Gender Differences in the Interpretation of Experiences of Patients with Tuberculosis in Medellín, Colombia

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Objective. This study sought to determine gender differences in the interpretation of tuberculosis (TB) in a group of patients from the city of Medellín. **Methodology.** This was a qualitative study, with the grounded theory method. Twelve semistructured interviews were applied to patients from both genders who were cured of TB. The sample was selected through convenience and for analysis the information was categorized through the Atlas Ti tool. **Results.** Regarding the symptoms, the most reported is cough, but men manifest expectoration more frequently. Men overstated the symptoms, while women tend to minimize them. Women report mental impairment and emotional-type manifestations produced by the disease. Men and women expressed ignorance about the disease upon diagnosis. Both manifested fear of infection, work incapacity, loss of employment, rejection by others, and death. Also highlighted is the importance of family support and of the healthcare personnel. Women expressed shame in that others knew of their disease and mentioned greater intolerance with taking the medications. **Conclusion**. The gender role constructed culturally constitutes the central axis that explains how men and women interpret TB and can be modified by educational and accompaniment processes. Family support plays an important role in the healing process. Although common aspects exist, delving into the gender differences against the interpretation of TB may permit a different approach of the disease and better control of it.

Key words: tuberculosis; gender identity; fear; social support.

Diferencias de género en la interpretación de las vivencias de pacientes con tuberculosis. Medellín, Colombia

Objetivo. Determinar las distintas interpretaciones con respecto a la tuberculosis (TB) a partir de las diferencias de género en un grupo de pacientes de la ciudad de Medellín. **Metodología.** Estudio cualitativo, con el método de la teoría fundamentada. Se aplicaron 12 entrevistas semiestructuradas a pacientes de ambos géneros curados de TB. La muestra se seleccionó por conveniencia y para el análisis se categorizó la información mediante la herramienta

Atlas Ti. **Resultados.** Con relación a los síntomas el más expresado es la tos, pero los hombres manifiestan con más frecuencia la expectoración. Ellos sobredimensionan los síntomas, mientras las mujeres tienden a minimizarlos. Estas, a su vez, refieren deterioro mental y manifestaciones de tipo emocional producidas por la enfermedad. Tanto hombres como mujeres expresaron desconocimiento sobre la enfermedad en el momento del diagnóstico. Ambos manifestaron miedo al contagio, incapacidad laboral, pérdida del empleo, rechazo de los otros y a la muerte. También resaltaron la importancia del apoyo familiar y del personal de salud. Las mujeres expresaron vergüenza de que otros supieran de su enfermedad y mencionaron mayores intolerancias con la ingesta de los medicamentos. **Conclusión.** El rol de género, construido culturalmente, constituye el eje central que explica la manera como hombres y mujeres interpretan la TB, lo que puede ser modificado por procesos educativos y de acompañamiento. El apoyo familiar juega un papel importante en el proceso de curación. Aunque hay aspectos comunes, la profundización en las diferencias de género frente a la interpretación de la TB, puede permitir un abordaje diferente de la enfermedad y un mejor control de la misma.

Palabras clave: tuberculosis; identidad de género; miedo; apoyo social.

Diferenças de gênero na interpretação das vivências de pacientes com tuberculoses. Medellín, Colômbia

Objetivo. Determinar as diferenças de gênero na interpretação da tuberculose (TB) num grupo de pacientes da cidade de Medellín. **Metodologia**. Estudo qualitativo, com o método da teoria fundamentada. Aplicaram-se 12 entrevistas semiestruturadas, a pacientes curados de TB de ambos gêneros. A mostra se selecionou por conveniência e para a análise se categorizou a informação mediante a ferramenta Atlas Ti. **Resultados**. Com relação aos sintomas o mais expressado é a tosse, mas os homens manifestam com mais frequência a expectoração. Os homens sobre-dimensionam os sintomas, enquanto as mulheres tendem a minimizá-los. As mulheres referem deterioração mental e manifestações de tipo emocional produzidas pela doença. Homens e mulheres expressaram desconhecimento sobre a doença no momento do diagnóstico. Ambos manifestaram medo ao contágio, incapacidade trabalhista, perda do emprego, rejeição dos outros e morte. Também ressaltaram a importância do apoio familiar e do pessoal de saúde. As mulheres expressaram vergonha de que outros soubessem da doença e mencionaram maiores intolerâncias com a tomada dos medicamentos **Conclusão**. O papel de gênero construído culturalmente constitui o eixo central que explica a maneira como homens e mulheres interpretam a TB e pode ser modificado por processos educativos e de acompanhamento. O apoio familiar joga um papel importante no processo de cura. Ainda que há aspectos comuns, o aprofundamento nas diferenças de gênero frente à interpretação da TB, pode permitir uma abordagem diferente da doença e um melhor controle da mesma.

Palavras chave: tuberculose; identidade de gênero; medo; apoio social.

Introduction

In 2012, 8.6-million new cases of TB were reported, along with 1.3-million deaths due to TB of which 2.9 million (33.7%) of the cases occurred in women and 410 000 (31.5%) of the deaths were also in women.[1] Although more men than women are diagnosed with TB in the world, over half a million women die each year due to this disease; this can be a reflection of the barriers related to gender with respect to diagnosis and treatment.[2,3] This proportion agrees with official data reported in Antioquia and Medellín, where most of the deaths occur in men; 80% and 77%, respectively, but the figures in women are also considerable; 19% and 33%.[4] Additionally, low-income populations have a higher risk of developing TB, especially women who, due to social and cultural factors, have less resources to pay for health services, less money

for transportation to these services, and many limitations because of their roles as housewives. In this sense, TB is a known cause of mortality in women (most during reproductive ages), which generates a bigger social problem given that many of them are mothers heads of household.[5]

Gender studies have frequently centered on aspects related to women´s health; however, the concept of gender has changed through history; hence, it is necessary to insist on a gender approach from the analysis of social relationships between men and women, which reveals social inequalities around the distribution of power and income that impact in differential manner on the health situation.[6] The concept of gender according to the WHO refers to "social concepts of the functions, behaviors, activities, and attributes each society considers appropriate for men and women". In this sense, it may be said that gender is the cultural construction that goes beyond the sexual difference and incorporates social relationships in continuous interaction. This study retook the concept of gender to refer to ideas and representations, as well as to the social practices of men and women, which implies a hierarchical differentiation of spaces and social functions and their expression when they suffer a disease like TB.[6]

Stigmatization of patients with TB is practically universal and it is originated in the feelings of guilt that have been historically related with the disease. The stigma affects not only patients, but also their families and generates isolation and rejection, creating a negative impact on the control of the disease due to resistance to the diagnosis, delays in starting treatment, and its abandonment.[7] It is fundamental to recognize that the social representations around health and the disease affect upon the care process in each population; likewise, the incidence of the disease, damage and/or suffering constitute a necessary structure for the production and reproduction of any society. That is, that "suffering and responses to the disease constitute structural processes in every system and in every social group and that, consequently, said systems and social groups not only will generate representations and practices, but will structure knowledge to confront, coexist, solve, and – if possible – eradicate suffering.[8]

This article contributes to the interpretation of TB from a gender perspective, bearing in mind the health/disease/care process as part of a social context within which subjectivity is collectively established and proposes elements for the knowledge of said subjectivity, as input for the construction of health programs. Additionally, it recognizes the importance of health professionals and particularly of nursing in the accompaniment of patients, with consideration of gender differences, on how the disease is perceived, how the symptoms are manifested, the type of accompaniment required, concern for the risk of infection, and how treatment is assumed.

Methodology

The target population was identified from the databases of the cohort study of cohabitants conducted in the city of Medellín as part of the activities of the Colombian TB Research Center (CCITB, for the term in Spanish) between 2005 and 2008.[9] The study is supported on the theoretical foundation of the symbolic interactionism with the grounded theory research method. To obtain information, 12 semi-structured interviews were applied to patients belonging to the cohort who had completed the antifimic treatment. The sampling was done through convenience, selecting six men and six women, index cases of the families monitored, and who had ended treatment.The interviews were designed with open questions, applied individually, and recorded with prior consent from the participants. An exploratory study was performed to evaluate the instrument and refine researcher training. Interviews were made with four patients, applying the first script designed; data analysis was done through coding from constant comparison. Thereafter, open coding was developed, as well as emergence of descriptive categories and the interview script was adjusted according to the findings.

During a second stage eight informant patients were interviewed and the modified script was applied, from the information obtained, axial coding was carried out and the analytic categories emerged. Lastly, the central theory emerged as axis of the grounded theory. The Atlas Ti program (Version 5.1) was used as tool for organization and information analysis. Within the framework of the cohort study of cohabitants, the informed consent process was carried out and it was approved by the Ethics Committee of the Medical Research Center in the Faculty of Medicine at Universidad de Antioquia.

Results

These findings describe the experience of the diagnosis and treatment of TB from a gender perspective. The participants in this study were men and women inhabitants in the Metropolitan area of Valle de Aburrá, mostly in the city of Medellín. Men reported a mean age of 43 years (interquartile range: 26 - 52) and women reported a mean age of 37 years (interquartile range: 27 - 39). Some social and clinical characteristics are described in Table 1.

Table 1. Social and clinical characteristics of the participants by gender

Characteristic	Values	Men	Women
Socioeconomic level according to public services	I	3	2
	II	0	1
	III	3	2
	IV, V, VI	0	0
Affiliation regime to the health system	Contributive	5	4
	Subsidized	1	1
	Registered	0	1
	Not affiliated	0	0
Bacilloscopy result	+	3	1
	++	3	4
	+++	0	1
Status at end of treatment	Cured*	5	6
	Ended treatment	1	0
Cough	No	0	0
	Yes	6	6
Expectoration	No	0	1
	Yes	6	5
Has any co-morbidity	Yes	1	2
	No	5	4
BCG vaccination scar	No	3	1
	Yes	3	5

*Cured: negative bacilloscopy at end of treatment

The following lists the categories and the corresponding subcategories that emerged during the analysis process: 1) clinical manifestations in relation to: types of symptoms (physical and emotional), individual perception of the symptom; 2) knowledge of the disease expressed

as: ignorance, inadequate information, forms of diagnosis, fear of infecting and to being infected; 3) social networks that generate: company, rejection, isolation, shame, loss of employment; 4) emotions and behaviors evidenced by: commitment to the treatment by the patient, neglect, guilt, economic limitations to help in taking the treatment, work incapacity. After experiencing tuberculosis, even several years after having ended the treatment, people remember emotively the experience in traumatic manner, as expressed by one of the participants: *you don't want to remember that; but you recall, day after day, the moments that transpired because you will never forget; it has been a while since I've spoken about it with anyone, it is something you want to leave behind...* (EM1). Hereinafter are presented the relevant findings from the categories that describe the experience, emphasizing on gender differences evidenced in the interviews.

How the disease is expressed

In general, the symptoms perceived by the men and women interviewed are the most commonly described for TB in literature: fatigue, weakness, fever, sweating, cough, and expectoration. However, the biggest gender differences in the perception of symptoms centered on three relevant aspects: 1) although men and women reported cough, the men interviewed expressed more frequently expectoration as a symptom, while the women interviewed do not mention it. 2) A difference is expressed in the symptomatological description. Some women tend to minimize the symptoms and one of them expressed it clearly: *…I had a cough that for me was insignificant, it was a dry cough and at times, for some days, no more...* (EM11); while men overstate their symptomatology, as described by one participant: *Yes, I sweated a lot at night, I felt my breathing labored; I was dying* (EH8). 3) Among the men and women interviewed, only women mentioned emotional impairment, aside from physical deterioration.

Prior knowledge of TB

In this study, men and women expressed ignorance or inadequate information on the disease at the moment of diagnosis, as illustrated by a participant: *…on the tuberculosis, I was not informed; you think your time has come and that you are in your last days* (EH7); both genders manifested imaginaries regarding the infection; they think it is a disease that does not affect them but others, that you are not infected by a close person, that it is transmitted by sharing utensils, by not washing their hands, and that it continues being dangerous even after being cured. Additionally, women expressed that ignorance misguides the patient and generates potentially fatal diagnostic delays: *My best friend died of tuberculosis… so it was very hard because from my perspective if he had been diagnosed much earlier and with certainty and if treatment had been started, he would have been able to take care of the disease* (EM12). Women explain the delays through the following causes: not thinking of the disease as diagnostic possibility, confusing the symptoms with another disease, late consultation after much time with a cough that does not improve, late diagnosis in a contact, delays caused by administrative procedures, no prior knowledge regarding the procedures that must be performed, not taking the samples to the laboratory on time, not recognizing the symptoms in spite of having information, and not taking tests due to ignorance of its importance. Lack of knowledge of the disease reinforces fears in the patients. Some of the men and women interviewed manifested fear of infecting other people and of being infected, of work incapacity or losing their jobs, of rejection by others, and reiteratively fear death due to possible failures in treatment; they also fear leaving the family or losing their health. One of the women interviewed expressed it thus: *Spiritually, I still remember that and feel like crying; not knowing that you suddenly got sick and above all with the fear of infecting someone living with you…* (EM4).

Support social networks

Men and women manifested that the lack of accompaniment from the family group, friends, or coworkers is perceived as loneliness and rejection; one of the women illustrates it in the following way:

that is what you fear the most about that disease, rejection from people… (EM1). Likewise, men isolated themselves for fear of getting worse or losing their job; one of them expressed it with the following words: *…I would be careful every time I coughed by covering my mouth or carrying a handkerchief; I tried to stay away from others because I didn't say I had TB in any of the institutions for fear of being fired, only the family knew* (EH6). Women, in turn, expressed shame of others knowing of the disease, as manifested by a participant: *During the day, I did not cover up with anything because I was ashamed; people didn't have to know that I was sick, but at night I wore a nose mask or opened the window – I tried not to cough next to anybody…* (EM1).

Men and women recognized accompaniment from the healthcare personnel and trust in the therapist as important aspects to follow the treatment and be cured; one of the women mentioned feeling accompanied by the healthcare personnel who cared for her at home and expressed it thus: *the doctors were spectacular, they treat you the way; they don't start covering up, they don't start saying that you are sick and that they have to afraid; they arrive with confidence, hopefully everyone in the field of tuberculosis always arrives giving you confidence. It is good to know you are there, that helps a lot…* (EM1). This trust was not openly stated when they talked about their relationship with the healthcare personnel in the institutions. Additionally, they felt rejected by some of the physicians and nurses who used nose masks.

All the participants highlighted the importance of family support during the healing process; however, some of them regretted not having had such *… the most critical part is that I was not supported at home…* (EM10).

Emotions and behavior modification…

The participants recognized that the resolution of TB implies commitment from the patient on aspects like nutrition and adherence to the treatment; one of the men expressed the importance of restricting life habits to get cured *… sometimes I used to like to have a drink and would be invited often, but I would leave it aside; first comes your health* (EH5). One of the women talked of self-care, justifying in function of others *…I love my family very much and say that this treatment and everything happening to me is for my family: my family, I want my daughters to be okay, I want my family to be okay…* (EM13). In another sense, neglect generates feelings of guilt regarding the disease and the outcome of the treatment; a woman expressed it thus: *…I got the fever so I say that most of all I am guilty of that because I don't think a person with good constitution doesn't get infected, because it did not infect my husband and we were together...* (EM1).

Treatment, according to that expressed by the participants, also represented difficulties like economic limitations to attend the supervised treatment, symptoms of asthenia and adynamia that complicated displacement to health services, and their strict schedules. Women mentioned greater intolerance to taking medications and men mentioned resistance to the treatment due to their fear of injections. As a result of the experience with the disease, some women spoke of having undergone emotional consequences, expressed in terms of denial, sadness, and traumatic memory of the experience, which were not explicit in the men. Both men and women express that they can help other patients by sharing the experience after the treatment.

Discussion

The perception of the symptoms of the disease is related to that learnt from the social stance, by the fact of assuming the role of man or woman. Assuming that role implies having knowledge conditioned by cultural factors, which involve the subjective configuration of the masculine and the femenine.[10] Likewise, the differences between men and women, in life styles and behaviors related to health, influence on the care of the disease

(perception of symptoms, search for healthcare or prevention behaviors). The women participants did not report expectoration as an important symptom, possibly in relation to socially accepted behaviors or to the physical inability, as referred by other authors;[3] in that sense, women tend to minimize the symptomatology of the disease in function of their role in the family as caretakers, while men exacerbate it. Regarding the search for care, in this study the exacerbation of symptoms in men pressures the search for care by the family, but this reason was not expressed in the search for medical attention. In a research by the WHO in Bangladesh, India, Malawi, and Cali-Colombia report that men due to male chauvinism delay the search for medical attention.[3]

Men overstate their symptomatology when they are sick, findings that correlate with that reported in literature, given that they tend to perceive that their capacities are diminished. They report hypersensitivity to pain, limit themselves to resting and recovering supported and cared by others; [11] similarly, they express expectoration as a frequent symptom, which coincides with findings from other studies.[12] In this study, it is women and not men who refer to the emotional impact generated by the process with the disease; women manifest feelings of guilt and shame from what they consider “neglect”. The interpretation of men on their own care and their own health is done in terms of avoiding excessive cigarette smoking and liquor intake, which makes them vulnerable to TB, as found in another study;[3] in them the emotional aspect tends to be absent, as evidenced in literature.[11]

One of the central categories that emerged in this study was the lack of knowledge and the inadequate information the participants from both genders had; this is cause for concern not only for the individual outcome, but also in the framework of programs to control the disease, given that the prior knowledge patients have about TB impacts upon the process of diagnosis and cure inasmuch as it permits assuming favorable attitudes and practices; also, it determines how they will relate with others as of the health/disease processes.

Ignorance about the disease also influences upon the election of different alternatives for its care. Health services and an inadequate physician-patient relationship are factors that generate delays in the diagnosis and failure to adhere to the treatment.[13] This study did not establish gender differences in the delays; however, the participants recognized the implications that such generates and the causes that originate them: additionally, the literature reports bigger diagnostic delays and of the initiation of the treatment in women, attributed to patients and to the healthcare personnel. It has even been reported that the principal factor related to delays in women is fear of social isolation social from the family or the community.[14]

The information provided by the healthcare personnel impacts directly upon the patients' healing process, given that insufficient knowledge about the disease and its symptoms and the beliefs associated with the social stigma favor diagnostic delay.[15]

Regarding infection, in both genders, the study found fear of infecting or of being infected; infection from people nearby is underestimated; however, the men interviewed manifested ideas referring to the infection in the community and the work environment, while women mentioned it with respect to their family group in the first instance, responding to the ethics of care and responsibility, as supported by Gilligan in his proposal on moral development.[16] Traditionally, care has been framed within the distribution of gender roles, where women are “caretakers” and men are the main beneficiaries of the care offered.[11] The aforementioned agrees with the evidence provided by the group of individuals interviewed with respect to accompaniment within the family context. This study highlights the importance of accompaniment by the family for men and women; it does not clearly identify a gender difference in this sense, as do other studies where women do not have support networks from relatives.[17] In another study conducted in Vietnam, isolation is a common factor between men and women with TB; that same study highlights that

men worry more about economic factors related to the disease and women are more concerned with social consequences.[18]

The participants referred repeatedly to social isolation, accounting for the stigma generated by the TB in the context where they operate, with the aggravating condition that the stigma remains even after ending the treatment and beyond the period indicated by the physician for the isolation, as substantiated in the literature.[18] In relation to the stigma, gender differences were not identified as they were reported in a study in Uganda where women experienced it due to the association with HIV.[19]

Individuals with chronic disease suffer because of the loss of their own image; the disease becomes a central aspect of their lives and they are discredited when they are devalued; they are not believed in and are excluded.[20] This is the case with TB, where the participants expressed persistent suffering even after having ended the treatment; loss of their own image was expressed by women referring to the mental or emotional deterioration they experienced.

Anti-tuberculosis treatment due to its prolonged duration, secondary effects, and supervised administration presents difficulties to patients, according to the findings in this study. Although treatment is free in Colombia, the participants referred to the economic difficulties generated by the supervised treatment dosage in health services; this constitutes a cause for delays, as reported by other studies.[14] Even though the treatment is related to curing, men and women manifested in the interviews that they self-medicated with home remedies to mitigate the secondary effects of the medications.

It is interesting in this study that upon asking the participants about the contribution they can make to society after having had the experience of the disease, they all recognize and value a "life lesson" and consider that from their experience they can help others understand and overcome the disease. This can become an opportunity for TB control programs to implement strategies that improve the care of patients with TB in aspects having to do with identification of cases and adherence to the treatment. The nursing staff has a fundamental role in these aspects due to their dynamic participation in the activities of the disease's control programs and to the closeness those dedicated to nursing achieve with patients in their role as caretakers.[21]

Finally, the gender role constructed culturally constitutes the central axis that explains how men and women interpret TB and it can be modified through educational and accompaniment processes. Family support plays an important role in the healing process of patients with TB. Although common aspects exist between men and women, delving into gender differences regarding the interpretation of TB may permit a different approach of the disease and better control of it.

Limitations of the study. The participants had been cured of TB at the moment of the study and this may have changed the perception of the disease over time. The interviews made may have been intimidating due to the stigma represented by TB in society, leading to their only mentioning "socially acceptable" aspects. The study only included TB index cases individuals who were part of a cohort study,[9] leaving out other subjects with the disease. The fact of having participated in the family follow up during the study may have modified the gender approach of the disease.

Recommendations. Promote the study of diseases from a gender perspective to strengthen healthcare programs, bearing in mind that the interpretation people make of the health/disease situation and the meaning they give to the diagnosis of TB is determined by the symptoms, prior knowledge, support from social networks, emotions, and behaviors, while it is part of the construction of the experience and shapes the behaviors or actions of each individual.

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