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RECOGNIZING UP AS A SUBJECT OF RISK: THE CONSCIENCE OF POSSIBLE HARMS OF TUBERCULOSIS[a]

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ABSTRACT

This paper analyzes from the users' perception adherent to treatment, the meanings attributed to the risks of the disease. The qualitative study was developed from the Grounded Theory. Data collection occurred through semi-structured interviews, with 19 users as subjects adhering to tuberculosis treatment. The project was approved by the research ethics committee of UFRGS. Survey participants indicate relational risks such as the possibility of harms that tuberculosis is the interaction of the patient with society, with interference with public and private dimensions of everyday life. The recognition of the participants as subjects of risks was part of a process that is producing identities, making them sought an image of the subject concerned with his care and the care of the other, preserving their personal relationships and interaction in society.

Descriptors: Risk. Tuberculosis. Health promotion. Nursing.

RESUMO

O artigo traz resultados de pesquisa qualitativa, desenvolvida com base na metodologia da Teoria Fundamentada em Dados, objetivando apreender os sentidos, atribuídos por usuários aderentes ao tratamento da tuberculose, aos riscos da doença. A coleta dos dados ocorreu entre maio e junho de 2012, por meio de entrevista semiestruturada com 19 usuários aderentes ao tratamento, atendidos no Serviço de Assistência Especializado de São Leopoldo - RS. Emergiu, da análise, destaque à atribuição de um sentido relacional para os riscos da tuberculose – possíveis danos às interações do indivíduo doente com a sociedade. Reconhecendo-se como sujeito de riscos, os participantes avaliam que riscos podem ser evitados a partir da adesão ao tratamento, assumindo uma identidade de sujeito cuidadoso - preocupado com seu cuidado e com o cuidado do outro -, preservando, assim, relações pessoais e o convívio na sociedade.

Descritores: *Risco. Tuberculose. Promoção da saúde. Enfermagem.*
Título: *Reconhecendo-se como sujeito de riscos: a consciência dos possíveis danos da tuberculose.*

RESUMEN

En este trabajo se analiza la percepción adherente al tratamiento de los usuarios, los significados atribuidos a los riesgos de la enfermedad. El estudio cualitativo se ha desarrollado desde la Teoría Fundamentada. Los datos fueron recolectados a través de entrevistas semiestructuradas, con 19 usuarios como sujetos de la adhesión a la terapia antituberculosa. El proyecto fue aprobado por el comité de ética de la investigación de la UFRGS. Los participantes de la encuesta indican riesgos relacionales como la posibilidad de daño que la tuberculosis es la interacción del paciente con la sociedad, con la interferencia de dimensiones públicas y privadas de la vida cotidiana. El reconocimiento de los participantes como sujetos de riesgos forma parte de un proceso que está produciendo identidades, por lo que buscaron una imagen de la materia, la preservación de sus relaciones personales y la interacción en la sociedad.

Descriptores: *Riesgo. Tuberculosis. Promoción de la salud. Enfermería.*
Título: *Reconociéndose como sujeto de riesgos: la conciencia de los posibles daños de tuberculosis.*

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INTRODUCTION

Tuberculosis continues to be a serious problem for public health. Epidemiological data shows that Brazil is in 19th place out of the 22 countries with the highest incidence of this disease in the world[1]. Amongst Brazilian districts, São Leopoldo, the site for this study, in 2009 presented some of the worst figures nationally for compliance with tuberculosis treatment, in relation to rates of therapy abandonment[1].

The resurgence of tuberculosis as a public health issue in a national and international context is related to the emergence of HIV cases in the 80s, with co infection leading to high rates of morbidy mortability all over the world , especially affecting the lower income part of the population[2]. The pathology affects mainly marginalized populations leading to social inequality, and so influencing the negligent manner in which this disease is being addressed.

Following orientations from the World Health Organization (WHO), the Brazilian Health Ministry (MS) has been investing in the maintenance of tuberculosis treatment as a pivotal point for the control of the disease. In this respect, the MS highlights that the promotion of adherence to treatment is the main challenge that the health services have been facing in the control of this disease[3].

The promotion of the adherence to treatment for tuberculosis is a process which requires the individual being treated to be convinced of the risk they are under, and so consequently stimulate an attitude of self preservation. So, as in the majority of initiatives for promoting health that include educational workshops, this adherence involves a process of awareness and responsibility of the individual in participating actively in the self preservation and recovery of his/her health, understanding the risks that he/she is exposed to and so acting accordingly[4].

The assumption that the dissemination of information about the risks of tuberculosis and not adherence to treatment is sufficient to provoke an adherent's behavior to not always be truthful, since guidelines for the treatment are not always followed. The replies to questions about the cause for not adhering to tuberculosis treatment are usually taken as a misunderstanding about the "risks of tuberculosis" by the individuals, and therefore they were not fully aware of how important it was to prevent it and how worthwhile the treatment was.

Seeking a broader view of tuberculosis and its risks in national publications, a search was made in the virtual library for health in March 2012, resulting in 57 publications all of a quantitative nature[5-6]. The findings suggest a predominance of Epidemiological studies on the subject of the risks of tuberculosis and quantitative data regarding the risk factors and risk groups and their potential to produce illness. Most studies referred to in these publications concentrated on the definition of groups, factors and the reasons for not undertaking the tuberculosis treatment, highlighting the individuals with the greatest propensity to failures and abandonment of the therapy.[5-6].

Considering the importance of adherence to the treatment in the context of tuberculosis and the predominance of the quantitative approach on the non adherence issue, an investigation was drawn up of a qualitative nature that could broaden the risks of tuberculosis, in order to answer the question: "What do the adherents to treatment understand about risks of tuberculosis and how does this understanding influence their behavior?"

METHODOLOGICAL APPROACH

The research had a qualitative character [7] being that the collection and the analysis of data was orientated by the Theory Founded in Data (TFD) or G*rounded Theory*[8]. In the TFD, collection and analysis of data occurs simultaneously, being characterized by a coming and going of data with constant comparison of the results encountered. The project was approved in the Ethics and Research Committee of the Federal University of Rio Grande do Sul, being registered under protocol nº 20018.

There were 19 subjects actively undergoing tuberculosis treatment, they were attended by a Special Assistance Service (SAE) of the São Leopoldo district – RS. São Leopoldo was chosen as an area of study because it had one of the poorest performances nationally in relation to the adherence to treatment for tuberculosis in the year of 2009. The choice of the SAE of São Leopoldo was taken because this is the referral service for the treatment of tuberculosis in the district sharing responsibilities with Family Health Planning.

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The subjects were chosen from the monthly appointments schedule and by following the criteria for inclusion: to be diagnosed with tuberculosis, to have been undergoing treatment in the SAE for more than one month and to be 18 or more years old. A period of one month undergoing treatment was considered the minimum time of adherence to the treatment where the subject could experience the effects of the therapy and show a clinical improvement, allowing them to evaluate the risks of maintaining or abandoning the therapy. Research subjects were identified through analysis of the medical records of patients with monthly appointments, taking into consideration the criteria for inclusion. After being identified, the subjects were invited to participate in the research. The interviews took place individually in an interview room made available by the SAE of São Leopoldo and before the collection of data the research was explained to the subjects and a form of clear and free consent was signed by them.

To attend monthly appointments, undertake routine exams and to take the prescribed medication for the control of the disease were the defining elements for adherence to the treatment adopted for the research, these being the same criteria used by the service.

The data was collected between May and June of 2012, through semi structured interviews undertaken individually with each research subject, totaling 19 interviews.

The criteria of theoretical saturation defined the final size of the sample, that is to say the collection stopped when it was evaluated that new interviews were not contributing any more to the formation of new concepts and the evolution of theory[8].

The interviews were recorded and transcribed in their entirety. After, they were analyzed in three simultaneous steps: open coding, axial coding and selective coding [8] with the assistance of the qualitative analysis software Qualitative Solutions Research Nvivo 9.0. The process made possible the grouping of analyzed units into categories and the reduction of the number of units of work.

Memorandums were also used in the data collection step, with the aim of registering daily information resulting from the field of study, thoughts, interpretations and directions to search additional data and questions that needed to be explored further [8]. .

At the end of the analysis we came to a central point "Self-realization as a subject at risk: the awareness of tuberculosis's possible harms" [9], put together from the other categories: "Living with a risk record: everything is risky in life", "Managing health risks: It is impossible to take care of one's health 100% of the time" and "Be committed to caring for yourself and others: relationship risks of tuberculosis".

RESULTS AND DISCUSSION

Taking the main issue "recognizing a subject at risk: understanding the possible harms of tuberculosis", the following paragraphs explore the way in which the "subject at risk" identify as evidenced in the analysis. The data suggests that it happens as the personal risks records of each individual are produced: How is a subject at risk in a social context, at risk in terms of health and finally at risk from tuberculosis.

In the literature which provided the basis for the study, the argument of the omnipresence of risks in contemporary life is highlighted [10], emphasizing how the individual lives on a daily basis with a variety of possible harms which have to be managed by themselves. It seems impossible to account for all of them, as new risks came up often even as our risk records were being updated. The term Risk Record was developed to designate a set of individual risk interrelated to those which we are exposed to routinely. And so, based on this characteristic, they take on a relative value when compared with one another.

Taking into account this argument, the research started with the search to understand the research participants' perception of their everyday risks, getting closer to the investigative field with emphasis on creating a broader understanding of risks [11]. During the analysis process this information gave rise to another category: "Living with a risk record: everything can be risky in life". This analysis corroborates the literatures arguments' about contemporary existence in a risky environment, explicit in the presence of reflexive styles of living and uncertainties [10].

> *On the streets or at home we can never predict what is going to happen. The risk is always there.... If I go out, I might be mugged...(P3).*

Too many people die on the construction site, it is very dangerous, you must be very careful otherwise you can fall from scaffolding and get seriously hurt… (P14).

You must be careful in traffic; there are too many accidents and they can also happen to you. (P16)

The situations shown as risky by the participants are part of the scene in big cities and are shared by everyone, identifying them as subject at risk .The analysis of the dialogues above, suggests that the participants also feel responsible for what is going to happen to them in the future, meaning that some of the risks could become harmful – *if I go out, I might be mugged, must be careful, cause you can fall* and *it can also happen to you.* The dialogue remits to us a double self-identification by the participants of the research: as people with an understanding of everyday risks – subjects at risk – and therefore fully aware and committed to self preservation and they were also identified as "caring individuals".

Returning to the notion of risk report [11], it can be argued that the diagnosis of tuberculosis and the knowledge of the risks of the disease and the risks of non adherence to the treatment have added new risks to the everyday set known to the patients. These new risks are given values related to the existing ones, which could increase or decrease the importance of the risks given to tuberculosis.

Continuing with the feelings assigned to risk, the analysis suggested that "risk" has a negative connotation – "you must be careful" – being associated with danger or potential harm – "might get mugged", *"too many people die there, it's very dangerous"*. As argued by the literature and proven by the research participants dialogues, to give meaning to risk entails a subjective judgment upon the influence of contextual social and cultural elements of where it happens.

Before the diagnosis of tuberculosis the research participants already made calculations of the probability of the harm they were exposed to, assessing and managing everyday- risks, often having to choose which risks were worth taking and which were not.

When they were asked about the risks related to their health, the research participants mentioned those risks most commonly emphasized in discussions on preventative measures for maintaining a healthy life style, leading to the second category: *"Managing health risks: It is impossible to take care of one´s health 100 % of the time"*.

The participants' awareness of health risks and how important it is to take care of oneself is evident in the dialogues below.

Health is important. Everyone should know that they need to be aware of what might happen and therefore do whatever it takes, otherwise they will suffer the consequences.(P11)

We must take care of ourselves, so we don´t get sick. We should know to prevent getting sick by finding ways to keep ourselves healthy, because health is your…(P17)

I have tried to stop smoking, but couldn´t. Here at the infirmary I lie, I say that I 've stopped otherwise they will not see me anymore… (P12)

The dialogue suggests that the individuals understand the health risks represented by smoking and alcohol, but despite this, keeping these habits is necessary for the moment, in order to face other problems and their related risks which at present need to be confronted. The parts in P11 and P17 – "should know" – sounds as if they considered a self-care attitude as a personnel and moral obligation highly favoring health.

The dialogue P12 suggests that the attitudes of research participants were not independent, they might have been pre conditioned by the imposition of the health care professionals who see them [5]. One of the ways for the subjects to minimize the pressure they suffer in the health service, when they're trying to control risks by regulating their autonomy, is in the omission of information that will free them of other risks. For example: denial of access to health visits.

In this context, the subject portrays a coherent identity according to health service expectations, and is seen as a "careful subject" who protects himself from risks caused by smoking with a self-care attitude. The production of this identity occurs, also from a mental exercise, not only about *"the person I wish to be"* – someone who acts positively with risks - *but* above all, the personal perception of what others want me to be.

The necessity to manage a life style puts the individual face to face with the possibility of choosing which path to take, which risks can be avoided and what identity to portray as a subject at risk constantly updating his position. The research participants revealed that even before contracting

tuberculosis, they took calculated risks with their personnel health, judging the probability of illness.

In the last category: "Be committed to caring for yourself and others: the relationship risks of tuberculosis", are included the data about risks to their personal life with the diagnosis of tuberculosis. The analysis suggests that to follow the recommended treatment doesn't mean to see yourself as exempt from the risks but to add to the identity of the subject at risk new characteristics and to the risks new meanings.

The diagnosis of tuberculosis seems to increase the "relationship risks" within the existing personal risk record of the research participants and they were defined as – the possibility of harm tuberculosis represents in the interactions of the sick individual with society with inferences in at least two dimensions: (1) referent to the public space where the sick people live with influence on the broader relationships with close society, (2) related to their private relationship space with influence on interactions between the sick individual and his/her family.

One of the elements which seems to contribute to how tuberculosis risks can be understood as a relationship risk in the public space is the perception of body changes due to the disease. For example: weight loss.

> *The body suffers with this disease. High fever every day, around 40 degrees at the end of the afternoon, constant coughs and visible weight loss. (P1)*

> *This disease finishes with you; I know this because I had it. Everyone said: " You must be very sick..." I weigh 75 kilos and I lost 13 kilos in three months.(P14).*

With the appearance of the first symptoms of the disease – weight loss, cough and fever – the participants become aware of their illness because of the changes with their body. The sudden weight loss associated with hemoptysis makes the patient see his illness as a serious one which is shown by his awareness of his body [10].

The social roles between men and women at different stages of their lives are also included in the data so as to understand the risks of tuberculosis as a possible harm to any relations in the public space. In justifying the adherence to the tuberculosis treatment, married women, emphasis their role as home makers and the married men as providers. Taking into account the social expectations related to their gender role, we can understand the positions taken by the participants as giving a relationship meaning to the risks of tuberculosis.

> *I didn´t want to have the treatment, but I do it because I have my granddaughter to look after and she gives me life. I have five grand children. The youngest is one year old; she talks and runs around the house calling my name... It makes me feel alive. You know, I am the heart of the house, I supervise everything. I am told to do this and that ... I cannot disappoint them.... (P17).*

> *I used to get very worried with my family, my sons. My younger daughter is the closest to me but it worries me that she is so close, I don´t want her to catch my illness. I try to isolate myself, moving away. But they think that I am rejecting them ...(P3)*

The statements suggest that despite having the disease, the participants, as with the majority of women, still believe themselves to be responsible for care of the family, especially of the children, although they cannot perform their household tasks as they used to. When they get ill, they are motivated to adhere to the treatment so they can recover and return to their functions as house makers [12].

In the P3 dialogue the motivation to adhere to the treatment is evidently for the preservation of the children's health, many times necessitating isolation from the family in order to protect them from coming to harm from the disease. The data suggests that the way that the tuberculosis sufferers and their families deal with the restrictions on interactions with each other imposed by the disease, such as, limited physical contact, can increase the potential risk by adding to the set of possible physical harms of tuberculosis to themselves and to the people closely related to them and also prejudicing the relationships between them.

However for the men, the relationship risks which seem to motivate, in a more significant way, adhesion to the treatment, are those associated with the desire of getting back to work and returning to the activities they did previous to the illness.

> *I think that the main reason for me to go ahead with the treatment is my work. Because, when I found out that I had tuberculosis I was in the process of being recruited to work for a food company. They told me to have the treatment and when clear get back to them. I am unemployed and I have 4 children to provide for. What do I do? (P9).*

Although it is not the focus of this research, it seems important to mentioned that according to the outcome of other studies [5-6] on the abandonment of treatment, in the evaluation of risks of staying without work and income and the risks of the disease, men have opted to guarantee the wellbeing of their family and their role in society. However for the married men who took part in this research the importance of work in the evaluation of risk functioned in the opposite way, motivating them to adhere to the treatment. What might support this difference is the apparent inability of these individuals to hide their condition or to grow accustomed to this identity [10].

With regard to the risks tuberculosis presents in the private space of relationships, the data suggests that in the evaluation of risks of the disease within the family environment relationship risks gain meaning. Difficulties related to the taking of medicines and their side effects, the care for their bodies and the many other routine activities are made easier by the presence and care of the family.

> *The first thing that keeps me having the treatment is my family. My family means everything to me and they give me the support I need. First is my daughter. She needs me and I cannot lose to this disease. (P14)*

> *I am undertaking the treatment because I want to get well soon, but I hate what my family did to me. But I don´t know... if you had tuberculosis I think I wouldn´t share my cup of tea with you. So, perhaps if I put myself in their shoes... It is a prejudice that I didn´t like, but perhaps I would have done the same thing… (P6)*

Studies [12-13] have pointed out the positive relationship between family ties and adherence to tuberculosis treatment and it is confirmed by the outcome of this study. The data suggests that family break-up can become a possible tuberculosis risk and adherence to treatment and consequent health recovery represent, on the contrary, the possible maintenance of family ties. In some cases, such as P6, the family doesn't have a positive reaction towards a family member infected with tuberculosis. Despite the prejudice, the subjects from this research kept their adherence to the treatment aiming for a quick recovery, contradicting other studies which relate this factor with the condition of abandonment [6-14].

To adhere to the treatment and guarantee a cure for the disease, will perhaps be an attempt to control the risks that the illness represents to family relationships of these subjects. Completing the treatment these risks might cease to exist, leaving the treatment, the relationship risks might even be more severe.

FINAL CONSIDERATIONS

This study presents contributions for nursing and for the work process of professionals who deal with the control of tuberculosis, providing contributions in the understanding of the process of adherence to treatment from an analysis of the understanding of the risks of the disease by those undergoing treatment.

The diagnosis of tuberculosis results in the addition of new risks to the personal record of risks already known by these patients. The data permits the conclusion that, for the participants of the research, "risk" has a negative connotation, being associated with the possibility of danger or potential harm. Such a process of attributing meaning involved subjective estimation and analysis influenced, by elements of the social and cultural context in which these individuals live.

It is possible to infer that the inclusion of potential harm from tuberculosis in this record does not open a new identity in the subject of risk. Just as, before receiving their diagnosis, the patients already recognize how as individuals they are exposed to risks, carrying out, routinely, estimates of probability, and taking action to manage these risks. So, the risks of tuberculosis constitute themselves as elements of an already existing portfolio of risks, and their meaning is formed in the context of and in relation to the whole range of possible harms found in daily life.

Self-identification as subjects at risk suggests that the participants of the study adhered to the treatment from the evaluations about what risks can and should be avoided with this attitude, adopting the posture and identity of careful subjects with a view to preserving their personal relations and closeness to society.

With a focus on relationships, it's taken as a limitation of the research the absence of analysis of the influence of other factors in this process, as is the case with conditions of life. Also recommended, is the realization of studies on gender and generation in the way that people behave when confronted with the risks of tuberculosis.

REFERENCES

1 Ministério da Saúde (BR), Secretaria de Vigilância em Saúde. Boletim epidemiológico: especial tuberculose. Brasília (DF): Ministério da Saúde; 2012. (v. 43).

2 Ferreira J, Engstron E, Alves LC. Adesão ao tratamento da tuberculose pela população de baixa renda moradora de Manguinhos, Rio de Janeiro: as razões do im(provável). Cad Saúde Coletiva. 2012,20(2):211-6.

3 Ministério da Saúde (BR), Secretaria de Vigilância em Saúde. Manual de controle da tuberculose. Brasília (DF): Ministério da Saúde; 2010.

4 Oliveira DLC. A 'nova' saúde pública e a promoção da saúde via educação: entre a tradição e a inovação. Rev Latinoam Enferm. 2005;13(3):423-31.

5 Giroti SKO, Belei RA, Moreno FN, Silva FS. Perfil dos pacientes com tuberculose e os fatores associados ao abandono do tratamento. Cogitare Enferm. 2010;15(2):271-7.

6 Silveira CS, Passos PT, Soder TCH, Machado CPH, Fanfa LS, Carneiro M, et al. Perfil epidemiológico dos pacientes que abandonaram o tratamento para Tuberculose em um município prioritário do Rio Grande do Sul. Rev Epidemiol Control Infect. 2012;2(2):46-50.

7 Minayo MCS. Pesquisa social: teoria, método e criatividade. 19ª ed. Petrópolis: Vozes; 2001.

8 Strauss A, Corbin J. Pesquisa qualitativa: técnicas e procedimentos para o desenvolvimento da teoria fundamentada. 2ª ed. Porto Alegre: Artmed; 2008.

9 Rossetto M. Reconhecendo-se como sujeito de risco: a consciência dos possíveis danos da tuberculose [dissertação]. Porto Alegre (RS): Escola de Enfermagem, Universidade Federal do Rio Grande do Sul; 2013.

10 Giddens A. Modernidade e identidade. Rio de Janeiro: Jorge Zahar, 2002.

11 Oliveira DLLC. Brazilian adolescent women talk about HIV/AIDS risk: reconceptualizing risky sex – what implications for health promotion? [tese]. London: Institute of Education, University of London; 2001.

12 Silva TS. Repercussão do diagnóstico de tuberculose na vida de mulheres na perspectiva de gênero [trabalho de conclusão de curso] Porto Alegre (RS): Universidade Federal do Rio Grande do Sul; 2012.

13 Gomes ALC, Sá LDD. As concepções de vínculo e a relação com o controle da tuberculose. Rev Esc Enferm USP. 2009;43(2):365-372.

14 Baral SC. Causes of stigma and discrimination associated with tuberculosis in Nepal: a qualitative study. BMC Public Health. 2007;7:211-21.

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