THE DAILY ROUTINE OF PATIENTS IN TUBERCULOSIS TREATMENT IN BASIC HEALTH CARE UNITS: A PHENOMENOLOGICAL APPROACH[1]

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This study presents a phenomenological reflection on the daily care routine of patients in TB treatment. It aimed to understand the routine of treatment delivered at the primary health care service. Phenomenological interviews were carried out with patients infected with TB and health professionals at Primary Care Units in Belém, PA, Brazil. Reports were organized in units of meaning and analyzed according to Martin Heidegger's framework. Hermeneutics revealed that infected people fear the disease and its consequences, care is provided in an impersonal way, responsibility for the treatment is emphasized by professionals and assumed by patients, and professionals' behavior is predominantly based on the biomedical technical standard. We conclude that there is a gap between the treatment offered and the expected humanized treatment with a view to successful control of the disease.

DESCRIPTORS: public health; tuberculosis; phenomenology

LO COTIDIANO DEL TRATAMIENTO DE PERSONAS ENFERMAS DE TUBERCULOSIS EN UNIDADES BÁSICAS DE SALUD: UN ABORDAJE FENOMENOLÓGICO

Este artículo presenta reflexiones sobre lo cotidiano asistencial del tratamiento a los portadores de tuberculosis, fundamentada en la fenomenología. Tuvo como objetivo comprender lo cotidiano asistencial del tratamiento de tuberculosis, realizado en servicios básicos de salud. El estudio fue desarrollado con portadores de tuberculosis y profesionales de salud en Unidades Básicas de Belém, PA. Se realizaron entrevistas fenomenológicas con los participantes. Los discursos fueron organizados en Unidades de Significado y, después, analizados a partir del marco teórico de Martin Heidegger. La hermenéutica mostró que los enfermos temen la enfermedad y sus consecuencias, el cuidado que se realiza de modo impersonal, la responsabilidad por el tratamiento enfatizada por los profesionales y asumida por los enfermos y que y las conductas de los profesionales se pautan, predominantemente, por las normas técnicas del discurso biomédico. Se concluye que existe un hiato entre el tratamiento ofrecido y el tratamiento humanizado que se pretende alcanzar con la finalidad de obtener éxito en el control de la enfermedad.

DESCRIPTORES: salud pública; tuberculosis; fenomenologia

COTIDIANO DO TRATAMENTO A PESSOAS DOENTES DE TUBERCULOSE EM UNIDADES BÁSICAS DE SAÚDE: UMA ABORDAGEM FENOMENOLÓGICA

Este artigo apresenta reflexão sobre o cotidiano assistencial do tratamento aos portadores de tuberculose, fundamentada na fenomenologia. Teve como objetivo compreender o cotidiano assistencial do tratamento de tuberculose, realizado em serviços básicos de saúde. O estudo foi desenvolvido com portadores de tuberculose e profissionais de saúde em Unidades Básicas de Belém, PA. Realizou-se entrevista fenomenológica com os participantes. Os discursos foram organizados em Unidades de Significação e, após, analisadas a partir do referencial de Martin Heidegger. A hermenêutica mostrou que os doentes temem a doença e suas consequências, o cuidado que se realiza de modo impessoal, a responsabilidade pelo tratamento enfatizada pelos profissionais e assumida pelos doentes e que e as condutas dos profissionais se pautam, predominantemente, pelas normas técnicas do discurso biomédico. Conclui-se que há um hiato entre o tratamento oferecido e o tratamento humanizado que se pretende alcançar com vistas ao êxito no controle da doença.

DESCRITORES: saúde pública; tuberculose; fenomenologia

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INTRODUCTION

Diverse factors, intrinsic to professional activity in health, do not always answer the challenges health services face to promote problem solving, qualified and humanized care. Human limitations are among these factors: the reality of the disease, the impossibility of always curing it or even taking care of problems in the best possible way, difficulties to provide aid in health services and the usual reality of proximity to death among patients with diseases. Permeating this set of factors, there is an aspect of great importance in professionals' practice in dealing with human dimensions, including emotions and affectivity, which should permeate the relation among nurses, technicians, patients and family members[1].

Throughout the history of humanity, men have been attempting to appropriately conceptualize the health-disease process. At each formulated concept, limitations that put in check its validity and functionality in the explanation process are appointed, as well as coping strategies. It has been observed almost always that the proposal of the newest formulated concept is to overcome past ones with a pretension to provide the "final version", the most relevant concept on the topic[2].

The representation of health and disease is also related to the degree of knowledge regarding this process and the resources available for coping, which can be observed in each historical period of humanity[2]. Being healthy, sick, in pain, weak, uncomfortable are ways people perceive these interactions with the environment, social conditions and physical conditions that follow in life. The need to know, represent and cope with diseases is part of human beings and permeates their whole life in society if one considers that this is one of the hardships to be overcome in the course of life.

Brazil occupies the 16th position among the 22 countries that concentrate 80% of the tuberculosis load in the world. The estimated prevalence is 58/100,000 inhabitants, 50 million of infected people are likely to develop the disease, 111,000 new cases and 6,000 deaths a year. The rates of cure and treatment abandonment are 75 and 12%, respectively[3].

To reduce treatment abandonment and increase cure rates, the DOTS (Directly Observed Treatment Short Course) strategy recommended by the World Health Organization (WHO) for priority countries has been successfully implemented in several Brazilian cities. Its implementation has not been homogeneously, however, some cities in São Paulo and Rio de Janeiro have presented good results in relation to patients' treatment. These results are very different from other Brazilian States that present high incidence of cases like Rio Grande do Sul, Pará and Bahia, which did not manage to make it feasible in local health units[3].

In the daily routine of outpatient clinics at basic health units that offer the Tuberculosis Control Program, the care delivered to infected patients is based on relations that vary from patients' total surrender to professional care to treatment abandonment for personal reasons or reasons linked to the care received at the health service.

In general, health care practices cause revolt due to the pressure exerted by demand, excessive bureaucracy and work processes that do not favor humanized health care. In this context, professional actions are presented as "dehumanized" and technically limited[4-5].

If a chronic treatment, like the TB treatment, presents nuances that can contribute to its success or, on the contrary, to negative outcomes that result in abandonment or death, we ask: What is not clear to those who work with a so socially complex disease? What to do at the services to achieve effective indicators? What attitudes should be adopted to minimize disorders TB imposes on the lives of patients and family?

This study aimed to get to know the dimension of the treatment for professionals and people with tuberculosis, through the understanding of the tuberculosis treatment routine carried out in basic health services.

METHOD

The study used Heidegger's phenomenology method, which is the description of the genesis of the phenomenon, description of essences, ways of being, making them visible. This study was carried out in a public institution at the State University of Pará and two health units in Belém do Pará, PA, Brazil. The self-administered and supervised therapies of the tuberculosis control program are offered at these services. Twenty-one patients in tuberculosis treatment at the outpatient clinic for at

least 30 days and older than 18 years participated in the study, in addition to 21 professionals: physicians, nurses, social workers, psychologists, nursing technicians and one communitarian health agent. Phenomenological interviews were used to collect data.

Ethical principles recommended for research involving human beings were observed and approval was obtained from the Research Ethics Committee at the Anna Nery Nursing School, Federal University of Rio de Janeiro. The project and objectives were presented to participants and interviews were recorded after they read and signed the free and informed consent term.

After authors complied with the requirements of the studied institutions, they got familiar with the research environment so as to previously know the routine of the care units.

Discourse analysis was carried out in two stages. In the first stage, the meaning units addressing the vague understanding of subjects in relation to what was asked was elaborated. The vague and average understanding was organized from the transcriptions of participants' discourse. The most repeated themes were collected, based on the meanings used by subjects to express their experiences. It is the most immediate understanding of what they experience in their daily life and characteristic of the ontic way, that is, the immediate world of busy daily life. In the second stage, we sought to unveil the meaning that supports the existence of the subjects in the dynamics of their life with tuberculosis by linking what had been said and its interpretation, which is the search for meaning. To base this analytical and hermeneutic interpretation, Heidegger's philosophical framework was used[6].

RESULTS

The vague understanding of tuberculosis and its treatment

Unit 1 – The confirmation of the tuberculosis diagnosis shakes patients' life

Users attempt to solve the problems the disease is causing to them. In general, patients do not search for health services right at the beginning of their respiratory symptoms and, when they do, their health is already weakened. Thus, when they discover the tuberculosis diagnosis, a tragedy happens in their lives and leaves them bewildered.

…when I heard I had the disease, my world collapsed. (Interview 8 – Infected).

We feel completely out of the world, it's very hard, complicated, especially in the first three months. I tried to live my life as normally as possible. (Interview 6 – Infected).

…the first day for them is chaos, they feel they're the worst people in the world, cry, don't accept, think they are going to die…(Interview 9 – Professional).

…I always try to be careful when I give them the diagnosis because it's a shock, even when the patient already suspects it, lots of people cry (Interview 10 – Professional).

The interviewees' statements show the impact suffered by someone infected with tuberculosis and its negative effects because the disease is viewed as a social punishment. Professionals who work in the Tuberculosis Control Program know the affliction that accompanies the moment of the diagnosis and patients are aware that tuberculosis, when not treated, progresses to a severe condition of physical deficiency, suffering, pain, respiratory difficulties and death. This is the disease's closest possibility, which requires professionals to adopt a sensitive, kind and respectful attitude at the moment tuberculosis is confirmed and adherence to treatment is expected.

Unit 2 – The tuberculosis treatment has different meanings for those infected and for those who treat it

Despite recommendations to adopt DOTS strategies in the services, we observe that the daily operation of the treatment by patients with tuberculosis is as difficult as in the self-administered treatment, due to changes that interfere in the continuity of activities, such as studying or being punctual at work.

…I can't work because of the treatment, which employer will want his employee missing work twice a week or once a month? So, working is out of the question. There're no conditions, we do the treatment but cannot work. And when I started the treatment I had to take an injection every day in the first two months, I had to take it every day when I started it … (Interview 5 – Infected).

I had to stop doing many things I like to do, had to stop walking in the sun, rain, having a more normal daily life, I had to stop studying to comply with the treatment, stop working, so it was extremely difficult (Interview 11 – Infected).

Another important aspect of the medication treatment is the imposition of a routine of obligations. In the supervised modality, daily or weekly attendance to take medication is required, which does not always permit the performance of previously routine activities. The patient also acknowledges the losses a debilitating disease like tuberculosis imposes on the individuals' body and disposition. Health professionals also acknowledge difficulties patients face for treatment adherence but, because these difficulties do not represent the same dimension in their lives, these are little explored in care dynamics. The following reports of professionals illustrate this issue:

...what matters to us is the duration of the treatment, six months of treatment, because improving the symptoms alone won't solve his problem (Interview 2 – Professional).

...the important thing is to orient the patient to adhere to the treatment because it doesn't help if we do everything, prescribe the medication, schedule a return visit for the next month if he isn't interested in the treatment, so we have to recommend taking the medicine every day... (Interview 12 – Professional).

The availability of means, resources and professionals linked to the Tuberculosis Control Program does not assure success in the treatment and cure of people with tuberculosis. The professionals' attitude, even when they emphasize the importance of treatment to obtain cure, could also focus on welcoming the person in his(er) singularity and not only emphasizing the follow-up, the treatment control.

Unit 3 – The tuberculosis treatment presents many difficulties to patients, which are not always understood by professionals

Following the treatment according to health professionals' recommendations is almost always a difficult task for patients because the therapeutic schemes mix at least three medications of prolonged use and, despite their efficacy, patients start to report digestive discomfort, nausea, vomiting and diarrhea.

...at the beginning you want to give up because the medication side effects are too much, it made me feel very sick, had to go hospital, my pressure would go up, I felt weak, it was really bad. At the beginning of the treatment I'd only lie in bed, had no energy to do anything, now I feel I have more disposition, even want to go back to work, I feel really well... I'm feeling really well, just my blood pressure is altered, I get swollen and my bones ache, but I'll get to the end of the treatment... (Interview 7 – Infected).

...it's really difficult to take all these medications the way they told me to. The red ones are easier, but the white ones (pause), these are difficult to swallow. Thanks God I'm already at the end of the second month and they told me I won't take these anymore. When I take the medication I feel sick, get weak and feel just like lying. At the beginning it was worse because I got sickness, stomachache, vomiting, but then it all passed. Now, I only have back pain and tiredness, but they told me it is like this, I have to be patient 'cause it'll get better. I almost can't close my hands because of my joint pain, sometimes I feel like stopping the medication, but I think about my family, myself and keep going, but I'm getting better (Interview 15 – Infected).

The healthcare routine imposes a mechanized dynamics, which is not reflected upon and does not favor the exchange of subjectivity between those who deliver care and the recipients of such care[6-7]. There is little time to answer individual demands during the shifts of the outpatient clinic. Professionals have to perform many activities and these demands impede that they provide exclusive care to each patient, which reinforces the prevalence of technical formalization. This is perceived in the excerpts below.

...I orient, say he is going to start the DOTS treatment, will have supervised medication, always orient about the disease, the time of treatment, medication side effects, the importance of the treatment, talk about food, hygiene and about the professionals at the unit with whom he is going to talk: nurse, psychologist, social worker. It is an orientation for them to understand this is a curable disease; the treatment is fast, six months (Interview 3 – Professional).

The patient with tuberculosis needs proper attention. In my experience, if the patient does not receive this, he doesn't finish the treatment... I spend at least 45 minutes to an hour with a patient with tuberculosis at the beginning of the treatment, so I explain everything since, how he got infected, what the disease causes, the treatment, what can happen if he skips the treatment, communicants, diet. Everything to clarify, and even so, there're people who abandon the treatment (Interview 17 – Professional).

Patients under treatment have pain, gastric discomfort, nausea, vomiting, among other more frequent manifestations, which undermine physical and emotional resistance. Educating patients regarding the disease, treatment, and potential side effects of medication, and also valuing their complaints, are among the main factors that ease adherence to therapy[8]. Professionals deal with these complaints but do not seem to value these complaints because patients keep suffering with adverse effects, which could be minimized or suppressed with the use of

conducts already described in the technical standards of the control program. Orientation not to stop treatment, emphasized during consultations, does not always assure confidence that a disease that makes them feel so weak and socially vulnerable can be overcome.

Unit 4 – For professionals, the cure of tuberculosis is directly related to the patient's responsibility in following the treatment

Another aspect that caught our attention is the responsibility for the treatment success. Patients assume or are impelled to assume such responsibility because, since the beginning, they are informed that they bear the largest share of responsibility for remission of clinical condition and disease control. This behavior can be observed in the following reports.

...we try to explain to them that the treatment will largely depend on them, that it is essential to know they will have the responsibility to comply with the treatment up to the sixth month, follow our recommendations... if they follow the treatment accordingly, follow our orientation, they will certainly get cured (Interview 7 – Professional).

...I guess that it's important: explain that he has conditions to take the treatment and be cured, and it largely depends on him, because the unit is available to give him all orientation he needs, care, but obtaining cure also depends on the patient (Interview 11 – Professional).

Apparently, professionals do not assume co-responsibility for the treatment and the patient is the only one responsible for its success. The health system already offers diagnosis, free treatment and professionals to attend people, so that potential failures will be a consequence of non-compliance with recommendations, even though therapeutic schemes combine at least three medications of prolonged use and might cause digestive discomfort, weakness, intense itching, joint pain and other adverse effects that may lead patients to reject medication and give up treatment because their quality of life is seriously affected[9].

DISCUSSION OF RESULTS – HERMENEUTICS

The produced units of meaning were the starting point for the analysis of the reports of professionals and patients under anti-tuberculosis treatment, that is, hermeneutics. The search for meaning and interpretation was developed as from the reading of descriptions contained in the units, to seize the meanings that emerged from their reports. An autor[10] presents the contribution of Heidegger to hermeneutics, he says: "understanding is trivialized, permeates all moments in life, so that it are we who have the meaning of existence. The practical way of being in the world opens up possibilities of understanding, so that understanding would not exist if one could not understand the context it emerges in".

In interpreting the facticity of being infected by tuberculosis, we can identify that, when people get sick due to the infection by Koch's bacillus, a major threat is presented: that of being subjugated by the disease. Tuberculosis is a threat that became concrete, because, from a feared disease, it now dominates the individual. About the fear, Heidegger[11] says that "...what one fears has the character of threat...what one fears comes to one's encounter because it possesses a circumstantial mode of damage... Fear confounds and makes one lose one's mind..." and opens up to a world full of not imagined threats, such as being rejected, the threat of a physical deficiency that can make them unable to maintain normal relationships and commitments. TB deprives people of the autonomy of life.

Another marked aspect in the patients' life is the difficulty to correctly follow the treatment because of the toxicity chemotherapy can cause. The severity of adverse effects is known by health professionals, as well as the measures for its correction, though, according to the patients' reports, it seems that professionals do not value their complaints, as if they were evitable, and as if patients should wait until such effects naturally stop. As patients, they are encouraged to overcome transitory difficulties caused by the treatment, because the ultimate objective is the cure. Yet, these difficulties leave permanent marks in patients' lives.

This way of being reinforces the impersonal character that prevails in health care environments, which show that the main concern is with the health problem and not with the person who presents the health problem. In Heidegger, we see that impersonality usually dominates relations between people and that, although this is one way of being, it is not the most appropriate way of dealing with them[11]. Professionals act immediately, concerned with the actions that have to be developed with all

patients. This impersonal care does not enable one to be in someone else's shoes, the patient's[6].

Another aspect that caught our attention is the responsibility assumed by patients regarding treatment success. The reports show the imperious need to control and assure that patients will correctly follow prescriptions. Heidegger appoints that the human being is responsible for his(er) own way of being[11]. When professionals see patients who need to recover, they are subject to what is determined by public health care standards. The outcome of the technical-scientific health discourse, already incorporated by society, is invariably concretized through the supply of non-authentic care. This care could have an enlarged meaning, and include protection and concern with the other[4], which is different from what has been observed: dealing with people through domination.

Concern with the reestablishment of health is common to patients and professionals, however, this concern has distinct characters for both. For patients, the treatment represents recovering an altered routine and, to achieve it, they follow medical recommendations as closely as possible, even if they mean to give up pleasant activities in their daily life. Professionals, based on scientific knowledge, believe the treatment is the adequate course to follow in order to achieve goals defined to control the disease. This way, they play their social role.

In this mode of care delivery, the professional's concern is not efficiently employed because the professional assumes the other's place and leaves no chance for the patient to participate in decisions related to his(er) condition. Thus, what must be done is almost always unilaterally established[6-7]. This is a paradoxical situation as, at the same time, it creates dependency on professional care. Professionals, in turn, insist that the responsibility for a successful outcome mainly lies with the patient.

This attitude limits the understanding of the disease process to its biological aspects, while there are other factors involved in the process that culminated with the persons' disease, who now need treatment and care. Their life history cannot be denied or provisorily let aside for the sake of one kind of treatment.

FINAL CONSIDERATIONS

When one reflects on the practice of health professionals in relation to a disease as frequent as tuberculosis, one also reflects on the concept of humanization, which is expected in services working in the Single Health System, oftentimes the main access available to solve the population's problems. The concretization of actions in the Tuberculosis Control Program indicates there is a lot to be done towards the understanding of the other's meaning of life.

This aspect, not yet emphasized in the routine of outpatient clinics that attend people with tuberculosis was also highlighted in Ayres[4], when the author appointed the need for dialog between interlocutors committed to let their experiences enrich the management of a disease that entails sanitary implications in the collective and personal scope. Attentive listening, adequate conducts, valorization of the meaning of self-care and patients' experiences are essential elements in humanized care.

We understand that nursing's main objective in basic health services is the human being, oftentimes unhealthy, who expects, from professionals, support or solution for his(er) problems[1]. To assume care as an authentic concern, it is necessary to adopt attitudes of respect and consideration with the other, respecting the being's ontological originality because this care means zeal, attention and helping the other to be free to his(er) closest being[11]. It is necessary to acknowledge that the technical-scientific knowledge in health practices does not possess all possibilities of care. It is important to share and value the experience of the ill as an essential element in the effective care that enables the other to be free in order to be cured.

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