# KNOWLEDGE OF THE FAMILIES OF PATIENTS WITH TUBERCULOSIS REGARDING THIS DISEASE: A TRANSVERSAL STUDY\*

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**ABSTRACT:** The article aimed to analyze the knowledge of the family members of the patients with tuberculosis regarding this disease. It is an epidemiological, descriptive and transversal study undertaken through a questionnaire applied to 50 family members of patients diagnosed with tuberculosis in Natal (State of Río Grande do Norte – RN) between March and August 2012. The data were analyzed through frequencies, percentages, measurements of central tendency and the combining of dichotomous variables using the Chi-squared test and Fisher's exact test. Among the interviewees, 34 (68%) stated that they had little knowledge, and 11 (22%) that they had no knowledge, regarding tuberculosis. In relation to the infectious period of the disease, 20 (40%) gave incorrect responses. It is concluded that the knowledge expressed by the family members regarding tuberculosis was satisfactory in certain aspects. However, it raised worrying characteristics in relation to the disease. In this scenario, it is essential to promote and disseminate information regarding the disease, as a form of controlling tuberculosis.

DESCRIPTORS: Tuberculosis; Knowledge; Family; Nursing.

#### CONHECIMENTO DAS FAMÍLIAS DE PACIENTES COM TUBERCULOSE SOBRE A DOENÇA: ESTUDO TRANSVERSAL

**RESUMO:** Objetivou-se analisar o conhecimento dos familiares dos pacientes com tuberculose sobre a doença. Estudo epidemiológico descritivo de corte transversal realizado com a aplicação de questionário a 50 familiares de pacientes diagnosticados com tuberculose em Natal - RN entre os meses março e agosto de 2012. Os dados foram analisados através de frequências, percentuais, medidas de tendência central e cruzamento de variáveis dicotômicas com os testes Qui-Quadrado e teste de Fisher. Dentre os entrevistados, 34 (68%) disseram possuir pouco conhecimento e 11 (22%) nenhum conhecimento sobre a tuberculose. Quanto ao tempo de transmissão da doença, 20 (40%) deram uma resposta errada. Conclui-se que o conhecimento expresso pelos familiares sobre a tuberculose em alguns aspectos, foi satisfatório. Entretanto, suscitou características preocupantes em relação. Frente a esse cenário é imprescindível a promoção e disseminação da informação sobre a doença, como forma de controle da tuberculose. **DESCRITORES:** Tuberculose; Conhecimento; Família; Enfermagem.

#### CONOCIMIENTO DE LAS FAMILIAS DE PACIENTES CON TUBERCULOSIS ACERCA DE LA ENFERMEDAD: ESTUDIO TRANSVERSAL

**RESUMEN:** El objetivo del estudio fue analizar el conocimiento de los familiares de pacientes con tuberculosis acerca de la enfermedad. Estudio epidemiológico descriptivo transversal realizado por medio de cuestionario a 50 familiares de pacientes con diagnóstico de tuberculosis en Natal-RN, entre los meses de marzo y agosto de 2012. Los datos fueron analizados considerándose frecuencias, porcentuales, medidas de tendencia central y cruzamiento de variables dicotómicas con los testes Chi-Cuadrado y test de Fisher. Entre los entrevistados, 34 (68%) afirmaron tener poco conocimiento y 11 (22%) ningun conocimiento sobre tuberculosis. Cuanto al tiempo de transmisión de la enfermedad, 20 (40%) contestaron equivocadamente. Se concluye que el conocimiento expreso por los familiares sobre la tuberculosis en algunos aspectos fue satisfactorio. Sin embargo, se revelaron características preocupantes acerca de eso. Delante del cuadro, son imprescindibles la promoción y divulgación de la información acerca de la enfermedad, como forma de control de la tuberculosis.

DESCRIPTORES: Tuberculosis; Conocimiento; Familia; Enfermería.

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### • INTRODUCTION

Tuberculosis (TB) continues, even in the 21st century, to represent a challenge to the health authorities in Brazil and worldwide due to its high incidence of mortality among the infectious-contagious diseases. Among the 22 countries which concentrate approximately 80% of cases of tuberculosis, Brazil is in 16th place in relation to the number of new cases, and in 22nd place in relation to the coefficient of incidence, prevalence and mortality. In 2014, the coefficient of incidence was 33.5 cases per 100,000 inhabitants, and a mortality rate (considering cases closed in 2013) of 2.3 deaths per 100,000 inhabitants; as a result, it is considered to be one of the priority countries for the control of this disease<sup>(1)</sup>.

Ignorance on the part of the family members in relation to the disease or illness in general terms, the progression of the clinical situation, the possible complications, the appropriate way of caring for the patient in the home and the physical and social demands all cause a vague unease<sup>(2)</sup>.

Therefore, it is necessary to investigate the factors associated with the families' knowledge in relation to TB, in order to identify the principal obstacles to the success of the treatment, and of the priority groups from the point of view of differentiated care. The family is a relevant factor which must be taken into consideration in the control of TB. The emergence of this disease in the family ambit has an impact on the relationships between its members, in relation to how it is to be dealt with.

These changes in individual and family behavior are directly related to knowledge and attitudes in relation to the disease<sup>(3)</sup>. Insufficient knowledge can affect how the disease is perceived and confronted, and can, therefore, increase vulnerability to TB.

In the light of this, the knowledge becomes a target for strategies which are essential for formulating effective health policies which aim to control the disease, holding the family as an important object of the nursing work process in Primary Health Care<sup>(3)</sup>.

It is essential to inform these subjects about the disease and remind people of the knowledge in relation to the health-illness process such that it may promote demystification and the reduction of the social stigma which is attached to diseases such as TB. In addition to this, one must take into account that the knowledge can influence practices in relation to prevention.

Understanding the family as the most constant health unit is a condition sine qua non for the institution of a health context, for the promotion of health, prevention of ill health, treatment and rehabilitation. In accordance with the concept of unit of care, the family is defined by its own members. In this process of care, the family is concerned not only with the ill individual's physical state of health, but also with her well-being and happiness<sup>(4)</sup>.

In this study, knowledge is considered as the remembering of occurrences or facts transmitted by the education system in which the subject participates, issuing concepts with the understanding acquired regarding a specified issue or event<sup>(5)</sup>. Primary Health Care (PHC), as proposed by Starfield, was used as the guiding theoretical reference for the development of the present study.

This study is justified based on the transposition of the focus of TB from the individual to the family member. This investigation will contribute to the reorganization of the work processes in Primary Health Care in the context of this disease, for the collective ambit, through elucidation and analysis of the knowledge found in the family environment regarding the disease. Furthermore, it will favor changes in practices which contribute to the control of the disease and the strengthening of PHC as an important place for controlling TB, through assisting in defining the priority actions for reducing the rates of this disease in the communities.

That said, this study aims to analyze the knowledge of the family members of the patients with tuberculosis regarding this disease.

## METHOD

This is an epidemiological, descriptive, transversal study undertaken in the municipality of Natal, RN, with family members and cohabitants of patients receiving treatment for pulmonary TB in Primary Health Care. Data collection took place between 1<sup>st</sup> March and 31<sup>st</sup> August 2012.

The criteria for inclusion in the study were as follows: subjects of both sexes were selected, in communication with TB patients, aged 18 years old or over at the time of data collection, resident in Natal and who were able to participate during the interview. Those lacking these characteristics were excluded. Sampling was consecutive, with 50 subjects being selected from the study's population of reference.

These individuals were recruited as a result of investigation by the nurses from the municipal units, who indicated the patients being treated for pulmonary TB. Following that, the family members or cohabitants of patients being treated for TB were identified, and these were invited to participate in the study through home visits, or at the time of consultations arranged for follow-up regarding the patient's treatment.

The instrument used for data collection was developed based on studies published regarding knowledge and attitudes<sup>(6-8)</sup>. The same was subjected to face and content validity by 10 judges, who are specialists on the issue, and was pre-tested with 10 family members of patients with TB. It is made up of 63 items which mainly follow the five point Likert scale (1 = never; 2 = almost never; 3 = sometimes; 4 = almost always and 5 = always), in which the participants stated the frequency with which they perceive the occurrence of a specified event. In addition to this, it had questions related to the sociodemographic aspects, clinical-epidemiological information, and the families' knowledge regarding the disease and regarding their attitudes in relation to the disease.

For the undertaking of this study, in specific, the following variables were used: marital status, age, educational level, formal occupation, religion, number of residents per residence, salary, access to the Internet, habit of reading magazines and newspapers and watching television, related to the sociodemographic profile, knowledge and attitude of families regarding TB.

Following the project's approval by the Research Ethics Committee of the Federal University of Rio Grande do Norte (UFRN) – under Opinion N. 323/2011, data collection was undertaken between March and August 2012.

The data collected were implanted in the Excel program, using independent double keying. After the verification of errors and inconsistencies, the analysis was undertaken using the Statsoft STATISTICA 9.0 software and the SPSS (Statistical Package for the Social Sciences) software for Mac. The study encompassed a descriptive phase, with exploratory analysis of the data, with the relative frequencies and measurements of central tendency (mean, median) being calculated. Following that, bivariate analysis was undertaken of the combining of the dichotomized variables – knowledge regarding TB and changes of attitudes with the independent variables (age, educational level, habits of reading magazines and newspapers, and access to the Internet) through contingency tables, at which point the Chi-squared test was applied, and, in the necessary cases, Fisher's exact test. In the 2x2 tables, the Odds Ratio was calculated, with a respective confidence interval of 95% (CI 95%). The probability of type 1 error accepted in the study was of up to 5%.

## • RESULTS

Table 1 shows the sociodemographic profile of the subjects of the investigation. It was observed that 43 (86%) of the interviewees were female, 34 (68%) were aged between 30 and 59 years old, there being a mean age of 46.64 years old and a median age of 46.50 years old. Regarding occupation, 24 (48%) were housewives, and had a monthly family income of over R\$1.000,00.

In relation to the knowledge of the family members of the patients with TB regarding the disease, 34 (68%) stated that they had little knowledge, and 11 (22%) stated that they had no knowledge. However,

31 (62%) reported knowing something about TB. Of the 50, 27 (54%) of the interviewees stated that they had never sought to obtain information about tuberculosis. In spite of this, when questioned as to whether information about TB tends to be enlightening in the situations in which they seek it, 22 (44%) responded that it was satisfactory. o

Figure 1 presents the opinion of the research subjects regarding the symptoms that they believe to be common to tuberculosis. Among the responses presented, the symptoms recognized were fever, chest pain, and back pain (46 subjects); followed by weight loss (45 subjects), inappetence and cough lasting more than three weeks (41 subjects).

In relation to the microorganism which causes TB, 18 (56%) subjects responded correctly, stating that the disease was caused by bacteria; 17 (34%) of the interviewees stated that they did not know, and 14 (28%) responded that TB is caused by a virus, while one (2%) participant reported that the causal agent is fungus.

The forms of transmission recognized by the family members of the patients with TB are highlighted in Figure 2. It may be observed that 45 subjects indicated that TB is transmitted when you are in the same atmosphere as the symptomatic ill person, while 40 associated TB with the shared use of plates, cutlery and cups.

In relation to the knowledge regarding tuberculosis, when the subjects were questioned regarding the time in which a person with pulmonary tuberculosis ceases to transmit the disease, 25 (50%) interviewees responded that they did not know, while 20 (40%) gave an incorrect answer. In relation to the issue addressed - whether after the beginning of treatment, the individual ceases to transmit TB - 22 (44%) stated yes. Regarding the infectious period, 40 (80%) of the interviewees responded correctly.

Table 2 shows the association of the variables of marital status, age, educational level, occupation, religion, number of residents per residence, salary, access to the Internet, habit of reading newspapers and watching television with knowledge regarding TB. Of the total of independent variables considered in this stage of the analysis, it was observed that the variable of minimum salary had statistical significance (p < 0.05), demonstrating an association of the variable of minimum salary with knowledge regarding TB. Table 1 - Sociodemographic profile of the family members, and degree of kinship, with patients being treated for tuberculosis. Natal, RN, Brazil, 2012

Variables	n=50	%
Age		
< 30 years	7	14
30-59	34	68
$\geq$ 60 years	9	18
Sex		
Male	7	14
Female	43	86
Occupation		
Housewife	24	48
Retired/Pensioner	8	16
Unemployed	4	8
Community Health Worker	2	4
Autonomous	10	20
Handyman	2	4
Income		
<r\$600.00< td=""><td>7</td><td>14</td></r\$600.00<>	7	14
R\$600.00-1.000.00	18	36
>R\$1,000.00	24	48
Educational level		
None	6	12
Basic education	25	50
High School	16	32
Higher Education	3	6
Degree of kinship		
Grandparents	1	1
Mother	12	24
Father	1	2
Son/daughter	7	14
Brother/sister	4	8
Grandson/daughter	1	2
Cousin	1	2
Spouse	14	28
Others	9	18

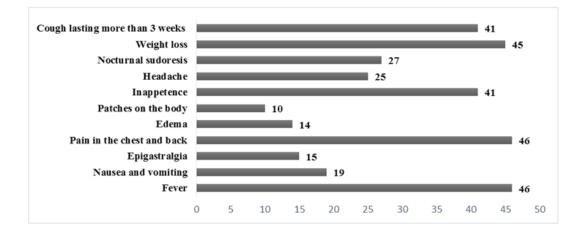


Figure 1 - Absolute frequency of the common symptoms of tuberculosis, indicated by the family members of patients receiving treatment. Natal, RN, Brazil, 2012.

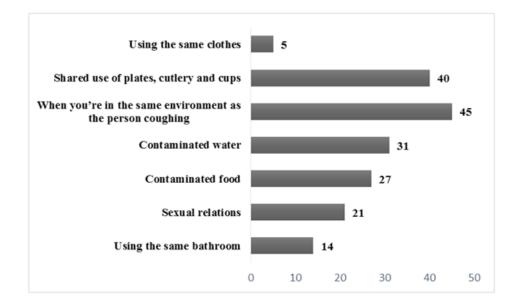


Figure 2 - Absolute frequency of ways of transmitting the disease, recognized by the family members of patients being treated for tuberculosis. Natal, RN, Brazil, 2012.

Table 2 – Factors associated with knowledge regarding Tuberculosis in families of patients diagnosed with the disease in Primary Health Care. Natal, RN, Brazil, 2012

	Knowledge						
Factors Associated with Knowledge	No		Yes		ODDS	CI (95%)	р
	n	%	n	%	Ratio		
Marital status - married:							
Yes	6	54.5	30	76.9	1	-	
No	5	45.5	9	23.1	2.778	0.684-11.27	0.252
Age							
< 47.04	7	63.6	18	46.2	1	-	0.306
> 47.04	4	36.4	21	53.8	2.042	0.513-8.119	
Educational level							
Yes	8	72.7	36	92.3	1	-	
No	3	27.3	3	7.7	0.222	0.038-1.310	0.111
Formal education							
Yes	0	0	5	12.8	1	-	
No	11	100	34	87.2	1.324	1.121-1.563	0.573
Number of residents per residence							
< 4	3	27.3	9	23.1	1	-	
> 4	8	72.7	30	76.9	1.250	0.273-5.725	0.528
Salary							
>1.7 M.S	2	18.2	23	59	1		
< 1.7 M.S	9	81.8	16	41	0.155	0.029-0.813	0.017**
Reads newspaper							
Yes	4	36.4	18	46.2	1	-	
No	7	63.6	21	53.8	0.667	0.168-2.65	0.734
Watches TV							
Yes	8	72.7	31	79.5	1	-	
No	3	27.3	8	20.5	0.688	0.148-3.203	0.688
Access to Internet							
Yes	1	9.1	11	28.2	1	-	
No	10	90.9	28	71.8	0.255	0.029-2.231	0.257

M.S: Minimum Salary

## DISCUSSION

It was proposed to investigate the knowledge of the families of patients receiving treatment for TB regarding this disease. Based on the results, one can observe the predominance of women, which may be explained by the data of the Brazilian Institute of Geography and Statistics (IBGE)<sup>(9)</sup>, which presents women as comprising 53% of the population of Natal. In addition to this, studies provide evidence that there is women provide help in the care of the family. In one study undertaken in Ribeirão Preto (SP) with families of patients with TB, the majority were female<sup>(10)</sup>.

In relation to educational level, it was identified that a proportion of the subjects had a low educational level, which reflects a situation of social vulnerability, which may influence the individuals not to seek information about the disease, neither information regarding health, generally. Furthermore, it may reflect a set of precarious socioeconomic conditions, which increase vulnerability to tuberculosis,

being a risk factor for tuberculosis, also contributing to non-adherence to treatment and to an increase in the rate of abandonment of treatment<sup>(11,12)</sup>.

The pattern of occurrence of TB is related to the social determinants, which are structured in the society's modes of production and reproduction, with the people who are most vulnerable to falling ill being those among the low income populations, with unhealthy housing conditions<sup>(6)</sup>.

Furthermore, in the present study, a concerning datum was observed, which is that the lack of knowledge regarding TB can affect how the community perceives and faces the disease. Hence, it is necessary to remind people of the knowledge which the population has regarding health-illness, in order to viabilize the planning of actions which promote the demystification of illnesses such as tuberculosis, and the breaking of prejudice and/or stigma<sup>(13)</sup>.

Regarding the symptoms of TB indicated, it is evidenced that the responses were satisfactory, as the majority of the interviewees stated that fever and pain in the chest and back are symptoms. A proportion of the interviewees also mentioned weight loss, inappetence and cough lasting more than three weeks, as well as headache.

In one study undertaken in a municipality in the State of São Paulo, cough lasting for more than three weeks, weight loss and inappetence were the symptoms presented most by the subjects as suggestive of tuberculosis, while nocturnal sudoresis was the least-recognized symptom, although 25% of the family members did not associate chronic coughing with TB<sup>(3)</sup>.

The clinical manifestations of TB can be varied. The classical symptoms of pulmonary TB are: a persistent cough, productive or not (with mucus and, eventually, blood), evening fever, nocturnal sudoresis and weight loss<sup>(14)</sup>. In this way, one can perceive coherence in the interviewees' responses regarding the symptoms. However, it was noted that symptoms which are commonly cited in the literature, such as nocturnal sudoresis, were not indicated by a relevant number of interviewees.

One can also observe that the number of participants who responded incorrectly, or who stated that they did not know the cause of TB, was fairly significant. Corroborating a study undertaken with students on this issue, in relation to the identification of the cause of the disease, the majority of the students (56.6%) responded that they also did not know; while some people who believed that they did know the cause of the disease responded in the following ways: "a disease produced by a virus", "a disease produced by being cold" or "a complication resulting from colds"<sup>(13)</sup>.

In relation to the ways of transmitting the disease, as this is a contagious disease, it is believed that many people generalize the means of contagion and believe that TB can also be contracted through the use of domestic utensils, hugs and shaking hands. In accordance with these findings, a study undertaken with health professionals and nursing students in the State of São Paulo ascertained that a proportion of the subjects of the above-mentioned study responded that one can contract tuberculosis from talking with people in general. The possibility of transmission through kissing people receiving treatment was reported by 86.5% of the participants. In addition to this, 85.3% of the interviewees stated that transmission is possible when sleeping in the same room as people with tuberculosis during this phase of the treatment<sup>(15)</sup>.

In the bivariate analysis, one can observe that the lowest monthly income was associated with knowledge; however, it was hoped that other aspects, such as educational level and access to the means of communication, might be linked to the sufficient (or not) knowledge of the families studied regarding TB.

Income below 1.7 minimum salaries was shown to be correlated with ignorance regarding TB. Possible explanations were raised for these findings, such as the allocation and distribution of the Family Health Strategy units in populational areas with less purchasing power; that is to say, the people with lower income usually live in areas on the periphery, where these primary health care centers are located. It is in these centers that these individuals find information related to their pathology.

In one study undertaken in the capital of the State of Pará, the results showed that the information transmitted by the professionals to the clients in their consultations was the principal source of

information regarding the disease, and that these, permeating their preexistent concepts, are configured as an important element in the formation of the representation of tuberculosis as a curable disease<sup>(16)</sup>.

It is worth emphasizing that, due to this being a study with convenience sampling, this association cannot be confirmed with accuracy, because these results may bring biases resulting from the selection process. As a result, further studies are suggested, with more robust and probabilistic sampling plans, with a view to verification of the strength of the link between the effect of the random variables - income on the knowledge produced by the families regarding TB.

As limitations of the study, it is emphasized that as this is a transversal investigation, there is the possibility of the existence of biases common to this type of study, such as those of information and of memory. In addition to this, the size of the sample investigated may hinder the generalization of this study's findings.

# CONCLUSION

The study evidenced that the knowledge expressed by the family members in relation to TB, in some aspects, was demonstrated to be satisfactory. However, it raised worrying characteristics in relation to certain factors, such as: the family members' lack of interest in seeking information on tuberculosis; the ignorance regarding the microorganism responsible for the disease; and the indication of contaminated water and foodstuffs as means of spreading the disease.

Regarding the factors associated with knowledge relating to TB, it was observed that the individuals with low income presented a smaller probability of having knowledge regarding the disease.

It is known that knowledge regarding the mechanisms of transmission, symptomatology and drug treatment, allied with attitudes and behaviors, opinions and perceptions in respect of tuberculosis can influence the entire process of health, falling ill, and cure of the disease. In this way, it is essential to promote and disseminate information in order to complement knowledge on the disease, which can be obtained through the different sectors of society, health and education, as well as through the media.

Therefore, this study's findings evidenced that the families are still not being considered in the PHC health practices. In this perspective, taking into account the weak points related to the care for the families, it is recommended to the professionals who comprise the PHC that the information regarding tuberculosis should be given frequently, both to the ill person and to his or her family members. It is necessary, therefore, that the viabilization of strategies for health education for this segment of the population should be an integral part of the treatment of TB offered by health centers, as stipulated by the Ministry of Health.

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