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STIGMA AS A SOURCE OF THE SOCIAL CONSTRUCTION OF THE CONCEPT OF PULMONARY TUBERCULOSIS: PERSPECTIVE OF NURSES

O ESTIGMA COMO FONTE DA CONSTRUÇÃO SOCIAL DO CONCEITO DE TUBERCULOSE PULMONAR: PERSPECTIVA DOS ENFERMEIROS

EL ESTIGMA COMO FUENTE DE LA CONSTRUCCIÓN SOCIAL DEL CONCEPTO DE TUBERCULOSIS PULMONAR: PERSPECTIVA DE LAS ENFERMERAS

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Objective: to describe the social construction of the social concept of pulmonary tuberculosis that, from the perspective of nurses, emerges from concepts based on stigma. Method: descriptive study, qualitative approach, with 12 nurses from centers of pneumological diagnosis in northern Portugal. Data collected in November 2020 and January 2021 by semi-structured interview, subsequently analyzed by content analysis methodology. Results: from the participants' discourses, the concept of pulmonary tuberculosis emerges. The understanding of the disease is surrounded by myths and taboos, with a bleak prognosis, causes fear of contagion, death, fear, shame, estrangement, social isolation and denial of the disease. Among nurses, talking about tuberculosis is a topic to avoid, it is an area that causes confusion and fear. Final considerations: the concept of the word tuberculosis persists rooted in concepts and prejudices. Social stigma remains at its core and perpetuates its negative concept to the present day.

Descriptors: Pulmonary Tuberculosis. Qualitative Research. Social Stigma. Nursing.

Objetivo: descrever a construção social do conceito social da tuberculose pulmonar que, na pesrpetiva de enfermeiros, emerge de conceitos alicerçados no estigma. Método: estudo descritivo, de abordagem qualitativa, com 12 enfermeiros de centros de diagnóstico pneumológico do Norte de Portugal. Dados colhidos nos meses de novembro de 2020 e janeiro de 2021 por entrevista semiestruturada, posteriormente analisados pela metodologia de análise de conteúdo. Resultados: dos discursos dos participantes emerge o conceito da tuberculose pulmonar. O entendimento da doença está envolto de mitos e tabus, com prognóstico sombrio, causa medo de contágio, de morte, pavor, vergonha, afastamento, isolamento social e negação da doença. Entre enfermeiros, falar de tuberculose é

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tema a evitar, é área que causa confusão e medo. Considerações finais: a conceção da palavra tuberculose persiste enraizada em conceitos e preconceitos. O estigma social permanece na sua essência e faz perpetuar o seu conceito negativo, até à atualidade.

Descritores: Tuberculose Pulmonar. Pesquisa Qualitativa. Estigma Social. Enfermagem.

Objetivo: describir la construcción social del concepto social de la tuberculosis pulmonar que, desde la perspectiva de enfermeros, emerge de conceptos basados en el estigma. Método: estudio descriptivo, de abordaje cualitativo, con 12 enfermeros de centros de diagnóstico pneumológico del Norte de Portugal. Datos recogidos en los meses de noviembre de 2020 y enero de 2021 por entrevista semiestructurada, posteriormente analizados por la metodología de análisis de contenido. Resultados: de los discursos de los participantes emerge el concepto de la tuberculosis pulmonar. El entendimiento de la enfermedad está envuelto de mitos y tabúes, con pronóstico sombrío, causa miedo de contagio, de muerte, pavor, vergüenza, alejamiento, aislamiento social y negación de la enfermedad. Entre enfermeras, hablar de tuberculosis es tema a evitar, es área que causa confusión y miedo. Consideraciones finales: la concepción de la palabra tuberculosis persiste enraizada en conceptos y prejuicios. El estigma social permanece en su esencia y hace perpetuar su concepto negativo, hasta la actualidad.

Descriptores: Tuberculosis Pulmonar. Investigación Cualitativa. Estigma Social. Enfermería.

Introduction

Pulmonary tuberculosis remains an important social health problem on a global scale and remains one of the top 10 causes of death worldwide [1-2]. All countries are affected by this public health situation. Its profile is broadly related to social vulnerability, such as poverty, poor living conditions and health inequities [1-3].

For decades, the Word Health Organization (WHO) has been making efforts to issue guidelines: some directed to the preventive treatment of latent infection, because it represents a large risk of evolution to the disease situation [1] and others, as observed in 2022, in order to make efforts to successfully treat at least 90% of diagnosed cases of pulmonary tuberculosis [2].

Effectively, the objectives proposed by the WHO are to reduce by 2035 the number of deaths from Tuberculosis by 95% and its incidence rate by 90% [4].

Portugal has seen a progressive reduction in the incidence of tuberculosis [4-5]. In 2021, 1,465 cases were reported, which corresponds to a notification rate of 14.3 per 100,000 inhabitants, with an increase in the notification rate in the North region. Portugal remains the Western European country with the highest incidence [5-6].

The success of its treatment depends on several factors that are interrelated with each other and have as a key factor the adherence to the drug regimen. A person-centered approach is one of the factors that enhances adherence to treatment and reduces the risk of abandonment [7-9].

Disease strongly influenced by social determinants and also by the social stigma related to the disease stigma. The social stigma in tuberculosis is described as an indicator of great importance in this relationship and has great impact on non-adherence to drug treatment [1,2,7-8-11].

Pulmonary tuberculosis is described in the literature as a disease that causes physical, economic, moral and even social suffering. Suffering also comes from the stigmatizing character of the disease, which is one of the causes of treatment abandonment [2,7-8-11].

Society stipulates the means that label people, thus placing them in categories. It also defines a set of attributes, which relate to each category. Such attributes, being present in people, associate them spontaneously to a certain category, thus manifesting their social identity, opening the way to social stigma [12].

As a social phenomenon, the stigma related to tuberculosis interferes with the quality of life and well-being of people with the disease [11],

leads to shame, fear of rejection, isolation and social exclusion [12-15].

Stigma is a concept created by the Greeks to refer to bodily signs, through which they tried to show something extraordinary, or bad, about the moral status of those who presented them. Such signs or attributes classify the person as being dangerous or weak, reducing him/her to a spoiled and even diminished person. Such a feature is a stigma [12].

As a social phenomenon and related to pulmonary tuberculosis, stigma interferes with the quality of life and well-being of sick people, promotes shame, fear of rejection, isolation and social exclusion [11-12-15]. It is also described as an important factor influencing adherence and treatment outcome [7-8,10-11,16,23].

Although numerous and diversified strategies for tuberculosis control are identified, the international literature describes them as still insufficient and sometimes ineffective. There is also insufficient evaluation of the social stigma related to the disease and experienced by the sick person, which is described as a potentiating factor of drug abandonment [2-3, 8-11, 15-16, 23].

Speeches of nurses who care for people with tuberculosis report that people affected with the disease suffer mainly from the possibility of experiencing fears, prejudices and taboos emerging from the social concept of the disease, which open the way to isolation and rejection of their social relations in general.

Therefore, it is considered relevant to integrate stigma as a focus of attention of health professionals in the planning and management of health care to users with pulmonary tuberculosis.

Although studies addressing the social construction of the social concept of pulmonary tuberculosis have been identified, after a bibliographic review study, we did not identify any study in this context in Portugal.

The study aimed to describe the social construction of the social concept of pulmonary tuberculosis that, from the perspective of nurses, emerges from concepts based on stigma.

The concept of stigma adopted referred to the situation of the individual who has something that prevents him/her from full social acceptance and related to a highly depreciative attribute [12]. The social stigma in pulmonary tuberculosis is associated with the social construction of the concept of the disease and is related to a mark or derogatory attribute that causes fear, shame, discrimination, social isolation. It causes physical and moral suffering, potentiates the abandonment of treatment and delays in the search for health care [13-14,16,23].

Method

Descriptive, cross-sectional study of a qualitative nature. It is part of a PhD thesis on stigma in people with pulmonary tuberculosis. It took place in Centers for Pulmonary Diagnosis (CPD) in the North of Portugal, in the year 2020 and 2021, in a sample of 12 nurses working in the CPD, having as inclusion criterion: having accepted to participate in the study. Data collection was carried out through a semi-structured interview, following a previously validated script and consisting of two parts: the first with questions related to the identification of socio-demographic and professional data; and the second consisting of four open questions [17,18]: 1) What do you think about pulmonary tuberculosis?; 2) What do users think about pulmonary tuberculosis?; 3) How do users react to the confirmation of the diagnosis of the disease? ; 4) How do you plan the intervention and treatment program for users with Tuberculosis?

Each interview was developed after signing the Informed Consent Form and had an average duration of 40 minutes.

All topics covered were audio-recorded in order to facilitate a sustained and reliable analysis of the contents, avoiding disturbing effects during the dialogue [19].

To ensure anonymity, they were qualified with the letter [E] followed by the assignment of a cardinal number indicating the order of the interview. Any content that could identify the participant or the place of collection of information has been deleted. The interviews were transcribed by an independent transcriber

who was asked to guarantee confidentiality. The full transcriptions were subsequently submitted to content validation by the researcher and the participants.

This article presents the content analysis as a data processing technique in qualitative research from the perspective of Laurence Bardin [20], predicting the three fundamental phases according to the author: pre-analysis, material exploration and treatment of results - inference and interpretation.

At first, the floating reading of the contents was carried out, organizing and defining categories, subcategories and units of record that emerged from the findings, seeking to respect the principles (homogeneity, completeness, objectivity and relevance), listed by Bardin, for the units of meaning [20].

Next, the data were interpreted, seeking to group the content underlying the reports obtained [20]. From the data obtained, emerging from the nurses' discourses, we sought to describe the stigma as the basis of the social construction of the concept of pulmonary tuberculosis.

The study respected the ethical-legal principles and was approved by the Health Ethics Committee of the Regional Health Management of the North, I.P., Porto, under number 021/2019. We used the strategy of informed consent (guarantee of the right to privacy), ensuring anonymity and confidentiality.

Regarding the presentation of the results and the characterization of the socio-professional variables of the sample, the sample was classified according to two age groups (31-14 years and 46 years or more). The intention was to analyze the prevalence of nurses according to gender; academic and professional qualifications; Time of professional exercise in the area of tuberculosis and specific training hours in the area of tuberculosis. This option was based on the results of studies, which identified a hypothetical relationship between being younger or not, level of education, professional and academic training, specific training in the area of tuberculosis, and the perception of stigma related to disease or having or not attitudes towards people with tuberculosis [7,13-14, 21-25, 27-29].

Results

Table 1 shows the socio-professional characterization of the participants, according to age.

Thus, from the analysis of the table, we found that most of the participants in the sample [12] are female (91.7%), registering a slight balance between those who are between 30-45 years and those aged 46 years or more. There is a slight superiority of participants with licentiate (58.3%), more prevalent in the age group of 31-45 years; however, further training (MSc or post-graduation) occurs in 41.6% of the participants, being more prevalent in the age group of 46 years or more.

Concerning the time of professional exercise in the area of tuberculosis, most participants (41.7%) have more than 11 years of exercise in the area, being more prevalent in the 31-45 years age group.

Regarding the training or scientific update in the area of tuberculosis, most of the participants of the two age groups performed more than 50 hours of specific training.

Table 1 – Characterization of the sample under study. Porto, Portugal – 2020-2021. (N=12)

(continued)

	30-45 years		46 years or more		Total	
	n	%	*n*	%	*n*	%
Sex						
Female	6	85.7	5	100	11	91.7
Male	1	14.3	--	00.0	1	8.3
Academic and professional degree						
Licentiate	6	66.7	1	33.3	7	58.3
MSc and/or post-graduation	3	33.3	2	66.7	5	41.7

Table 1 – Characterization of the sample under study. Porto, Portugal – 2020-2021. (N=12) (conclusion)

	30-45 years		46 years or more		Total	
	n	%	*n*	%	*n*	%
Years of professional exercise in the area						
up to 4 years	2	22.2	2	66.7	4	33.3
5 - 7 years	3	33.3	---	---	3	25.0
> 11 years	4	44.4	1	33.3	5	41.7
Training or scientific update in the area of tuberculosis						
8 - 21 hours	--	--	1	14.3	1	23.5
22 - 50 hours	1	16.7	2	28.6	3	23.5
> 50 hours	4	83.3	4	57.1	8	52.9

Source: Created by the authors.

From the discourses of the participants, whose narratives suggest, from the perspective of nurses, that the social concept of the word tuberculosis, currently, still emerges in concepts based on stigma, the category related to stigma as a source of the social construction of the concept of pulmonary tuberculosis was built and analyzed. Three substantiated sub-categories have emerged from this category, each of them by the respective registration units described below:

Social representation of the concept of the word tuberculosis

In fact, in the light of the discourse of the interviewed nurses, the starting points for the perceptions about pulmonary tuberculosis are permeated by fears, myths and taboos related mainly to the historical perspective of the disease.

Nowadays and although pulmonary tuberculosis is a curable disease, it is a disease that scares a lot and carries with it an imaginary belief based on the credulity of those who currently accept it.

The speeches collected reveal that the disease is around a myth and social taboo, even among the youngest. Understanding the disease and its prognosis is bleak and involves fear of contagion and even death. It is a feared disease that limits and subdues people. These aspects are negatively linked to the word tuberculosis, whose negative connotation persists to this day and is supported by the following discourses:

> *The word tuberculosis is very scary* (E3).

> […] *I thought there was already some demystification of this disease* [...] *it is a myth* [...] *after all, it is very common here among these people* (E4).

> […] *no one likes to have tuberculosis, the disease is a taboo* [...] *we have people who are very terrified of the diagnosis, this is normal given the social taboo of tuberculosis* (E6).

> […] *large part of the population, I would say that the reaction is almost like the time of leprosy* [...] *and this is very bad* (E8).

> […] *they [sick person] have this idea: I have this disease, I will probably die.* [...] *pulmonary tuberculosis meant death. This hasn't happened for many years* [...] *it was a very bad word* […] *the word tuberculosis scares* […] *the word tuberculosis is not as tolerated as pneumonia or legionella* (E9).

> […] *the youngest, those aged 25-30, don't know very well what tuberculosis is, it is no longer a disease of their time, so to speak, but they are perplexed when it comes to its treatment and the care to be taken* [...] *we're starting to hear less and less about it, young people commonly speaks: I didn't even know this disease existed.* [...] *many people have never heard of this.* [...] *they often say: this will be my end* (E10).

> […] *there is still that concept of tuberculosis from the past that subjugated and limited people* [...] *people used to go to sanatoriums, be isolated from everyone else* (E12).

The impact of the news of tuberculosis diagnosis

Assuming that the understanding of pulmonary tuberculosis is surrounded by the social construction of its meanings over time, receiving such a diagnosis causes astonishment

and can trigger negative feelings and emotions related to fear and perplexity, in the person with the disease and more sharply in people with higher literacy. These, because it is difficult for them to understand why they have tuberculosis, require explanations about the disease and its forms of contagion, perhaps because the concept of tuberculosis is still strictly related to poverty, poor living conditions, behaviors that still stigmatizes sick people.

However, this behavior is not exclusive to the sick person, nurses also manifest feelings of fear, which supports the difficulty of addressing issues related to the disease.

The complexity of the emotions and reactions related to the news of the disease is drawn in the speeches of the participants from the discourses:

> [...] *some are still stunned and wonder how they got this* (E2).
>
> *There are people, after all, who are very terrified of the diagnosis, such is the stigma that the disease carries* (E6).
>
> [...] *at the first consultation, the patient is frightened by the diagnosis.* [...] *people with more literacy are perplexed* [...] *it's harder for them to understand, they need more justifications: why did I get this, how did I get this? And they even want to understand who transmitted the disease to them* (E7).
>
> [...] *they hear about tuberculosis and are completely terrified* (E8).
>
> *They [sick people] get terrified, ashamed, it* (the disease) *is still seen as a disease of poor people* (E12).
>
> [...] *it's an area that we normally don't approach because it's an area that gets us confused* [...] *it's an area that scares us a lot* (E9).

Person's reactions to the diagnosis of tuberculosis

It should be noted that the reactions to the diagnosis of the disease are directly influenced by the meanings attributed by sick people, being evidenced fear, withdrawal and silencing as immediate responses. People with pulmonary tuberculosis use denial and the concealment of the diagnosis as a way to move away from the social ideology of the disease, perhaps because, at present, the disease is still based on a stigmatizing burden that persists. This behavior is more evident in people with more literacy, as expressed in the following speeches:

> [...] *there are those who say nothing* [...] *they stare at us, quietly, they isolate themselves* (E1).
>
> [...] *in a first consultation* [...] *the most literate people* [...] *have more difficulty accepting the disease, they deny it, they don't want anyone to know* [...] *these reactions are understandable, because it is still a disease with a huge burden of stigma* (E7).
>
> *They* [sick people] *stand still as if in shock, completely silent* [...] *they don't process information very well, they don't feel prepared to accept that they have the disease* [...] *It's the stigma that the disease has, of course* (E8).
>
> [...] *absolutely nothing else entered their mind other than tuberculosis* [...] *they can't even react, they're scared* (E9).

Discussion

The stigma that supports the social concept of the word tuberculosis is, in the light of nurses' discourses, manifested by sick people. It was also identified that the stigma is also perceived by nurses, when expressing that, clearly, there is currently a social stigma related to pulmonary tuberculosis.

It is worth emphasizing that other studies also corroborate our findings [24,25], when they identified that the most participants had the opinion that there was stigma in pulmonary tuberculosis, even more pronounced than in HIV. In summary, health professionals also considered pulmonary tuberculosis a stigmatizing disease and sometimes also feel stigmatized.

Other findings in the literature of studies with people with tuberculosis refer to the awakening of stigma and prejudice related to the disease, causing negative feelings in sick people, because the disease is still currently interpreted as something that causes fear and that distances people from their socio-family relationships [14, 29].

It is unequivocal that the word tuberculosis and the disease itself cause undesirable reactions in sick people and in people who care for sick people, even though they have knowledge about the disease. This finding is also corroborated by other studies [14,27-28]. It was also identified that these reactions are also present in health professionals, despite

their academic and professional training, specific training in the area and time of professional exercise in the area of tuberculosis (Table 1).

As for the stigma in health professionals who provide care to people with pulmonary tuberculosis, findings in the literature [29] report that these health professionals usually face secondary stigma, which can bring to these professions considerable psychological and social consequences, for themselves and for the quality of care they provide [29]. In fact, our study also identified the stigma felt by health professionals, however, we do not have data that allows us to refer to its implication in the quality of care provided.

Regarding stigma in health professionals, convergent findings were identified in other studies which describe the health professionals' fear of tuberculosis [9,24-25]. In addition to being afraid of contracting the disease, they also fear stigmatization by their co-workers. In this particular, it is worth mentioning the relationship referred in the literature between time and professional exercise with people with pulmonary tuberculosis and greater knowledge about the disease [24].

In fact, the relationship between having higher vocational training, higher level of education and even good knowledge about tuberculosis and more positive attitudes or feelings towards tuberculosis and person with pulmonary tuberculosis has been controversial. Moreover, the literature reports that health professionals who received specific training in the area of tuberculosis, regardless of the extent of training, had significantly higher levels of knowledge than their co-workers [24-25].

Nevertheless, if training in the area of tuberculosis and vocational training is a strategy to improve the knowledge of professionals and people in the area of disease [24], in our opinion, this rooting of the social stigma related to the disease identified in our study should not occur. Even because, according to the analysis of Table 1, it is verified that 41.7% of the participants worked in the tuberculosis area for more than 11 years and 52.9% reported having more than 50 hours of specific training in the area. No nurse was identified without any specific training or experience in the area. However, a study in the literature with participants who had good knowledge about tuberculosis and higher education level had positive attitudes towards tuberculosis and had stigma related to the disease. About 63.6% of participants felt compassion and a desire to help people with tuberculosis. However, about 47.1% of the participants reported that they would feel uncomfortable being close to people with pulmonary tuberculosis [29].

Recent data from the General Health Management (GHM) indicate that Portugal is a country where the highest percentage of people (65%) with a 'sufficient' level of Health Literacy was registered at present, of which 5% with an 'excellent' level and only 7.5% of the people were classified with an inadequate level and 22% were classified with a problematic level [4], however, the data of our study do not allow us to know the scope in the area of pulmonary tuberculosis.

Several surveys of nurses providing care in the area of tuberculosis and related to the social stigma related to pulmonary tuberculosis have been conducted worldwide. After a literature review study, we did not identify any study in this area in Portugal.

Our study has some limitations: Although the study and the sample size have been limited to the Northern region of Portugal, we recommend an extended study to the country that can confirm these results or produce new findings.

The strong point of the study is the fact that the research was conducted by the same interviewer, ensuring that all key points of the script were present in all interviews, allowing comparable answers.

Furthermore, the interviews were conducted in the participants' own professional environment at the end of the working day, which may have provided discomfort so that professionals could express their experiences and ideas after a continuous and exhaustive day in the health units that participated in the study.

Final Considerations

From the perspective of nurses, this study allowed us to verify how stigma is the basis of the social construction of the concept of pulmonary tuberculosis. It also allowed us to understand the stigmatizing character surrounding the conception of the disease, which has prevailed for decades and remains rooted today. Nevertheless, it does not exhaust the various aspects of this theme, in both dimension and depth.

This study enabled the identification that the stigma in pulmonary tuberculosis is recognized and even experienced by nurses. Future studies may suggest measures and strategies that enable work environments where stigma is not present, and may contribute to the satisfaction of health professionals.

The stigma in pulmonary tuberculosis remains a reality, which scares, causes fear and shame, isolation, subjugates and limits people, induces the concealment of the disease.

Since it was not possible to identify the influence of stigma, from the perspective of nurses, on the quality of care provided, a door opens to broader studies on the subject.

Understanding this phenomenon invites us to reflect more comprehensively on the social exposure of the sick person and even the health professional. In this way, it is considered appropriate to suggest integrating it comprehensively in the decision-making process when planning person-centered care.

Collaborations:

1 – conception and planning of the project: Maria Isabel Pereira da Silva, Beatriz Rodrigues Araújo, João Manuel da Costa Amado;

2 – analysis and interpretation of data: Maria Isabel Pereira da Silva, Beatriz Rodrigues Araújo, Camila Aparecida Landim Almeida and João Manuel da Costa Amado;

3 – writing and/or critical review: Maria Isabel Pereira da Silva, Beatriz Rodrigues Araújo, Camila Aparecida Landim Almeida and João Manuel da Costa Amado;

4 – approval of the final version: Maria Isabel Pereira da Silva, Beatriz Rodrigues Araújo, Camila Aparecida Landim Almeida and João Manuel da Costa Amado.

Competing interests

There are no competing interests

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