Health needs according to the perception of people with pulmonary tuberculosis

NECESSIDADES EM SAÚDE SEGUNDO PERCEPÇÕES DE PESSOAS COM TUBERCULOSE PULMONAR

NECESIDADES EN SALUD SEGÚN PERCEPCIONES DE PERSONAS CON TUBERCULOSIS PULMONAR

Paula Hino[1], Maria Rita Bertolozzi[2], Renata Ferreira Takahashi[3], Emiko Yoshikawa Egry[4]

ABSTRACT

The objective of this study was to identify the perceptions of people with tuberculosis regarding their health needs. This qualitative study was performed in the administrative district of Capão Redondo, São Paulo. Data collection was performed in January of 2010 via semi-directed interviews. The interviews were conducted with eleven people undergoing tuberculosis treatment. The participants were at least eighteen years of age and presented no cognition limitations. The empirical material was decoded through discourse analysis. The health needs perceptions are related to the difficulties that emerge in the health-disease process, and acknowledging health needs appeared to be tied to the current illness. The identified needs result from biological alterations, changes to their daily lives, and the limited availability of healthcare services. The quality of assistance offered to people with tuberculosis is a condition of factors related to identifying and meeting their health needs.

DESCRIPTORS

Tuberculosis
Needs assessment
Health Services needs and demand
Public health nursing

RESUMO

O presente estudo teve como objetivo conhecer as percepções sobre necessidades em saúde de pessoas com tuberculose pulmonar. Trata-se de estudo qualitativo, desenvolvido no distrito administrativo Capão Redondo, São Paulo. Os dados foram coletados em janeiro de 2010 por meio de entrevista semidiretiva. Foram entrevistadas onze pessoas em tratamento contra tuberculose, com idade mínima de 18 anos e sem limites de cognição. O material empírico foi decodificado a partir de técnica de análise de discurso. As percepções sobre necessidades em saúde estão relacionadas às dificuldades enfrentadas no processo saúde-doença, e o reconhecimento das necessidades em saúde mostrou-se condicionado à vigência do agravo à saúde. As necessidades identificadas decorrem de alterações biológicas, do cotidiano e de insuficiências no processo de produção dos serviços de saúde. A qualidade da assistência às pessoas com tuberculose está, entre outros fatores, condicionada à identificação e ao atendimento de suas necessidades em saúde.

DESCRITORES

Tuberculose
Determinação de necessidades de cuidados de saúde
Necessidades e demandas de Serviços de Saúde
Enfermagem em saúde pública

RESUMEN

Se apuntó a conocer las percepciones sobre necesidades sanitarias de personas con tuberculosis pulmonar. Estudio cualitativo, desarrollado en el distrito administrativo de Capão Redondo-SP. Datos recolectados en enero 2010 mediante entrevista semidirigida. Fueron entrevistadas once personas en tratamiento antituberculoso, con edad mínima de 18 años, sin limitación de tipo educativo. El material empírico se decodificó mediante análisis del discurso. Las percepciones sobre necesidades en salud están relacionadas a las dificultades enfrentadas en el proceso salud-enfermedad y el reconocimiento de necesidades en salud se mostró condicionado a la vigencia del padecimiento. Las necesidades identificadas derivan de alteraciones biológicas y cotidianas, y de insuficiencias en el proceso de producción de los servicios sanitarios. La calidad asistencial a personas con tuberculosis está, entre otras, condicionada a la identificación y atención de sus necesidades sanitarias.

DESCRIPTORES

Tuberculosis
Evaluación de necesidades
Necesidades y demandas de Servicios de Salud
Enfermería en salud pública

[1]RN. Post-doctorate by the Collective Health Nursing Department at School of Nursing, University of São Paulo. CNPq fellow. São Paulo, SP, Brazil. paulahino@usp.br [2]RN. Associate Professor of the Collective Health Nursing Department at the School of Nursing, University of São Paulo. São Paulo, SP, Brazil. mrbertol@usp.br [3]RN. Associate Professor of the Collective Health Nursing Department at the School of Nursing, University of São Paulo. São Paulo, SP, Brazil. rftakaha@usp.br [4]RN. Full Professor of the Collective Health Nursing Department at the School of Nursing, University of São Paulo. São Paulo, SP, Brazil. emiyegry@usp.br

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INTRODUCTION

The aim of working with humans is to satisfy needs. The intention behind work processes is social and not individual. As such, work is guided by the social needs that justify it. Health needs are socially and historically determined, as are other human necessities[1].

Health needs are located between nature and culture; in other words, they are not concerned only with the preservation of life, but also with the execution of a project through which the individual becomes more humane, acting as a bridge between the specific and the generic[2].

Needs are central to healthcare and can function as *analyzers* of healthcare practices since integrality, which is operationalized in healthcare, can be defined as the health team's effort to translate and satisfy, in the best way possible, the always complex needs of individuals, received in their individual expression[3].

Tuberculosis (TB) is a disease that is closely related to low standards of living and can be better understood through the Theory of Social Determinants of Health-Disease Process. Controlling the occurrence of TB, as well as that of any disease resulting from social inequality, requires changes in health conditions and in the organization of healthcare. Thus, it is important to know the health needs of the carriers of the disease, so that the assistance rendered is of a higher quality and properly fulfills the identified needs.

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The individual's socioeconomic situation significantly affects adherence to treatment, as well as other factors such as: the side effects of tuberculosis drugs, alcoholism, drug addiction, low levels of education, ideas regarding the health-disease process and lack of motivation to follow the prescribed treatment. Some factors that contribute to the non-adherence to treatment are related to healthcare, especially the organization of the work process, as well as the physical structure of and access to healthcare[4].

Many times treatment abandonment, when attributed exclusively to the disease carriers, is interpreted in a limited way, resulting in focused interventions restricted to the individual and related to the clinical and biological sides of the disease. However, when adherence to treatment is analyzed from another angle, not as the result of the behavior and attitude of the individual but with the aim of identifying the potential to adhere to the treatment, the interventions' focus grows.

Adherence can be understood from three angles: the first one concerns the aspects related to the individuals affected by the disease, such as their concept of health-disease; the second refers to the social place occupied by the disease carrier, which views the battle against the morbid condition from different possibilities that involve access to healthcare and leading a dignified life; and the third, which involves the process of health production and the health demands' locus that might (or might not) be recognized as health needs[5].

There are three facts that justify this study. First of all, TB is a socially determined disease; in other words, its occurrence is associated with the organization of the social production and reproduction processes, which are directly related to the individual's ways of living and working. Secondly, the persons' affected by this disease have specific needs, in addition to common ones; in general, these persons' low living standards can be considered potential determinants of treatment abandonment. Lastly, the theme's relevance and the lack of scientific production regarding the health needs of TB carriers justify its execution.

With this in mind, this study aims to understand the perceptions surrounding the health needs of persons with pulmonary tuberculosis.

METHOD

This is an exploratory, descriptive study with a qualitative approach regarding the health needs of persons with TB, living in the administrative district of Capao Redondo, located in the suburbs in southern Sao Paulo.

According to data from the State Data Analysis System Foundation (*Fundação do Sistema Estadual de Análise de Dados*), in the year 2009 the district's population was approximately 272,103. The growth rate was estimated to be 2.9% per year and the human development index (HDI) was 0.782, making it clear that this region presents social inequalities with important social deficiencies.

Data were collected during the month of January, 2010, in two Family Health Units, which presented the highest number of notified TB cases in 2009 in Capao Redondo. The criteria for inclusion of the cases were: persons who were undergoing treatment for TB, aged 18 or older and who presented no cognitive limitations. All subjects that fit these pre-established criteria agreed to participate in the research.

A semi-structured instrument was used, made up of closed questions concerning the sociodemographic variables and the health-disease process. For guiding reasons, the question, *Tell me how your life changed after the TB diagnosis* was asked. The medical records of the TB carriers were consulted, when necessary, to obtain answers to sociodemographic and epidemiologic questions.

The interviews were recorded and transcribed in full. The empirical material was analyzed using the technique

of discourse analysis, allowing the identification of two analytical categories: perceptions of the health-disease process and perceptions of health needs. In the study's contextualization, the depth and literal meaning of the subjects' discourses were privileged and repeated readings were performed to identify underlying themes. The discourses are expressions of real life, and hold the persons' world view, which materialized in the representations regarding the elements of the objective reality[6-7].

The discourses were decoded and synthesized in thematic phrases that constituted the deponent's perceptions, rather than testimonies/discourses. Following, the theme phrases were grouped according to central cores, which guided the presentation and the results' discussion. It should be noted that not all theme phrases were used in the analysis, as only the ones that better related to the study object were chosen. The Theory of Social Determinants of Health-Disease Process theoretically guided the analysis phase and the discussion of this study's findings.

Most interviews (n=9) were conducted in the health unit, on the occasion of the client's arrival at the unit for supervised medication administration, medical appointments or for delivering samples for examination. The interviews lasted an average of 20 minutes and took place in a designated room, avoiding possible interruptions and preserving the privacy of the participants. To guarantee data and interviewee anonymity, the subjects were identified by the letter E, and were numbered from 1 to 11.

Being a research that involves human beings and complying with the ethical-legal rules of Resolution Number 196/96, the project was approved by the Research Ethical Committee of the Sao Paulo University Nursing School (ruling number 783/2006). The subjects were invited to participate and those who agreed to do so signed a free and clarified term of consent.

RESULTS

Eleven subjects were interviewed (six men and five women), between the ages of 20 and 68. Most of them were in the age group of 20 – 29; six were married, four were single and one was divorced. Six were from northeastern municipalities and five were from the southeast. Most of them had little education: nine did not complete a fundamental education and two were illiterate. The average number of children per interviewee was 3.9, with the lowest being one and the highest being 12 children. When asked about their occupation, two women answered that they did not work outside their homes and three were housemaids. The remaining subjects stated they worked as: a hydraulics auxiliary, a cook, an ice cream delivery person, a waitress, a construction worker and a gardener.

All participants had pulmonary TB and only one case was a relapse, with the remaining being classified as new cases. The treatment period varied from less than a month to seven months. All participants were undergoing supervised treatment, most of them in the health unit. At the time of data collection, only two of them were under home medication supervision.

When analyzing the testimonies, it was found that the TB carriers' perception of their health needs was linked to hardships experienced during their illness. When asked about their health needs before the diagnosis of TB, some of the interviewees denied having any unmet needs:

> (...) there were no needs, since I didn't even know I was sick (...) (E1).

The reported needs were almost always linked to biological complaints and, sometimes, to health care needs, as exemplified in the following excerpt:

> (...) before TB, I thought that needs consisted of measuring your blood pressure, monitoring your anemia (...) (E8).

Thus, it can be asserted that the recognition of health needs is connected to the manifestation or presence of a health problem. Frequently, health needs were associated with other pathologies, such as diabetes mellitus, kidney failure, asthmatic bronchitis, gastritis and pneumonia.

Analysis of the health needs identified in the TB carriers' testimonies shows that these needs are not restricted to the biological sphere, but also affect the persons' life in society and the production processes of healthcare; more specifically, the organizational structure of the services and the operational method of the assistance model. There is no linearity when it comes to the moment when the health needs first become evident, because some of them are present before the disease's first signs and symptoms, and remain until the conclusion of treatment, while other needs are manifested during the treatment.

Thus, the first need identified in the testimonies appeared in the phase before diagnosis, due to the emergence of signs and symptoms and changes in body functioning, such as fever, coughing, thoracic pain, anorexia, weight loss, fatigue, weakness and hemoptysis, that led the study subjects to seek care. Higher severity was given to the presence of certain signs, such as hemoptysis, which determined a more immediate visit to the health service, as is revealed in the following testimonies:

> (...) since I wasn't spitting up any blood, there wasn't a problem (E6).

> (...I thought I was having a stroke when I coughed up blood (E3).

On the other hand, a certain trivialization of the symptoms was noted, exemplified by the following testimony:

> (...) I felt very hot at night, has a fever, lost weight, I didn't think that it could be TB, I thought it was something worse (...) (E6).

In this case the TB diagnosis brought relief, which is a curious fact. The worsening of symptoms and the visit to a health service, associated with insufficient availability of medical appointments and longs waits for examinations, made it difficult to obtain the TB diagnosis and also showed how important a fast, precise and definitive diagnosis really is, being highly dependent on the production process of health services. This need became evident in the gamut of feelings experienced by the participants, who waited a long time to receive the correct diagnosis and felt fear, anxiety, weakness and insecurity. These feelings can last throughout the treatment, even if caused by other conditions.

It should be noted that this need was fulfilled, because the interviewees expressed positive feelings in relation to healthcare; in other words, when access to healthcare brought a fast and reliable diagnosis, it generated a feeling of positivity in terms of receiving care. Healthcare was appreciated by these individuals because it provided an accurate diagnosis and offered treatment after a long journey through many healthcare services.

Disclosure of the TB diagnosis, ignorance regarding the disease and other meanings attributed to the disease that are present in popular culture generate further needs, including: knowledge of the disease, information about treatment and to how it is provided, support in sharing the diagnosis with their families, being welcomed by the professionals who treat the disease and handling the emerging emotions following diagnosis. Such needs are associated with facing the process of disease and cure, which includes receiving knowledge about the disease, health care, transmission prevention, drug treatment follow- up and other life changes resulting from the health-disease process.

Ignorance or misinformation about the disease was frequent among the research subjects. Some believed that their disease was a result of previous ailments, such as: *a strong or improperly treated flu, bad pneumonia or practices such as getting rained on or using contaminated dishes(...) I caught TB because I used a dirty glass in a commercial establishment (...) (E1).*

Ignorance regarding the transmission period of Koch's bacillus was evident in a subject's worry about transmitting the disease to their children or other family members, and about dying and leaving their children as orphans, even though the person was one month away from completing their treatment.

The fear of being discriminated against for having a transmissible disease and of their family's and friends' reaction when faced with the diagnosis resulted in the need for support to share the diagnosis because, as one of them stated:

> (...) people don't understand the disease and are prejudiced (...) (E4).

Even though progress has been made, thanks to the spreading of information regarding the subject both in the scope of healthcare and through efforts of the National Program for Tuberculosis Control that transmits television announcements, the disease is still stigmatized, as is evidenced in the following testimonies:

> (...) TB is linked to people with HIV (...) (E6).

> (...) TB is a disease in which even the name is ugly (...) (E7).

Preconceptions related to the disease conditioned some of the carriers' reactions, who expressed fear of being alienated from other people.

The process of coping is, in part, guided by the understanding of the health-disease process that is endured. It is also the product of beliefs, knowledge and experiences in living with the ailment, culturally transmitted throughout history that, when associated with the experiences with the disease, end up acting as intermediaries in this process. Interpreting the disease as divine punishment, because something that shouldn't have been done was in fact done, when associated with negative feelings such as guilt, depression, concern and fear, made adhering to treatment more difficult. However, it was noted that when beliefs were associated with willfulness, hope for a cure and courage to persevere with the treatment, they contributed to the completion of the treatment.

When TB carriers had previous experience with the disease, such as knowing someone who had the disease and was cured or knowing that it is a curable disease, it was easier for them to consider it as a regular disease, helping them to adhere to their treatment, as is shown by the following testimony:

> (...) no one is immune to the disease; it's just a disease (...) (E3).

The process of integrating the drug treatment plan into the persons' daily life contributed to the adherence to the therapeutic plan, as was mentioned by one of the patients, who takes the TB drug as if it were a normal drug and noted an improvement in signs and symptoms soon after the beginning of treatment. Adherence was also assisted by having the desire for cure as a goal, as well as wishing to avoid transmitting the disease to other people and fearing a worsening of their own health status. However, improvement was interpreted as cure by some, who denied continuing on with the therapeutic plan because they were no longer feeling ill.

Another fact that contributed to adherence to treatment was having a goal in life. Thus, following through with the treatment was necessary to accomplish their lives' plans. More so, the reason for following through with the treatment was linked to the person's own determination, being an important element for adherence to the treatment. For most, success was also achieved with the assistance of family support.

Availability of medication in public healthcare was also mentioned as another favorable aspect, because many TB carriers admitted that they did not have the financial means to buy their medication. Being a TB carrier also enabled them to make medical appointments at their health units whenever they was needed, which does not always happen for other clients requiring services.

The uncertainty of a cure, the medication's side effects and the treatment's length may hamper adherence to the treatment. Regarding the last aspect, the belief that treatment would be faster and better if carried out in a healthcare unit was voiced. Treatment length and the complications that were faced during that period, coupled with a lack of belief in allopathic treatment, caused some subjects to seek out alternative therapies, as reported by one of the research's subjects:

> (...) in order to get well, I would take any homemade medicine (...) (E6).

Some of the participants experienced slower clinical improvement, stronger and longer reactions to medication, and conditions that required absence from work, increasing the risk of losing their job. One of the subjects said there were problems in providing for their family, since they needed to be away from work for four months.

The fact that TB interrupted their paying jobs, due to physical debilitation and/or treatment length, caused consternation especially for those who were homemakers, raising another necessity: going back to work to provide for their families. In the same way, the need to gain back the ability to perform daily activities, usually lost because of TB, pushed them towards adherence to the treatment.

Supervised treatment, depending on the person's health status, can be regarded as a need. For one of the interviewees, undergoing medication supervision in the health service wasn't a difficulty because the daily visit to the health service was integrated into their daily life. For others with an impaired health status, the supervised treatment at home was a health need.

In terms of the scope of healthcare, feeling welcomed by health professionals also assisted the participants in facing the disease, since the TB carriers emphasized the need to feel well, to feel appreciated and not feel prejudged, leading them to believe that they could trust the health team, and that the team also wanted them to be cured. In a testimony excerpt, the appreciation for the health service is evident when an interviewee states that they were supported by the health team as if they were part of their family. Thus, the building of a bond between the professionals and the TB carrier was indicated as being an important need.

Almost all of the subjects made reference to behavioral changes as a result of the disease, both in their way of thinking about life and in their regard for their own health. Living with TB imposed on them the responsibility to take better care of themselves and adopt certain habits, such as the need to follow the treatment as directed, attend all medical appointments, eat better, avoid the rain, wear adequate clothing and go to sleep earlier.

DISCUSSION

The subjects' testimonies made their fear of prejudice clear, as well as fear of the resulting isolation that could ensue, either from their families or their work environments, which resulted in many of them opting to avoid revealing their diagnosis.

It is observed that TB, not only in the past but also today, is considered a disease that results from a life dedicated to *excesses* or unruly behavior, including the use of illicit drugs or abuse of alcohol, in opposition to socially acceptable standards.

Even after the discovery of its cure the persistence of a stigma is observed, which continues to create diverse feelings, both in individual and collective spheres[8].

From the moment that healthcare professionals learn about a health need, it becomes the center of their practices, helping them to better listen to the healthcare clients, providing a qualified and humane service[3].

Knowledge of the TB carriers' needs allows the health team to understand and support them. This can only happen after establishing a trusting and co-responsible relationship between the subjects involved in the therapeutic process. The bond that is established in such a relationship is fundamental for the treatment's success[9-10].

In a study conducted in Ribeirão Preto (SP), which aimed to evaluate the health services' performance in controlling TB, it was noted that the health services with the lowest number of patients presented a more favorable performance in terms of establishing a bond between the carrier and the health professional. This shows the necessity of listening and commitment building, which requires involvement and qualification of the health professionals in assisting individuals with TB[11].

Interaction between the health professional and the TB carrier immediately impacts treatment adherence, as was verified in the present study's findings. It is believed that adherence is directly related to the satisfaction of health needs; thus, it is proposed that:

> (...)it isn't reduced to an act of volition, disconnected from the subject's reality, but depends on a series of actions that involve the individual, the process organization in health work and accessibility at large, that concerns the processes that lead (or don't) to the development of a dignified life[9].

A research conducted in a municipality in the Brazilian northeast with nine participants aimed to analyze the relationship between the factors relating to TB treatment

abandonment and the attention received from the family health team, in light of the bonding concept. There was evidence that the therapeutic relationship that involves commitment and bonding between the client and health professionals, that make the client feel appreciated, support adherence to the treatment. On the other hand, some elements are seen as negative factors influencing adherence, such as asymmetric, vertical relationships in which the professionals don't respect the clients' life plan and dominate the relationship. Nevertheless, such an attitude opposes the aim of humanized care[12].

Aiming to analyze the reasons for abandonment of TB treatment, a study was conducted in a basic health unit in the municipality of Joao Pessoa, Paraiba, with four healthcare clients. Results provided evidence that there are many and complex reasons for abandonment, which are related to the client, the drug treatment and the operationalization of healthcare assistance.

To guarantee adherence to treatment, health professionals should be aware of the clients' health needs and *adapt* the assistance provided to them, building co-responsibility in the treatment plan and building relationships based on acceptance and connection, which are guiding principles in the Family Health Strategy[13].

Gentle health technologies have the potential to support adherence to TB treatment and are produced in interactive and subjective relationships, made possible by acceptance, bonding and support for independence[14].

The health team's behavior is of extreme importance to treatment success, either for the provision of information or for the bonding between the TB carrier and the health professional. It is needed to educate the family and the carrier regarding the illness, the treatment length, the occurrence of side effects and the consequences of interrupting the treatment[4]. Therefore, there must be a change in how the attention to the population's health is processed, basing it on the practice of active listening, dialogue and co-responsibility[15].

In this study it was noted that some health needs, in the perspective of TB carriers, are related to the biological aspect of the disease, while others are related to other aspects that go beyond the disease. Thus, these persons' perceptions contributed to their needs in going through the process of medicalization.

Medicalization is a socio-historical concept in which health needs are reduced to biomedical matters. Therefore, such necessities generate conflict in the use and process of healthcare production focused on clients' complaints. In regards to this theme, a study was conducted in four Brazilian municipalities. It verified that, in the clients' opinions, medication prescribed based on laboratory exams was an adequate approach to fulfilling health needs. In the same study, health professionals indicated problems in carrying out interventions aimed at the clients' health needs, arguing that they seek out healthcare in order to be cured. Therefore, the need to deconstruct the idea of medicalization is emphasized, for both the clients and the health teams, since it is not the only nor the best way to meet client's needs[16].

Health needs are produced individually, but they are historically and socially constructed. Often, it is a certain *need*[1] that motivates the pursuit of healthcare. This method of learning about needs is hegemonic, both for the client and for the health professional. In the healthcare professional's work, tasks are increasingly oriented towards identifying physical needs[16], ignoring the possibility of needs that are linked to life processes and that are not restricted to the clinic or to biology, but that represent the fundamental need of human beings: the capacity to relate.

It is believed that the practice of healthcare must use technological advancements that make adequate care possible, at the same time taking into consideration TB's social determination and recognizing its association with the population's life conditions.

The creation of instruments that aid in the recognition of the TB carriers' needs is fundamental in guiding the work processes, which should aim to fulfill these needs. It is believed that such instruments can contribute to the health professionals' practice, in so far as there are special circumstances regarding this group's health needs, such as the disease's unique clinical nature and its social nature.

Using a tool to identify the needs of people suffering from TB requires thought and qualification on the part of the health professionals involved in caring for this population, considering the importance of listening and identifying the client's needs and the characteristics of the health-disease process[17].

Aiming to understand the meaning of the health-disease process for people undergoing TB treatment in an administrative district in the municipality of São Paulo, an exploratory study with a qualitative approach was conducted during the month of January, 2010. It was determined that TB continues to be a stigmatized disease, referred to as *it*, *this disease* and often times remaining unnamed. A form of prejudice that was manifested was the alienation of friends, which caused the sufferer to conceal the diagnosis in their work environment. Awareness of the diagnosis caused feelings of panic, distress, revulsion, preoccupation, depression and discouragement resulting from ignorance regarding the disease, the possibility of not being cured, family distancing and the possibility of being unable to work.

In order to better impact TB control, it is imperative that the health service avoid viewing its main duty as simply treating the carrier. Efforts must be directed towards a more general approach, which involves understanding TB as part of the context of the population's life conditions and the environment around it[18].

Since TB is a socially determined disease, which most frequently affects persons of a lower socioeconomic status, it is noted that poverty can contribute to treatment abandonment, representing one of the main problems related to control of the disease. In many cases, even though the individual has free access to tuberculosis medication, their financial conditions are not sufficient to buy food, which makes social support a main factor in improving quality of life, self-esteem and personal autonomy[19].

CONCLUSION

This study made it possible to analyze the TB situation in light of the health needs of carriers of pulmonary TB. It is expected that this study's results will support the reorganization of health practices in Family Health units, so that they provide assistance to persons undergoing TB treatment and can contribute to nursing knowledge, in addition to supporting and re-thinking the health professionals' practice, in so far as TB control actions are focused on understanding and meeting identified health needs.

The results made it possible to recognize the lack of perception of the research subjects in relation to life's social factors that may have favored becoming infected with TB. This is an important distinction, because as long as healthcare services are simply performing bacilloscopies and offering drug treatment, without offering answers to the social needs of these people by means of partnerships with other branches of the local government, TB will continue to decimate society's lower levels.

The importance of promoting debates within health teams that work in the area of Collective Health is obvious, and must address the health needs concept from an operational perspective, considering both individual and collective issues. In other words, specific individual needs that refer to the place occupied by the TB carrier in society, which causes unique difficulties, as well as the needs within the collective sphere must be identified and addressed. Therefore, it is the health professional's role to be open to identifying and understanding the needs of people with TB, in spite of the existing limits represented by the health services' production process.

It is important that this theme be incorporated in the health professionals' education so that they are alert to, and learn to deal with, the population's health needs in daily life. Learning how to listen and respond to health needs demands that the professional transcend the idea that health is limited to the clinical and interventional aspect and learn that it refers to the need to interact with service clients, aiming at giving them their freedom in health care.

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Correspondence addressed to: Paula Hino
Av. Dr. Enéas de Carvalho Aguiar, 419 - Cerqueira César
CEP 05403-000 - São Paulo, SP, Brazil