Tuberculosis treatment drop out and relations of bonding to the family health team*

ABANDONO DO TRATAMENTO DE TUBERCULOSE E RELAÇÕES DE VÍNCULO COM A EQUIPE DE SAÚDE DA FAMÍLIA

ABANDONO DEL TRATAMIENTO DE LA TUBERCULOSIS E RELACIONES VINCULARES CON EL EQUIPO DE SALUD FAMILIAR

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RESUMEN
La investigación objetivó analizar la relación entre las singularidades del enfermo con historial de abandono del tratamiento de la tuberculosis y la atención dispensada por el equipo de salud familiar a la luz del concepto vincular. La construcción del material empírico se realizó a través de entrevistas grabadas, en el período de julio a setiembre de 2008, utilizando la Historia Oral Temática. Se identificó que un vínculo de cierre para el tratamiento de la tuberculosis, en dos municipios de la región metropolitana de João Pessoa, Paraíba, Brasil. El análisis se realizó de acuerdo a la técnica de análisis del discurso. Se identificó que una relación terapéutica, con reparto de compromisos y valorización del usuario, fortalece el vínculo y pro-duce una democratización de la gestión de atención. Asimismo, una relación vertical, con vínculo fragilizado, se opone al propósito de una práctica intersubjetiva en la perspectiva de la cogestión del tratamiento.

RESUMEN
A pesquisa objetivou analisar a relação entre as singularidades do doente com histórico de abandono do tratamento de tuberculose e a atenção dispensada pela equipe de saúde da família à luz do conceito de vínculo. A construção do material empírico deu-se por meio de entrevistas gravadas, no período de julho a setembro de 2008, utilizando-se a História Oral Temática. Identificou-se que uma relação terapêutica, com partilha de compromissos e valorização do usuário, fortalece o vínculo e produz a democratização da gestão do cuidado. Por outro lado, uma relação vertical, com vínculo fragilizado, opõe-se ao propósito de uma prática intersubjetiva na perspectiva da co-gestão do cuidado.

ABSTRACT
This study aimed to analyze the relation between the singularities of the sick subject with the history of dropping out of the tuberculosis treatment and the care given by the family health team in light of the bonding concept. The empirical material was built through recorded interviews, in the period from July to September of 2008, using the Thematic Oral History methodology. Interviews were taken with nine users whose drop out was the criteria for closing the treatment to tuberculosis in two municipalities of the metropolitan region of João Pessoa, Paraíba, Brazil. The analysis was performed according to the discourse analysis technique. The study identified that a therapeutic relation, sharing commitments and the user’s valuation, strengthens the bonding and produces the care management democratization. On the other hand, a vertical relation, with fragile bonding, is opposed to the purpose of an intersubjective practice in the perspective of the care co-management.

KEY WORDS
Tuberculose.
Recusa do paciente ao tratamento.
Patientes desistentes do tratamento.
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DESCRIPTORES
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INTRODUCTION

The history of tuberculosis (TB) shows that the technological advancements related to the discovery of prevention and healing strategies in the twentieth century brought important changes in the treatment and social representation of TB. Paradoxically, despite the advances, tuberculosis remains a global public health issue. In this context, Brazil ranks 18th place among the 22 countries responsible for 80% of all TB cases in the world. In the year 2006 a total of 94,000 new cases (50/100,000) and 7,600 deaths (4/80% of all TB cases in the world) were reported in Brazil in all forms of the disease[4].

Currently, in Brazil, the biggest challenge of the National Program for Tuberculosis Control (PNCT, acronym in Portuguese for Programa Nacional de Controle da Tuberculose) is to use the Supervised Treatment (ST) strategy to expand TB control action, reduce the number of noncompliance cases and increase cure rates[5]. It is emphasized that the expansion of ST coverage is related to political-managerial, technical-operational and financing dimensions of TB actions[5]. Thus, the Policy for Tuberculosis Control in Brazil, in compliance with the pillars of the Directly Observed Treatment, Short-course (DOTS), emphasizes the importance of establishing a decentralized diagnosis and treatment network that is integrated with Primary Health Care (PHC) in order to level the activities of surveillance, prevention and disease control, by incorporating these assignments to the teams of the Family Health Strategy, considered from the PHC perspective, the front door to the health system.

The process of expansion of the Family Health Strategy is in a transition stage, characterized by insufficient sustainability. The advancement of this strategy, especially in large urban centers, has been hindered by challenges related to the complexity of social, political and economic contexts, which are implied by the family receiving care. For this reason, its consolidation as a strategy for the organization of the Unique Health System (the national public health system in Brazil: SUS - Sistema Único de Saúde) requires continued efforts to expand health care coverage and improve the quality of this PHC model, the political commitment of the management and community participation so it is possible to make a paradigmatic change in the current health care system[4].

The decentralization of TB control actions to the front door of the municipal health systems has been hampered by the same obstacles put to the expansion of the Family Health Strategy. It is observed that weaknesses in the delivery of care to TB patients have contributed to the occurrence of treatment discontinuation. The little importance assigned to the socio-cultural context of the patient when developing individualized treatment plans, added to a weak bond with the professionals of the Family Health Team (FHT) and poor welcoming have cooperated to increase the TB treatment abandonment rates.

OBJECTIVE

Considering the complexity of the care to users with a history of abandoning TB treatment and decentralization of disease control actions to the Family Health Units (FHU) - the front door to the system as per the design of PHC - the objective of this article is to analyze the relationship between the singularities of patients with a history TB treatment abandonment and the health care delivered by the family health team. From a theoretical point of view, to give sustainability to the analysis, this relationship was seen under the concept of bonding, which presupposes the existence of a regular source of care and the establishment of strong interpersonal bonds, showing mutual cooperation between the health team and the referred community[5].

METHOD

This is a qualitative study, performed in two municipalities in the metropolitan region of João Pessoa, Paraíba state, Brazil, considered priorities for TB control in that state.

One city, Bayeux, has a territory of 32 km² and 92,891 inhabitants[6]. According to information from the coordinator of the Tuberculosis Control Program (TCP), in Brazil, the Family Health Strategy covers 92% of the population and counts on the work of 28 teams. Since 2003, given the implementation of DOTS, TB care has been organized in a decentralized manner at FHU’s. In 2007, 50 TB patients were followed in Bayeux; 40 of which were new cases and 31 had positive sputum-smear (BK+). The abandonment rate for the same year was 5%.

The other city, Santa Rita, has a territory of 727 km² and population of 122,454 inhabitants[6]. According to information provided by the coordinator of the local TCP, the municipality has 36 FHU’s, distributed along urban and rural areas, ensuring 100% coverage of the municipal population. The local TCP was established in 1999 and is currently decentralized to the primary care network. In 2007 there were 40 reported TB cases in Santa Rita, 38 of which were in the urban area, and the abandonment rate for that year was 5%.

Thematic Oral History[7], was used as the methodology for this study. The construction of the empirical material was carried out from July to September 2008 upon the following procedures: a taped interview, transcript of the recorded material, typing, transcribing and, finally, the material was reviewed for use and publication.

The little importance assigned to the socio-cultural context of the patient when developing individualized treatment plans, added to a weak bond with the professionals of the Family Health Team (FHT) and poor welcoming have cooperated to increase the TB treatment abandonment rates.
Participants were nine users of areas covered by the FHU’s in the two referred cities, who had abandoned the TB treatment. The delineation and location of the subjects was possible by the information provided in the information system of the Tuberculosis Section of the Municipal Health Departments of Bayeux and Santa Rita, as well as through the support of the FHS responsible for the areas in which the subjects lived.

After completing the treatment of the data from the interviews, the statements were categorized and analyzed as follows: the texts were printed and read and the themes related to the object and purpose of the study were identified; the texts containing recurring themes presented by the subjects were clipped and excerpted; the texts that referred to the same themes were grouped, permitting to form blocks of meaning, thus guiding the construction of sub-categories, which explains the large empirical category identified.

The thematic discourse analysis was used in the analysis process, considering it is indicated for qualitative studies as it permits to associated material that involve value, necessary and preferable judgments as arguments, or as means capable of revealing the individual's view of the world and, therefore, the ideological point of view of the discursive subject.

This study was performed in compliance with the ethical and legal norms for studies involving human subjects, as per Resolution 196/96 of the National Health Committee. The statements were presented using the following code rule: C1, C2, C3, C4, C5, C6, C7, C8 and C9, to represent the study subjects. Moreover, the names of the people stated by the interviewees were replaced by fictitious names to ensure anonymity and preserve the subjects' privacy as to the confidential data involved. The project that originated this study was approved the Research Ethics Committee at the Center for Health Sciences at Federal University of Paraiba on March 2nd 2008, under document number 0067.

RESULTS AND DISCUSSION

Regarding the description of the study subjects, five are male, represented by C1, C2, C3, C6 and C9 and four are female (C4, C5, C7 and C8). The level of education reported by all respondents is incomplete primary education.

C1, 43, married, smoker, worked as a butcher. Own the house he lives in with other three people. The family income is about R$200.00 per week. C2, 19 years old, single, student, lives with three people in a house that he owns. C3, 33 years old, single, alcohol user, smoker, unemployed, lives with five people in a house that he owns. The mean family income is R$415.00. C4, 39 years old, single, housewife smoker, alcohol user, former user of illegal drugs. She lives with twelve people in a rented house and family income is about R$1,000.00. C5, 33, married, housewife, lives with four people in a rented house, and has a family income of about R$300.00. C6, 25, single, alcohol user, smoker and illicit drug user. She owns the house she lives in with other two people and the family income is R$415.00. C7, 61, widow, housewife. Lives in a borrowed house with three people and the mean family income is R$585.00. C8, 43, married, housewife, smoker, owns the house she lives in with nine other people and the mean family income is R$330.00. C9, 50, divorced, craftsman, alcohol user, smoker. He owns the house he lives with one other person and the mean family income is R$415.00 (at the time US$1.00 was approximately R$1.60).

The brief characterization presented above shows the socioeconomic weakness of most TB patients. It is observed that all subjects live in areas covered by the FHU’s and, besides this characteristic, they also share a history of abandoning the treatment, low educational level and a precarious financial situation, as all have a monthly income of less than three minimum salaries. The situation that is briefly illustrated herein confirms that TB control is an important social marker of the precarious conditions of people living in metropolitan regions.

The relationship between TB patients and the Family Health Team

One of the fundamental principles of the Family Health Strategy is building bonds between the health team and the referred community, with the purpose to maintain the care offered to individuals and families over time, by means of a proactive attitude in view of the health-disease problems.

The word bond (vínculo, in Portuguese) has its origin in Latin- vinculum, which means tie, connection. It is a concept that suggests interdependence, exchange relationships, humanized care and health care comprehensiveness. The bond exists when there is a transferring of affection between those becoming connected, and may thus be defined as the circulation of affection between people.

The forming of bonds is, intimately, related with the practice of health care, translated into attitudes of concern, interest and attention. That relationship may be observed in the statements of the following collaborators:

I really miss the team from the health unit [FHU], because they were really good, modest and treated everyone well (C9).

The only one who cares about us is Ms. Maria [Community Health Agent - CHA]. If she sees a sick person, she’s immediately all over that person. She talks to the doctor for us when needed. And wherever you go, people here always talk about her, because she helps everyone around here (C8).

I really like Ana [nurse] and I really missed her when she moved from this unit [...] Ana was tops, really friendly, she was considerate with everyone (C5).
Bonding, as a comprehensive health care practice, guides towards a new type of care that involves humanization, assigning responsibilities, and the need to integrate the user’s voice, producing changes in the health care model[16].

Care is an attitude of affection, zeal and responsibility towards others[13]. Caring requires knowing the project for happiness of the individual receiving care and actively participating in the construction of that project[16], which suggests that there is no possibility of exiting care in the absence of bonding between subjects, thus requiring the production of subjectivities that emerge and grow stronger, or not, throughout the treatment.

In the health area, bonding is a basic element in the treatment and is, therefore, essential. The Greek root for the word therapeutic- therapeutike means care[11]. Hence, the bonding created in health practice occurs in the context of care relationships.

The loss of the caring dimension in every part, as well as the loss of the connection with the whole, has sustained the current technical scientism, and this fact requires the development of a care knowledge ethics[13]. This understanding, in the context of health practice, represents overcoming a practice of simply offering services and proposes an advancement towards the incorporation of the technologies of the relationships of interaction and subjectivity, because the process centered on soft technologies and soft-hard technologies is the essential condition for a service to become a producer of care[13].

The bond between the FHS and TB patients, particularly those who abandoned treatment, favors the active maintenance of care, by monitoring the health condition of users and their family, considering the perspective of the broader concept of health and the uniqueness of the individual which walks away from the possibility to take care and be careful. A closer approach of the health team to the life context of TB patients enhances the bond, as reported by an employee:

They made efforts to know my family [...] I noticed their interest. I think the health service is perfect (C1).

Moreover, the disregard towards the life conditions of TB patients and their family by the FHS weakens the bond in the treatment process, as seen in the following report:

I think the team is somewhat distanced from my family, they are not aware of our needs. I think there should be more attention (C2).

It is observed that the implementation of the Family Health Program (FHP), in some municipalities, accounted mostly for an institutional change that, in fact, an approach to the everyday life of families and family care. Consequently, the family term has lost its specificity, as family health is a term used to refer to the traditional practices of individual approach or relationship with the community group[16].

Considering that the family is an area of care relationships, as seen in the following reports, it is essential that the FHS involves the relatives of TB patients in the development and implementation of the treatment plan:

I spend four, five days in bed, discouraged, then my daughter wants to call the ambulance (C8).

My sister called me to get an X Ray [...] when I had a fever, I went back to the health unit with my sister and we got the medication (C2).

I went with my mother around every health center (C3).

I ate too much mastrazu (Dysphania ambrosioides) with milk. My mom is from the interior state region and recommended it for me (C4).

In general, TB patients assisted at the FHU’s develop stronger bonds with the health professional responsible for their treatment that is more familiar with the cultural and socio-economic context of the family. The relationship established between them - FHT, patient and family, is permeated with trust, respect and solidarity, as shown in the following statements:

Among the health team professionals, Tereza (CHA) is who actually knows my life situation. She always comes here. She is an old friend. She’s a really nice person, she’s there for me, she’s polite and gives me a lot of advice (C9).

I don’t look for the doctor here because the only one who cares about me is Ms. Maria [CHA] [...] My happiness is first Jesus and then Ms. Maria (C8).

I like the people from my unit, but I’m closer with the health agent. She knows my situation (C3).

Who really took care of me was Ana [nurse]. If it weren’t for her, I don’t know what would have become of me. She gave me a lot of strength(C5).

[...] Carla was the one from the team who took care of me the most [CHA] (C6).

Regarding the bond between TB patients and health professionals, it was found that the Community Health Agent (CHA) holds a prominent place, justified by the fact that they share the daily life of the user, regarding the organization of the community, the economic and social context of the population and its forms of expression, culture and values. CHA’s know the needs of the families and community, and speaks the language of the people, sharing of local customs and, therefore, their performance relies on the concept of the bond between the health service and the community[17]. Collaborator 8, speaking of the CHA of his micro, described her as

[...] a woman who talks to everyone [...] runs to the unit, and when she cannot take us, she calls the unit for help.

The CHA is seen as a representative of the health team in the community, therefore, sometimes when he or she cannot play the role of being the link between the assisted
population and the health service, users tend to distance from the FHT. Collaborator 7, when referring to the home visits by the CHA, reported the following:

If they visit at all, it's once a month. If I do not talk to her, she doesn't even come in my house to know how things are. Sometimes she asks me how I am, but she does that from outside. That's why I stopped going to that unit.

TB patient follow up during the treatment should be intensified in the first three months, because it is a critical period for abandonment\(^{18-19}\). Home visits enhance this monitoring process and should occur regularly, allowing for stronger bonds between the FHT, users and their family, enabling, most of all, the development of family-centered continuous care, in which the individual must be considered in their daily environment and assessing the health needs extends to the family context\(^{20}\). Moreover, in the context of tuberculosis control, the importance of the quality of information flow in health, which permits to follow up with treatment outcomes of TB patients\(^{20}\).

Stressing that attachment permits to form bonds\(^{21}\) and promotes empathy and solidarity among health professionals and the user, it is also important, when delivering care, to exist interaction between the FHT and the user. Furthermore, it should be emphasized that the TB patients' adherence to treatment depends on health professionals being engaged in the care of TB patients\(^{21}\), as shown in the following statement:

Ana [nurse] was a friend to me. She went to my house, had some coffee, ate a snack. I really like Anna and I really missed her when she left that unit [...] After Anna left the unit, it's very hard for me to go there\(^{25}\).

When the TB patient feels valued by the health team, due to the bond that is established, there is an incentive for adherence to treatment. This idea can be proven by the statement given by collaborator 9:

[...] I did everything they asked, because I liked them [crying]. [...] During my treatment, I had everything. Everybody liked me.

Thus, it is observed that it is important to develop soft technologies for health care as a factor to strengthen patient adherence to TB. The statements of the collaborators showed that the way that the FHTs welcomes users and participates in their family life is the key to establishing bonds and must be seen as an important factor to ensure treatment continuity. Moreover, it is also noted that the distance between their team and users and the family unit, loosens the bonds, thus favoring treatment abandonment.

The referred singularities show the level of complexity of the problem of those who abandon the treatment. It is observed that a successful treatment outcome also depends on the relationship that the FHS established with the other sectors of society and the political commitment of managers to guarantee policies that promote care in the perspective of comprehensiveness. It is believed that the understanding the singularity of TB patients is what establishes the bond, which goes beyond the treatment plan, creating the possibility of a health care practice from the perspective of co-management.

**The bond and the development of a treatment plan for TB patients from the perspective of co-managed care**

Co-managed care implies establishing an inter-subjective practice in which health professionals and users establish exchanging relationships and develop the strong sense of dialogue from the perspective of hermeneutics: the fusion of horizons, defined as the production of sharing, becoming familiar, and mutual ownership of what until then was unknown, or only supposedly known\(^{14}\).

For health sector resources to be put at the service of the success desired by users, it is necessary for the fusion of horizons to permeate the entire process of building the line of care, which represents a flow of comprehensive care drawn from the moment the user enters the healthcare system to all points of care in the system, coordinating activities and services, creating bonds and integrating the various participants of a treatment plan, which is built based on the health needs of the user, which is the structuring element of the entire process of health production\(^{15}\). Sometimes, however, the patient assumes a condition of an object, placed outside the treatment plan, when they should actually take the leading role in the process of care management. Collaborator 7 gives a report on this aspect:

I was told to follow the treatment because I have tuberculosis, but until now I don't know [...] What good would it do? Without knowing what it really is? Because the person is taking medication for one thing but has something else... I did a lot of sputum smears and they were all negative. The first time I was treating at the other unit, I went for an X-Ray and the doctor said I had pulmonary emphysema and I don't know what that means [...] I don’t know about anything here, except for the medication\(^{27}\).

The statement above shows the absence of bonds and how the used was assigned the condition of an object, being left on the side of the treatment plan, evincing the weakness of the management of her care. This same collaborator shows how the uncertainty towards the diagnosis of the disease, associated with her lack of familiarity with the information resources regarding the disease and treatment, affected her attitude of abandoning the TB treatment.

The girl from the hospital called me asking why I did not go there to get my medication, but I didn't even go there because how should I follow a treatment for something I'm not even sure about? [...] I quit the treatment because I don't know what I have \(^{(C7)}\).

Recognizing the subject condition of users in health practices fits with the Paideia idea of health, a method that originates from the Greek concept of comprehensive human development. It represents an effort to bring health and citizenship closer, as it aims at the co-production of...
subjects with the capacity to analyze and co-manage their own lives and institutions. The Paideia attitude causes to break with the power/knowledge relations historically constructed between health professionals and users, in which the former hold the so-called scientific knowledge and, therefore, define the best treatment management. Accordingly, the Paideia method enhances educational health projects that enhance the active participation of users in the management of health problems. 

It is important for user to be involved in all stages of TB treatment and for the FHT to encourage that participation by providing the necessary information - using accessible language - and checking that users assimilate the information that is provided. The statement below, by collaborator 8, points out communication difficulties between the user and health professional, which destroy the process of health education:

I don’t know if I have lungs. The doctor said I have to remove it. The other day, when I took an X-ray, there was only one lung, but I took another X-ray the week before, and I have two. I have one under my ribs. I didn’t even see the flesh of my ribs. And I asked the doctor where the other was. I think this medication is making me crazy (C8).

It is necessary to develop a communication channel in the relationship between the FHT and the TB patient, through which health professionals understand the perception of patients about their disease, and, thus, patients can understand the objectives of the proposed treatment indications, so that both participate in the construction of the treatment plan.

The first appointment is the right time for the health professional to talk to the TB patient about the disease, treatment and participation in the care management. This attitude reduced the possibility of noncompliance related to the patients’ inadequate assimilation of information and permits to start and maintain the bonding relationship that should exist between both, in order to promote a therapeutic interaction.

The therapeutic relationship between health professionals and TB patients is affected by the conditions in which that interaction takes place. The psychological aspects of users regarding their disease, the technical skills of health professionals, working conditions in the unit and the feelings experienced by the professionals (anxiety, fear, frustration, compassion), among other things, create the atmosphere of the therapeutic encounter, which may favor the construction of the bond and the development of co-management of care, or impede patient adherence, resulting in the abandonment of treatment.

Sharing responsibility in the co-management of care is essential to enhance the involvement of the TB patient with the treatment. Collaborator 1 made a report on this regard:

They told me to take care of myself and taking the medication to heal.

This statement demonstrates the team’s work in relation to encouraging self care among TB patients. However, there is a need to find balance in this process, because the team cannot be dismissed from its share of commitments in the management of care, because

for the treatment of tuberculosis to succeed there must be a shared commitment, involving the health service and the patient, through the creation of agreements that address the needs of both parties.

Sometimes, despite the efforts by the FHT for establishing the co-management of care, with clear definition of shared responsibilities, the TB patient escapes from this process, as shown in the following statement:

What was missing was me wanting to even myself, but I’m the one who didn’t want it. It was my fault, because I spent those months taking the medicine, I thought I was strong, I thought I was well (C3).

The bond, from the perspective of Paideia Health, should boost the development of practices that recover the autonomy of individuals, because any care that does not help others help themselves cannot be considered comprehensive. Considering the notion of care politics, it is observed that care may protect or emancipate people. It is believed that developing subjects towards assuming the main role in the care process and fostering citizenship are the highest goals of health practices permeated by the principle of comprehensiveness. Collaborator 8 shows the deconstruction of user autonomy in the following report,

The health unit is not good. The doctor there tells me to do a test, but when I go there for the results, no one tells me. That’s why I don’t go to any health unit at all (C8).

Considering that the bond between the TB patients and the FHT can be positive when there is autonomy, or negative when it produces dependence and insecurity for users, it is stressed that the health team must perceive that users, provided they have support, can overcome adverse conditions, facing health problems from their real life conditions. Otherwise, there will be a tendency to establish a pattern of paternalistic bonds. Therefore, to produce comprehensive care, permeated by bond, it is essential to invest in the reconstruction of citizenship and subjectivity of users, especially those with a tendency not to adhere to treatment or with a history of abandonment, i.e. who have difficulties to defend their own life.

It is believed that, to deal with the abandonment of TB treatment, there must be an involvement of different social actors - civil society, research centers and universities, health professionals, managers and governments, so there is a coordinated duplication of efforts, and, within the desired context of reducing social inequalities, it is possible to achieve the goals related to reducing the number of abandonments and increase cure rates.

**CONCLUSION**

Reflecting on the relationship between the singularities of tuberculosis patients with a history of noncompliance,
and the care delivered by the family health team under the light of the bond, implies first recognizing the importance of the design of individualized treatment plans, translated as happiness projects, in which the participation of users and the health team result in a process of co-management of care.

Strengthening the bond between the family health team and the TB patient favors the production of care from the perspective of co-management through a relationship of trust and shared commitments. The bond has a close relationship with the practice of care, considering that both promote harmony, exchange of feelings and a potential reconstruction of autonomy.

It was found that the bond favors the continuity of care and that the health team’s knowledge about the socio-economic-cultural life of users and their family strengthens the therapeutic relationship. In this respect, the community health agent was highlighted as a member of the healthcare team with whom the TB patient develops a stronger bond.

Involving TB patients in every stage of the treatment plan and establishing communication channels between users and the healthcare team promote patient adherence to the treatment.

It was identified that a therapeutic relationship, with an emphasis on shared commitments and user valorization, strengthens the bonds and produces democratization of care management through the participation of users in decisions about the health they want to achieve. Furthermore, vertical relationships, in which the bond becomes occasional and the health team does not respect the patient’s life project, maintain domination power relationships and therefore oppose the purpose of a practice from the perspective of intersubjective co-management of care.

REFERENCES