

ORIGINAL ARTICLE

## Social Representations About Family Care to Children with Pulmonary Tuberculosis

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Highlights:

1. The representation of care meant increased zeal.
2. It was highlighted the stimulus to food, promotion of personal and home hygiene.
3. The care also involved the formation of a social support network of the family.

### ABSTRACT

The objective was to know the social representations about family care for children with pulmonary tuberculosis. This is a qualitative, descriptive study carried out in three municipalities in Rio Grande do Sul, Brazil, based on the Theory of Social Representations. Thirteen family caregivers of children undergoing treatment for pulmonary tuberculosis or who underwent treatment in the last five years participated. Data collection took place through interviews. The discourse of the collective subject was used for data analysis. The representation of care meant increased zeal and greater attention because it was a child. It was highlighted the stimulus to food, promotion of personal and home hygiene, concern with health (avoid cold, rain and closed environment), in addition to the administration of the medication and monitoring in health services and during hospitalization. The care also involved the formation of a social support network of the family that provided support and assistance in the care of the child. It was concluded that the family should be more valued by public health policies for its important role in tuberculosis control, being the core for children to achieve a cure.

**Keywords:** Pulmonary Tuberculosis; Children Care; Children; Family; Nursing.

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## INTRODUCTION

Tuberculosis (TB) is caused by the bacterium *Mycobacterium Tuberculosis*. It affects about 30,000 people worldwide<sup>1</sup>. Despite being a disease that can be cured and prevented, it is among the top ten causes of death from a single infectious agent. The 2022 Global TB Report gathered data from 202 countries and territories with more than 99% of the world's population and found that approximately 1.6 million people died from tuberculosis in 2022, including 187,000 people with Human Immunodeficiency Virus<sup>2</sup>. Due to the fact that it persists, its control plans must take into account humanitarian, economic and public health aspects.

In the Americas, Brazil has the highest number of reported tuberculosis cases. The disease killed about 78,000 people in the country in 2022. The World Health Organization (WHO) estimates that one million children fall ill with tuberculosis annually. This accounts for 10 to 11 percent of all TB cases<sup>3</sup>. Despite the availability of modern technologies such as nucleic acid amplification tests (NAAT), diagnosing tuberculosis in children remains a challenge<sup>4</sup>. When compared to adults, it is more difficult to diagnose tuberculosis in children. This is mainly due to some specificities to be taken into account during the research, such as the absence of sputum, as well as the presence of often nonspecific symptoms that can be confused with infections typical of this stage of life. This further weakens the understanding of childhood tuberculosis<sup>5</sup>. Due to the difficulties of microbiological confirmation, the diagnosis of pulmonary tuberculosis in children is difficult and depends on clinical signs, radiological changes, and history of contact with a adult carrying the bacillus and interpretation of evidence of tuberculosis<sup>6</sup>.

Experts in childhood tuberculosis say that the approach to estimate cases may be flawed because it is the same used in adults and depends mainly on microbiological tests, which value this criterion for the diagnosis and notification of the disease. Diagnosis is difficult for health professionals and services and disease control has been neglected by governments, programs and civil society<sup>7</sup>. Many cases in childhood are not identified, which leads to a large number of children dying without receiving a proper diagnosis or treatment<sup>7</sup>. The World Health Organization estimates that in 2016, 12,000 new cases were not identified in Brazil. Of these cases, about 3500 between 0-4 years and 5000 between 5-14 years<sup>8</sup>.

Precarious socioeconomic conditions and contact with intra-domiciliary tuberculosis increase the risk of contagion among children. Exposure to *Mycobacterium tuberculosis* is possible for children who live or spend some time in an environment where there are people with active tuberculosis and are more likely to contract the disease<sup>6</sup>. Due to the lack of knowledge of the evolution of the disease and treatment, families who receive this diagnosis feel insecure and guilty. Treatment causes discrimination and rejection in the family's daily lives, which can lead to isolation, feelings of uselessness and financial dependence<sup>9</sup>.

Nurses must have the knowledge and skills necessary to meet the health needs of the population, with emphasis on the Unified Health System, ensuring comprehensive care, quality and humanization of care. When it comes to caring for children with TB, it is critical to expand their approach beyond the clinic to gain a better understanding of the singularities and subjectivities involved in the care process. The family must be taken into account and included in the illness process so that the children can receive treatment and be cured<sup>10</sup>. In this sense, the objective was to know the social representations about family care for children with pulmonary tuberculosis.

## METHOD

A study was carried out with descriptive qualitative method<sup>11</sup>. The theory of social representations (SR) was the theoretical framework chosen for the execution of the work. This is based on the

social constructions of everyday life, which are socially constructed and in the sense of interpreting, thinking and acting on the reality of common sense. This is the result of various elaborations and changes that have occurred over time and over subsequent generations<sup>12</sup>.

Anchoring and objectification are the two main processes of SR formation by which the subject performs this construction. In SR, anchoring allows the subject to give meaning to the object that presents itself to his/her understanding, giving meaning to this object and being able to relate it to some reference of his/her memory, where the object will be classified. Objectification, in turn, has two functions: naturalization, which brings elements of reality that have meaning; and classification, which allows one to choose between systems of categories, rules of conduct and separation between beings and attributes<sup>12</sup>. The SR is composed of a set of information, beliefs, opinions and attitudes of a social object with a central center. The core is resistant to change, ensuring the continuity of social representation. The peripheral elements, which tolerate contradictions and changes, are organized around it<sup>12</sup>.

The context covered three municipalities of the 3<sup>rd</sup> Regional Health Coordination in Rio Grande do Sul, Brazil. These municipalities had children with pulmonary tuberculosis on treatment or had received treatment during the last five years. During this period, these municipalities contributed to 64% of new cases of tuberculosis and 80% of treatment dropouts in Rio Grande do Sul<sup>13</sup>. As an inclusion criterion, it was adopted that the family caregiver had to be 18 years old or older and provide care to the children with tuberculosis at home. Family members who eventually took care of the child were excluded. To invite them to participate in the study, the State Department of Health provided the researchers with the telephone numbers and addresses of the families.

Prior telephone contact was made with the health services of each municipality to combine data collection. The interviews were conducted in the participants' homes. Data were collected through individual semi-structured interviews in the first half of 2019<sup>11</sup>. A script of questions related to SR on family care for children with tuberculosis was made. Data collections were conducted by the study's principal investigator. The interviews lasted an average of 60 minutes and were audio-recorded for later transcription.

Social Representation was rescued with the use of the Discourse of the Collective Subject (DCS)<sup>14</sup>, maintaining the individual and collective articulated dimensions. In the form of DCS<sup>14</sup>, the Social Representations are close to the opinions of the collectivity of the social actors of the study. In this method, the synthesis discourse is systematized and standardized from excerpts of participants' discourses that have a similar meaning. The implementation of the technique is made possible by the extraction of each of the testimonies of the Central Ideas (CI) or Anchorages, as well as their corresponding Key Expressions (KE). DCS<sup>14</sup> are composed of at least one synthetic discourse similar to CI.

The Ethics Committee of the Federal University of Rio Grande (FURG) and the person responsible for the Technical Area of the State Department of Health of Rio Grande do Sul, Brazil, approved the research through Opinion number 162/2019, in accordance with CNS Resolution number 466/12. The participants' speeches were identified by the letter F (Familiar), followed by the interview number, to ensure anonymity. Participants were given information about the purpose of the study, its justification, its methodology, benefits, risks and the methods by which the results will be disseminated. All participants signed the Informed Consent Form.

## RESULTS

Thirteen family caregivers of children undergoing treatment for pulmonary tuberculosis or who underwent treatment in the last five years participated in the study. Twelve were mothers and one was the child's grandmother. As for age, one was 45, 61, 29, 35, 39, 42 and 43 years old, respectively,

three 29 years old, two 36 and 31 years old. Three were separated, one single, one widowed, eight married. Regarding the level of education, 10 participants had incomplete elementary school, two completed high school and one completed university education. As for the profession, two reported working as a companion, one as a app delivery girl person and a security guard, six were housewives, one general services, one pensioner, one public servant and one elderly caregiver. Regarding family income, seven mothers had an income of two regional minimum wages, four one minimum wage, one less than one minimum wage and one more than five minimum wages.

The SRs about family care for children after becoming ill with pulmonary tuberculosis meant giving greater attention because they were children. As forms of care, they highlighted the encouragement of food, promotion of personal and household hygiene, concern with the prevention of diseases and complications of tuberculosis and the administration of medication treatment. The family's social support network consisted of family members, friends, colleagues, parents' employers and teachers who provided support and assistance in caring for the children.

**Central Idea 1:** One of the main cares for the child involved encouraging his/her eating with the intention of improving his/her health condition.

**DCS 1:** I take care of the food. We pay more attention, try to feed as much as possible. The food I tried to increase, I make her eat it first before taking the medication. He was well fed all the time, with juice and yogurt, fruit. I've always taken care of the food. I would do my best for him to eat, to strengthen himself (F1, F2, F4, F6, F7, F8, F10, F11, F12, F13).

**Central Idea 2:** Family care of children with pulmonary tuberculosis was associated with medication administration during treatment. Thus, the family caregivers encouraged the children by talking about the importance of treatment and taking the drugs to be cured.

**DCS 2:** I gave the right medication, I didn't let it fail. I took care of him; I had to take him every day at the post to take the medication. I always gave it, usually, with a fruit, water, natural juice and I gave the medication. I took care of the medication, I gave it to him. He takes the medication with the yogurt and then eats the food. (F2, F3, F4, F5, F6, F7, F8, F9, F10, F11, F12, F13).

**Central Idea 3:** The care of the children by the family caregivers meant adopting some simple prevention measures based on their understandings to avoid a new illness and even the transmission of tuberculosis.

**DCS 3:** You have to be extra careful. On rainy days I don't send him to school; It's a matter of prevention. I wouldn't let him go outside on a cold day. The person's hygiene, he was always clean. She slept with her sister in a double bed, I moved her to the living room because it is more airy. I tried to leave him at home more at first to recover. (F1, F4, F5, F7, F8, F9, F10, F11, F13).

**Central Idea 4:** Facilities to care for the children were anchored in a formal and informal social support network.

**DCS 4:** My friend, cousin and colleague took care of him. I always had a lot of support from my family and my boss. The Neighborhood. The father also took him to take his medication. My mother-in-law helped me a lot, my sister and my brother-in-law. The school principal and teachers supported me. Family support. My mother-in-law took care of her all the time. The health center, the nurses. Her aunts helped a lot. My family supported me all the time (F1, F2, F3, F4, F5, F6, F7, F8, F9, F10, F11, F12, and F13).

## DISCUSSION

The representations attributed by family caregivers of children with tuberculosis to care and the way they provide it are influenced by the Theory of Social Representations. Family members' SR knowledge about care is based on their personal experiences of caring for someone<sup>15</sup>. From a

cross-sectional study conducted in Mexico City on the profile of caregivers of children with chronic diseases, it was concluded that caregivers have psychosocial characteristics that need more attention. Therefore, strategies are necessary to combat adversities, risks and vulnerabilities, since the care of the ill child demands affection, love, zeal and acceptance<sup>16</sup>.

The SR on family care for children with TB showed that the family gives greater attention because it is a child. Children with TB need specific care to cope with the disease and ways to prevent others in the family from becoming infected. In addition, the family is concerned about the possibility of the child suffering discrimination because it is a contagious disease. Thus, talking about the disease in the community and health services is challenging and complex, as it can make it difficult to receive support and welcoming in social relationships<sup>17</sup>.

We observed SRs of family caregivers on the need for a redoubled care of the child and a clean and ventilated environment with promotion of personal hygiene of the child and the home. In addition, they talked about how to protect the child from exposure to rain and cold to avoid complications and worsen his/her health already compromised by tuberculosis. To prevent tuberculosis, the role of the environment is crucial. If there is no bacillus, there is no tuberculosis. Rapidly identifying tuberculosis patients and providing treatment reduces the likelihood of airborne contamination and, if there is no airborne contamination, prevents transmission of the bacillus to others<sup>18</sup>.

The SR of care was associated with the change of habits for the children and the family to improve their health. Caregivers cared about feeding their children better, encouraging them to drink more water, yogurt, and fruit, and keeping them away from rain, cold, and serene, according to current research results. For family caregivers, SR involving the care of children with pulmonary tuberculosis meant worrying about food. Research revealed that families are responsible for feeding the children, providing food and stimulating food<sup>19</sup>.

The SR of these family caregivers on the importance of ventilating and aerating the environment as a basic measure of tuberculosis prevention is based on the scientific point of view. This simple transmission control measure is based on the principle that the greater the removal of particles from the environment, the lower the risk of tuberculosis infection<sup>18</sup>.

The study pointed to a link between tuberculosis and poverty due to conditions of social vulnerability. Therefore preventing tuberculosis involves improving social and housing conditions to decrease the chance of contagion. If there are many people sleeping in the same room, in poorly ventilated homes and where the sun does not shine, the risk of transmission is much higher<sup>18</sup>.

In the present study, the SR of family caregivers in this study included administering self-administered medications to children and accompanying them to the health service. The responsibility for administering medication treatment or taking the child to the health center to receive daily medication rests with each family. In a study conducted in Peru, it was demonstrated that adherence to tuberculosis treatment is an extremely important factor, and that it suffers from difficulties. Some factors such as the offer of therapy directly observed at home, the reduction in the number of pills, the provision of guidance on the need to adhere to treatment and the strengthening of caregivers' capacities in relation to child support contribute to treatment and cure<sup>20</sup>.

SR was found to be concerned with the prevention of tuberculosis diseases and complications. The support and care of the family, as well as the necessary attention, food and assistance in the routine were considered actions for the prevention of TB. Family caregivers also described these data as essential care for the children, so that the family can act effectively in the prevention of tuberculosis and its complications, specific health education actions are necessary, allowing the reduction of cases, minimizing its damage<sup>21</sup>.

In this study, the SR about the family's social support network for children care showed that it was made up of family members, friends, colleagues, parents' employers and teachers who provided support and assistance in children care. A social support network was formed by the family members themselves, as well as by friends, colleagues, neighborhood, parents' employer, teachers, school management and health professionals, who helped the children after becoming ill with pulmonary tuberculosis. Through support and permanence with the children, monitoring to the health unit for treatment and regular consultations, the network helped the children to recover in the hospital and at home.

A study showed that the family needs a social support network to help in this care. Family caregivers found support from the extended family, which contributed with physical and emotional resources to maintain the health and balance so necessary in this moment of restructuring<sup>22</sup>. Research highlighted findings regarding the presence of sources of support in children health care, such as family (husband, children, grandparents, uncles and siblings), institutional (school, nephrology service, health system) and spiritual environments. However, the absence of sources of support by some caregivers was also highlighted, which generates an impact in terms of overload of daily care<sup>23</sup>.

Other sources of support, such as formal or informal social networks, arise as a response to changes in family dynamics when a child becomes ill, as they can provide resilience and strengthening for the challenges imposed by the disease<sup>24</sup>. The SR on the support network for caregivers of children with tuberculosis meant care and mutual support to the child's family.

The ways in which SRs are imposed and transmitted are not always related. Thus, they are the result of many modifications and elaborations that have occurred over the years and over subsequent generations<sup>15</sup>. To assist in the patient care process, evaluation of the social support network should include protective factors, increase treatment adherence, and allow for complete patient- and family-centered care<sup>25</sup>. A study that examined the support networks of families for the care of children with cerebral palsy pointed out that they provide emotional, financial support, transportation, medications and guidance of health/nursing professionals<sup>26</sup>.

In a study that examined how social support for families of children with congenital heart disease affects their quality of life, it was found that favorable socioeconomic conditions and adequate social support are factors that positively impact the quality of life of caregivers. The study pointed out that increasing social network and social support, as well as strengthening existing connections, can help identify mental health problems earlier and alleviate the problems caused by the child's disease<sup>27</sup>.

The families' need for social support is dynamic and changes with the child's treatment and growth. At more critical times, the need for support is greater, but decreases when the disease is more controlled. For social support to be effective in the lives of these families, it must meet their expectations; otherwise, it can be perceived as absent or negative<sup>27</sup>.

In this study, nurses were praised for helping families throughout treatment and caring for children with humanization. They also praised the treatment and attention the nurses gave. Some guardians said that the children liked to go to appointments because the nurses cared for them well. To increase knowledge about childhood tuberculosis in mothers, nurses used a virtual informational approach that was more effective than the conventional educational approach<sup>28</sup>. Nursing professionals have the responsibility to teach caregivers and families so that they have the knowledge and skills necessary for care practices.

The study on the approach of nurses to people with tuberculosis showed that assistance was based on actions such as visits, general guidelines, educational activities, treatment monitoring, consultations, medication orders and test requests, among other things<sup>29</sup>. It is verified that they play an important and participatory role that extends from anamnesis, physical examination, monitoring and guidance on medication therapy, as well as how to organize care against tuberculosis in homes.

## FINAL CONSIDERATIONS

The study aimed to know the social representations about family care for children with pulmonary tuberculosis. For family caregivers, the SR of the care given to the child meant increased zeal and greater attention because it was a child. As forms of care, we highlight the encouragement of food, promotion of personal and home hygiene, concern with health (avoiding cold, rain and the closed environment), in addition to the administration of the medication and monitoring in health services and during hospitalization. The care also involved the formation of a family social support network consisting of family members, friends, colleagues, parents' employers and teachers who provided support and assistance in caring for the child.

This study showed the importance of the care given to the children by the family caregivers. Without the care practices adopted, with increased zeal, encouragement of food and treatment, monitoring of the health service, it would not be possible to achieve a cure for tuberculosis. The family was responsible for the adherence to the child's treatment; the family took direct care of the child from the diagnosis until the moment of cure, prepared the best food for the child, encouraged him daily to take the medications and was present in the difficult moments.

Based on the data, it was considered that illness due to tuberculosis presents itself as a transforming and multifaceted event of family dynamics. It is considered necessary to value more the role of the family in this conjuncture as a way of also exercising control of the disease, since the family has the main role of acting in the scope of the treatment of the child.

The study data pointed to the need for the family to be informed about tuberculosis, oriented about the manifestation of symptoms, etiology of the disease, form of transmission, treatment, general care and even the demystification of some protective behaviors that the family caregivers adopted, such as the separation of household utensils and rooms, which significantly contributed to the permanence of stigma. Health services and professionals must ensure the inclusion of the family and the care practices exercised by them as potentiating tools for tuberculosis control.

It was concluded that the family was the core so that the children could reach the cure. Support and dialogue with families need to be prioritized from the moment they enter the health system through primary care and travel countless paths within the service network until they find the resolvability of their needs

It should be mentioned as one of the limits of this study the field of research itself, the territory where families of children with tuberculosis live is marked by unfavorable socioeconomic conditions, in which situations of violence, assaults, trafficking zones, prostitution and dominance of criminal factions are found. Thus, the researcher's safety was compromised and she was not always able to count on the help of Community Health Agents, since some Health Units were not a Family Health Strategy (FHS) modality and, therefore, do not have this professional in the team.

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