE TO PATIENTS IN THE FAMILY HEALTHCARE STRATEGY

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ABSTRACT: Qualitative study that aimed to analyze the reasons why the tuberculosis patients abandon treatment in the metropolitan region of João Pessoa-PB. Was used as a theoretical to comprehensive care. Data were collected from October to November 2008, by means of semi-structured interview. Participated nine users who abandoned the treatment of tuberculosis. In the identification of the units of meaning, the technique of analysis of content was used. The results show inconsistencies related to the holistic care of the sick, when it comes to doctrinal guidelines of the Unified Health, the consideration of socio-cultural context of the user with tuberculosis and the weaknesses in continuity of care, and the inadequate monitoring by the network of health care. These aspects, complicate the construction of a network of care and support for tuberculosis patients and their families, contributing to the abandonment of tuberculosis treatment.

DESCRIPTORS: Tuberculosis. Primary attention to health. Refusal of the patient to the treatment.

ABANDONO DO TRATAMENTO DA TUBERCULOSE E INTEGRALIDADE DA ATENÇÃO NA ESTRATÉGIA SAÚDE DA FAMÍLIA

RESUMO: Estudo qualitativo que objetivou analisar os motivos que levam o doente de tuberculose a abandonar o tratamento, em municípios da região metropolitana de João Pessoa-PB. Como referencial teórico utilizou-se a integralidade do cuidado. Os dados foram coletados no período de outubro a novembro de 2008, mediante entrevista semiestruturada. Participaram nove usuários que abandonaram o tratamento da tuberculose. Na identificação das unidades de significação, utilizou-se a técnica de análise de conteúdo. Os resultados mostram inconsistências relacionadas ao cuidado integral do doente, no que tange à diretriz doutrinária do Sistema Único da Saúde, à consideração do contexto sócio-cultural do usuário com tuberculose e às debilidades na continuidade da atenção, mediante inadequado acompanhamento do mesmo na rede de atenção à saúde. Esses aspectos, ao dificultarem a construção de uma rede de cuidado e apoio ao doente de tuberculose e sua família, contribuem para o abandono do tratamento da tuberculose.

DESCRIPTORIOS: Tuberculose. Atenção primária à saúde. Recusa do paciente ao tratamento.

EL INCUMPLIMIENTO DE TRATAMIENTO DE LA TUBERCULOSIS Y LA ATENCIÓN INTEGRAL EN LA ESTRATEGIA DE SALUD DE LA FAMILIA

RESUMEN: Estudio cualitativo que tuvo como objetivo analizar las razones que llevan al paciente a abandonar el tratamiento de la tuberculosis en la región metropolitana de João Pessoa-PB. Como referencial teórico se utilizó el cuidado integral. Los datos fueron recolectados en octubre-noviembre de 2008, por medio de una entrevista semiestructurada. Participaron nueve usuarios que abandonaron el tratamiento de la tuberculosis. En la identificación de las unidades de significado, se utilizó la técnica de análisis de contenido. Los resultados muestran inconsistencias relacionadas con la atención integral de los enfermos, cuando se trata de lineamientos doctrinarios del Sistema Único de Salud, la consideración del contexto socio-cultural del usuario con la tuberculosis y las deficiencias en la continuidad de los cuidados, por medio de la supervisión inadecuada por parte de la red de atención de salud. Estos aspectos, obstaculizan la construcción de una red de atención y apoyo a los pacientes con tuberculosis y sus familias, contribuyendo al abandono del tratamiento antituberculoso.

DESCRIPTORIOS: Tuberculosis. Atención primaria de salud. Negativa al tratamiento.

INTRODUCTION

This present study aims to analyze the reasons why Tuberculosis (TB) patients abandon treatment in red-flagged metropolitan municipalities in the Greater João Pessoa, State of Paraíba, Brazil. Theoretically grounded on the conceptual perspectives of the comprehensive healthcare practice, the study highlights both the principle applied in the Unified Health System (*Sistema Único de Saúde* - SUS) and the production of healthcare in which the patient's context is taken into account.

TB stands out as a global public healthcare challenge due to the high prevalence of the disease in several countries – among them, Brazil – and is closely connected to social-economic conditions¹. The effective control of the disease in the world is hindered by factors associated with prevention, diagnosis, treatment, quality of healthcare services², as well as specificities of TB patients.

In the current perspective of the battle against TB, the abandonment of treatment rises as a major challenge to the Brazilian healthcare system. The treatment abandonment status is consolidated whenever the patient fails to attend the healthcare service for over thirty consecutive days past the scheduled return date.³

The lack of success of the treatment resulting from the patient's abandonment can lead to an extension of the infectious status, thus enhancing the odds of the transmission and development of multi-resistant bacilli; in other words, these bacteria display *in vitro* resistance against rifampicin, isoniazid and a third drug present in standardized TB treatment schemes⁴. Understanding the factors associated with TB treatment abandonment processes, on its turn, is quite relevant toward the identification of the obstacles that may take patients not to fully adhere to the treatment.⁵

In order to control TB, the Brazilian Ministry of Health has adopted the Directly Observed Therapy, Short-course (DOTS). This internationally recommended strategy is based upon five pillars, namely: standardized treatment schemes and directly supervised treatments, at least once a week in the first treatment month; a regular and continuous supply of standard medications; creation of an efficient case recording and reporting system; identification of cases through sputum lab-based exams; and political commitment.⁶

Despite the implementation and execution of the DOTS, treatment abandonment figures are still very high, although the Directly Observed

Treatment (DOT) has proven to be capable of reducing abandonment indexes.⁷ Other factors, such as drug addiction, social vulnerability situations, and lack of access to information increase the complexity of TB treatment abandonment processes and force the healthcare service to innovate. The fragilities that empower treatment abandonment processes³ are observed both in the perspective of the healthcare integration and in the individual healthcare services.

TB treatment abandonment processes are more acute whenever the disease control actions are not based on the conception of the patient's comprehensive care. In this sense, it is worth highlighting not only the polysemy involved in the terminology, but also the two-fold materialization of the term.

The first aspect is directly related to the SUS doctrinal principle and defines the comprehensive care as an articulated, continuous set of preventive and curative, individual and collective actions and services demanded for each case in all levels of complexity of the system⁸. Such focus points to the "coordination" dimension of the Primary Health Care (PHC). Despite presupposing the continuity of healthcare processes by means of follow-ups provided by one single professional, the strategy also demands medical records, recognition of prior and new problems, including the reference and counter-reference⁹ specialized service care that adopts the network system's healthcare concept.

In order to achieve comprehensive healthcare, this study undertakes the healthcare network concept. This relevant component causes the organization of services to be oriented toward non-hierarchical relationships, where several players share goals and exchange resources among each other. Such understanding will open way to the consolidation of a horizontal healthcare network of distinct technological densities and supportive systems, without generating higher or lower degrees of importance among them.¹⁰

By overcoming reductionisms of a biologist practice that denies the overall needs of patients, the second aspect toward comprehensiveness is directed to the attributes of the healthcare practices. We need to notice that the production of healthcare takes place in the practical field, and such practical field occurs in the encounter between professional and patient. Under the comprehensiveness perspective, the specific contexts of each encounter between healthcare team members and patients

must be taken into account. Bearing this in mind, a technical knowledge-based attitude that both identifies prevention and care-related needs and elects interventions to be offered within the context of each encounter¹¹ must be adopted.

The predictive factors of the treatment abandonment process is believed to be strongly related to the way TB control actions are carried out in the PHC, specifically in the Family Healthcare Units (FHU), as well as in the relationship of both factors with other healthcare attention networks in the sectorial and intersectorial framework, whenever a broader healthcare concept and the TB social expression are taken into account.¹² It is also believed that the healthcare service directed to people with TB is centered on technical procedures and protocols that do not encompass the patients' lifestyle. The lack of knowledge of the patient's singularities causes their personal needs not to be assisted. As a result, such failure will directly impact the provisions of the healthcare service, which is now solely comprised of medicine-based treatments.

The TB abandonment process is a widely known phenomenon and a major challenge toward the control of the disease. Once a successful treatment demands the comprehensiveness conception to permeate all control actions both in the perspective of the SUS principle and within the framework where the patient's singularity is fully considered, this study aimed to analyze the reasons that lead sick people in the metropolitan area of João Pessoa (PB) to abandon the treatment.

In spite of the adoption of the DOTS and all efforts toward decentralizing TB control actions in the Family Healthcare Strategy (FHS), as well as other comprehensive health-related actions, changes are not so clear.¹⁰ In this aspect, the identification of the reasons and the analysis of the characteristics that may potentialize actions toward coping with TB treatment abandonment practices, as well as strengthen the care process offered to patients in all attention network are crucial steps. In addition, the elaboration of the TB patient's therapeutic project must be grounded on his or her personal needs; on their turn, these needs must be viewed through the social, cultural and economic specificities surrounding the disease.

METHODOLOGY

The efforts toward improving the results of the TB treatment require the understanding of the

obstacles presented to the patient's adherence to it. In this sense, the qualitative-based approach applied in this study can significantly contribute to such comprehension.¹³

This study was carried out in the municipalities of Bayeux and Santa Rita, in the Metro Area of João Pessoa, Paraíba, deemed to be priorities toward the implementation of TB control actions. In 2000, when the DOTS began to be implemented in the State of Paraíba, these cities displayed high incidence indexes of TB (48.8/100,000 inhabitants in 2001); deaths reached over 5%; healing percentage was found below 85%; and the treatment abandonment index was higher than 10%.

In the beginning of the study, in order to guarantee the quality of the investigation, the scenario was assessed by mapping out the patients followed-up by the FHS that had abandoned the TB treatment. From the 27 patients registered in the Information System for Notifiable Diseases (SINAN), six were not living in the same address anymore; one had died of TB; one refused to take part in the study; one was in prison; one did not display a conclusive diagnosis; and eight were not located. Therefore, nine patients participated in the study. Upon the guidance and support of Community Health Agents (CHA), the subjects were located and the interviews were carried out in their homes.

The information collection process took place between October and November 2008. The study employed semi-structured recorded and transcribed full-length interviews. Data were submitted to thematic content analysis,¹⁴ comprised of a sequence composed of three basic phases in order to organize and explore the data originated from the interviews: brief reading (pre-analysis); exploration and/or codification of the material; and treatment of results – inference and interpretation.¹⁵⁻¹⁶

In the stage of pre-analysis and constitution of the *corpus*, all the nine interviews were selected. Next, the recordings were listened to; all materials were explored and achieved results were interpreted. Last, each subject's recorded material was transcribed. In order to ensure the full quality of the empirical material, the interviews were once more listened to, so that eventual corrections and adjustments could be done. After being transcribed, information homogeneity, representativity and pertinence were checked out in the material.

The next phase following the pre-analysis was the brief, longitudinal and cross-sectional reading. The first was individually carried out by a researcher; the second was performed by two research team members, followed by a discussion about the coherence and pertinence of contents; the transversal reading triggered the codification process, based on the record units, and the formulation of pre-hypotheses.

Aiming to reach the proposed objective and taking into account the previous analysis of the interviews, record units have been highlighted. On their turn, such record units produced the following meaning units: between care and negligence; relationships between TB treatment and coordination of healthcare services for TB patients.

Next, convergent, divergent and repeated meaning units identified in the statement were taken into consideration. Hence, excerpts from the speeches corresponding to each meaning unit were produced. Such layout allowed for the election of the core thematic unit: TB treatment abandonment and comprehensive care to patients in the FHS.

The study complied with Resolution 196/96 of the Health National Council, which elaborates on research regulating norms and guidelines involving human beings. The research proposal was approved by the Research Ethics Committee of the Lauro Wanderley University Hospital (CEP/HULW) under number 0067/08. In order to ensure the subjects' anonymity, the speeches were codified under alphabetic letters and Arabic numbers.

RESULTS AND DISCUSSION

The analysis of the empirical material was laid out in two meaning units. The first approaches the fragilities observed in the care relationships between health professionals and patients. Among them, we highlight the absence of a supportive hearing that could allow for a broader apprehension of the patient's health needs; the implementation of a treatment status focused on the biological dimension of the disease process; the incipient autonomy of the patient in his or her therapeutic project; and the hardships toward the production of attachments, turning the adherence to therapy into a difficult process. The second meaning unit deals with the articulation between the health care network and the healthcare professionals, shedding light to the existing relationship between the healthcare service coordination and the integrated functions of the TB patient's care network services.

Between care and negligence: TB treatment relationships

As the TB patient is followed up, the health-care team must record the evolution of the disease, monitor the medicine therapeutic scheme, as well as identify the patient's needs, not only those related to the universe of the disease, but also related to other features in his or her social surroundings. This study observed that the care is provided directly by the healthcare professional; the contents of the interviews did not show any team-based action. The care process is limited to verify whether or not the TB patient has adequately eaten, as well as to some clinical aspects shown in the following speeches: *I was just asked whether or not I had taken the medicine, or if I was feeding properly (S02); She kept asking me what I was feeling [...], whether or not I was dizzy. That's what she kept asked me (S03).*

It is clear that the healthcare care offered to the TB patient during the treatment is far away from a caring dimension grounded on the comprehensiveness principle. The absence of hearing spaces during the appointment for the patient to express himself regarding the disease, the treatment or any other issues strengthens the distance between the healthcare professional and the sick person, thus compromising the therapeutic project, especially the treatment adherence process. *I was told nothing [...] I was just given the medicine, I have never had any advice [...] Then, I quit the treatment for some days (S06).* It must be highlighted that the attachment produced in the healthcare environment takes place within the context of the care relationship.

Taking into account the strategies aimed to improve access and develop comprehensive care-based practices, the creation of attachments and the accountability principle are recognized as comprehensive practices¹⁷ that favor the comprehensiveness of care processes. The implementation of intersectorial measures and the encouragement of the patient's autonomy, articulated with the efforts of the FHS toward establishing strong attachments with the sick person and his or her family, are believed to provide TB patients with comprehensive care within the scope of the PHC.¹⁸

The embodiment of the comprehensiveness meanings in the care of patients and their family, thus producing attachments and offering support toward facing the illness, promotes the therapeutic success, and particularly prevents treatment abandonment processes.¹²

All practices contrary to health care comprehensiveness actually highlight the fragmentation and the reductionism of the healthcare resulting from the overvaluation of the analytical cutout of the human body and its organic systems in order to comply with the competences of medical specialties, thus denying broader needs of patients and strengthening the biologicist vision of the healthcare actions.¹⁹ The poverty status, among other situations, common to many TB patients¹⁸ and that may favor the practice of the treatment abandonment, must be taken into account.

The analysis of the statement reveals that the follow-up of TB patients undergoing treatment is not aimed at their autonomy, their adherence to the treatment and the quality of the rendered service. Such observation leads us to conclude that comprehensive care-based healthcare actions must be intensified, thus allowing for the expansion of care to the TB patient, taking into account the complexity of the health-disease process and its various dimensions – biological, cultural, psychological and social. Prevention, cure, rehabilitation and health promotion can also be inserted as relevant components of integrated actions. For that purpose, intersectorial, interdisciplinary, intergovernmental and interinstitutional articulation processes must be very effective toward the improvement of healthcare levels and the quality of life of people at large.¹¹

Taking into account the broad healthcare concept and the comprehensiveness of the process, it can be affirmed that the scarcity of intersectorial actions toward fighting TB weakens the relationship between patients and the FHS, as they directly impact the resolution of needs demanded by these people, as well as the reliability of the healthcare professionals at the eyes of the patients.¹⁸

In the broad relationship scope between healthcare professionals and patients, some elements associated with the treatment abandonment were identified. Among them, we highlight the uneasiness provoked by the ingestion of medications and their collateral effects. [...] *I quit it because the medicine was too strong, it tore me apart. I was so hungry. And even when my mother said, 'go to work', I just couldn't (S03); I could not take it [medicine] anymore. I cried everyday due to so many medications [...] I felt dizzy and had light headaches, I ended up sleeping. The medications were very strong (S05).*

Several TB patients finish the treatment without displaying any collateral effect resulted from the ingestion of anti-tuberculosis drugs.

However, there are some cases in which the side effects are often present and eventually contribute to the interruption of the treatment. In this sense, healthcare professionals should definitely sensitize patients toward the possible emergence of side effects and adverse reactions resulted from the medication therapy, thus becoming protagonists in the therapeutic process and holders of the treatment-related knowledge, in such a way that patients can keep it going.³

A poor follow-up usually generates circumstances that stimulate patients to abandon the treatment; this can be prevented by a pro-active attitude of the Family Healthcare Team toward the TB patient and his or her family. The encounter between patient and professional must be deemed to be a singular moment for the construction of the therapeutic project which both parts will be committed to.

In view of the above-mentioned proposal, the recognition and appreciation of the hermeneutic perspective in the way the care process is operated implies the assumption that the objectuality inherent to any given healthcare action must not be the product of an exclusively instrumental knowledge resulted from the scientific-technological armory possessed by either a professional or a service applied unto a passive substrate, that is, the patient or the population.²⁰ Therefore, under such perspective, the objectuality must be a consequence of the encounter between authentic subjects in search for convenient, mutual solutions to the prevention, overcoming and/or recovery from sickening processes.²⁰

The therapeutic project built in these encounters demands the employment of educational actions directed to the promotion of autonomy and the participation of the patient in the treatment. In any transforming perspective, such as the processes focused on the Health-based Permanent Education (HPE), the lack of TB-related health-based educational actions discourage patients in the search for a change in their health status. With this in mind, health teams ought to insert educational actions aimed at the sick person and family that are not bound to lectures and brochures. *I'm not aware of anything around here, except the medications. Visitors just come once a month. If I do not talk to her [Community Health Agent] she just won't come to my house in order to know how I am feeling [...]. That's why I'm not attending these places anymore. I used to go there and ask for them [the medical referrals] and she wouldn't give them to me (S07).*

The attachment concept, as a dimension of the PHC, potentializes the actions of the health strategy and favors the involvement of patients in the therapeutic process whenever they are recognized by the professionals in their status of subjects. Thus, it is necessary to rescue the dialogue art between the professional and the patient, health team and family, institutions and society. The construction of the professional-team-patient attachment definitely favors the transformation of the health care practice. The attaching principle refers both to the search of success regarding the enhancement in the percentage of healing processes and the constitution of adequate spaces toward the production of autonomous subjects. No attachment is ever constructed, unless patients are recognized in their status of subject.²²

Therefore, the recognition of the patient as a subject in the therapeutic process and his or her involvement as a participant of their own history are translated into the comprehensive care-based practice, thus opening way to the adherence and the continuity of the treatment.

The coordination of health services toward TB patients

The coordination of the health care network can be understood as an articulation among the various services and actions related to a given intervention, in a way that such services are synchronized and directed to a common purpose²², regardless of the place they are provided. In order to keep the care process on the move, this coordination requires both a means to convey information and the comprehension of such information by the health professionals, in accordance with the healthcare network principle.¹⁰

The concept of the healthcare service system as a coordinated network that ensures the access and the continuity of the care process must take into account that the dots connecting the intersections of the network can only operate as a result of the consolidation of a complex web of interactions among those who respond for the organization of the system (managers), those responsible for the configuration and execution of services (service providers and professionals) and the patients in the healthcare system. These are deemed to be the three general coordination/integration elements of the healthcare service system.²³ [...] *they forward us to this doctor, then to another doctor, and nobody knows which doctor will assist us anymore* (S03); *At*

the hospital, they say that the referral is there [at the Family Healthcare Unit] [...]. The exam document was at the unit, but that was all they handed me (S05).

The continuity of the care process allows for the organization of the patient's flow among the several dots of the health care network. The lack of communication observed in the above-mentioned statements stands against the conception of the network organized system and contradicts the comprehensive care-based practice as a doctrinal principle of the SUS.

Under the perspective of comprehensiveness, reference and counter-reference provisions articulate the healthcare services in network-organized systems. Reference provisions are related to the change from a light technology (for instance, family healthcare units) to a hard technology (hospitals). Conversely, counter-reference provisions comprehend the change from a hard to a light or light-hard technology.²¹ Notwithstanding, the responsibility for assisting TB patients is usually transferred to hard technology services. [...] *everything – sputum exam, medication, X-ray – took place in there [reference hospital], lung stuff, it all happened there* (S06); *The doctor here [FHU] assists me, but every time I get there he ends up saying, 'her case is not supposed to be assisted here; she must go to Clementino [reference hospital for TB treatment]'. They just pile us up there, then I stay there* (S08).

These statements clearly point out the fragility of the decentralization process of the TB control actions in the PHC services, or more specifically, in the Family Healthcare Units. The decentralization proposal, which implies the transfer of policies and competences from the central level to the local level, presupposes the agreement and the definition of new competences of the involved federated entities, as well as the configuration of new administrative structures. This is yet a big challenge to the SUS.²⁴ In order to trigger this new arrangement²⁵, the institutional capacity and learning process to the execution of new functions, as well as the interaction of competences in other government spheres, must be taken into account, so that a permanent negotiation is kept among the different national and subnational levels.

Referrals – targeted, necessary recordings within the health care network – are capable of guaranteeing the communication flow among the services and the effectiveness of the TB care. The relevance of the referrals is observed whenever they allow patients of the healthcare public service to feel guided toward the treatment process. The

communication process, once again, is deemed to be essential toward informing and orienting people in the service, in a way of providing the network's healthcare needs with an effective health care, creation of attachments and trust in the Family Healthcare Team. This equation will certainly generate a stronger adherence of the patient to the TB treatment process.

It is worth highlighting here the need of introducing new strategies in the work process, so that the care is provided under the guidance of a health care co-management framework based upon the comprehensiveness principle proposed by the SUS.

The disease-centered traditional care model needs to be urgently turned into a model that recognizes the expectations of the patients, counting on the involvement of both the family and the community's organized segments and incorporating patients into the treatment process as a wider integrative dimension in the conception of healthcare promotion model. In this way, the social support can be considered as one of the most indispensable factors toward improving the quality of life, self-esteem and autonomy of these people.¹⁷

FINAL REMARKS

The elements related to the TB treatment abandonment process are directly connected with the way FHS professionals carry out the care toward TB patients and their families, as well as with the service organization of healthcare processes, or in other words, the way these services are coordinated and how TB patients are followed-up throughout the treatment.

Contradictions have been identified between the real health care process provided by the team and the recommended one. Such incompatibilities are related to the comprehensiveness of the health care process based on a medication-focused therapy that ignores the social-economic-cultural complexity of TB patients, thus producing a direct impact in the perception of the disease and in the adherence or lack of adherence to the treatment. Such fact points to the fragilities seen in the health care process developed under the perspective of comprehensiveness. Additionally, results show that the low level of information patients have on the disease, as well as the fragile follow-up provided by healthcare services other than the FHS, corroborate to the abandonment of the TB treatment.

FHS teams are deemed to be quite relevant in the comprehensive care of TB patients by getting to know their real needs, persisting in getting them involved in the healthcare rehabilitation process and strengthening the three-fold patient-professional-health service attachment. This equation allows actions to be coherently carried out regarding both the reality of individuals with TB and the comprehensiveness principle recommended by the SUS.

The existing contradiction between the way comprehensiveness is conceived as a principle of the SUS and the negligence of sick people and their life contexts weakens the continuity of the care, discourages the adherence to TB treatment processes, and opposes the action coordination principle recommended by the comprehensive care-based PHC dimension.

TB control, and more precisely the prevention of the abandonment, stands out as a challenge for the health care management. Coherent actions grounded on the recommendations of the FHS - in which TB is one strategic area - should be urgently prioritized and planned out. Such actions allow for the coordination dimension to become a strong axle in the SUS operational framework by means of the establishment of defined organizational functions and the concrete implementation of the integration of healthcare services.

It can be realized, therefore, that the comprehensiveness notion is still incipient in the daily practices of the healthcare services, the scenario of this present study, regarding the follow-up and the treatment of TB patients in the SUS. The statements of the interviewees point out either informative or bureaucratic disorders in the attention network's continuous care and a direct care status centered on the biological aspect of the disease only.

Although the results of this study were drawn within the context of the work process and the framework/organization of the healthcare services, our conclusions go beyond local-regional specificities, as they contribute both to the advancement in the production of knowledge and to a broader debate on the TB treatment abandonment problem as a relevant challenge for the TB control actions in the national and global levels.

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