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## **THERAPEUTIC ITINERARY REVEALED BY THE FAMILY MEMBERS OF INDIVIDUALS WITH MESOTHELIOMA: MULTIPLE CASE STUDIES**

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### **ABSTRACT**

**Objective:** to describe the therapeutic itinerary revealed by the relatives of individuals with mesothelioma.

**Method:** a multiple case study with a qualitative approach. Six family members of the cases occurred in the state of Paraná (Brazil). Data was collected from medical records and interviews between January and July 2016 and submitted to comparative and content analysis, supported by the Health Care System framework.

**Results:** seven categories emerged from the data: Acknowledgment of the illness; Popular care and the attempt to escape from the illness; The popular subsystem directs to the professional subsystem; Professional subsystem: unraveling the mystery of the disease; Family: care supremacy; Religion: hope and encouragement; and Disease due to mesothelioma from the perspective of the family member.

**Conclusion:** the therapeutic itinerary was built from early symptoms detection and common sense practices. The family was the central unit of care; the professional subsystem, with the challenge of diagnosing the disease, and religion, which represented the person's and family members' hope. Studying the topic can contribute to improve the planning of the health actions promoted to individuals with mesothelioma, from the diagnosis process, treatment to death.

**DESCRIPTORS:** Attitude to health. Mesothelioma. Family relationships. Health care. Case studies.

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# ITINERÁRIO TERAPÊUTICO REVELADO POR FAMILIARES DE PESSOAS COM MESOTELIOMA: ESTUDOS DE CASOS MÚLTIPLOS

## RESUMO

**Objetivo:** descrever o itinerário terapêutico revelado por familiares de pessoas com mesotelioma.

**Método:** estudo de casos múltiplos com abordagem qualitativa. Participaram seis familiares dos casos ocorridos no Estado do Paraná (Brasil). Os dados foram coletados em prontuários e por entrevista entre os meses de janeiro a julho de 2016 e submetidos à análise comparativa e de conteúdo, sustentado pelo referencial do Sistema de Cuidados à Saúde.

**Resultados:** dos dados emergiram sete categorias: Reconhecimento do adoecer; Cuidados populares e a tentativa de escapar do adoecimento; Subsistema popular direciona ao subsistema profissional; Subsistema profissional: o desvendar do mistério da doença; Família: supremacia do cuidado; Religião: esperança e alento; e Adoecimento por mesotelioma sob a ótica do familiar.

**Conclusão:** o itinerário terapêutico foi construído a partir da detecção dos primeiros sintomas e das práticas baseadas no senso comum. A família foi à unidade central do cuidado; o subsistema profissional, com o desafio de diagnosticar a doença, e a religião, que representou a esperança da pessoa e dos familiares. O estudo da temática pode contribuir para a melhoria do planejamento das ações em saúde promovidas às pessoas com mesotelioma, desde o processo de diagnóstico, tratamento até a morte.

**DESCRIPTORIOS:** Atitude frente à saúde. Mesotelioma. Relações familiares. Assistência à saúde. Estudos de casos.

# ITINERARIO TERAPÉUTICO INFORMADO POR FAMILIARES DE PERSONAS CON MESOTELIOMA: ESTUDIOS DE CASOS MÚLTIPLES

## RESUMEN

**Objetivo:** describir el itinerario terapéutico informado por los familiares de personas con mesotelioma.

**Método:** estudio de casos múltiples con enfoque cualitativo. Participaron seis familiares de los casos registrados en el estado de Paraná (Brasil). Los datos se recolectaron en expedientes médicos y por medio de entrevistas entre los meses de enero a julio de 2016 y se los sometió a análisis comparativo y de contenido, sustentado por el marco referencial del Sistema de Cuidados de la Salud.

**Resultados:** de los datos surgieron siete categorías: Reconocer la enfermedad; Cuidados populares y la tentación de escapar de la enfermedad; El subsistema popular direcciona al subsistema profesional; Subsistema profesional: aclarar el misterio de la enfermedad; Familia: la supremacía del cuidado; Religión: esperanza y aliento y La mesotelioma desde la perspectiva del familiar.

**Conclusión:** el itinerario terapéutico se construyó a partir de detectados los primeros síntomas y de las prácticas basadas en el sentido común. La familia fue la unidad central del cuidado; el subsistema profesional, con el desafío de diagnosticar la enfermedad a su cargo y la religión, que representó la esperanza de los enfermos y de los familiares. Estudiar la temática puede ayudar a mejorar la planificación de las acciones en salud promovidas en las personas con mesotelioma, desde el proceso de diagnóstico, pasando por el tratamiento y hasta el momento de la muerte.

**DESCRIPTORIOS:** Actitud frente a la salud. Mesotelioma. Relaciones familiares. Asistencia a la salud. Estudios de casos.

## INTRODUCTION

Mortality due to mesothelioma is a public health problem. According to a study published by the World Health Organization (WHO) in 2011, mortality from mesothelioma reached 92,224 people in 83 countries.<sup>1</sup> In Brazil, cases of disease underreporting do not show the reality of the illness and of deaths due to mesothelioma.<sup>2</sup> In this regard, an epidemiological study conducted in southern Brazil found that hospital data on mesothelioma present inconsistent information and misleading coding. This result confirms the importance of disease-specific records.<sup>3</sup>

According to the available data for Brazil, malignant mesothelioma occurrence is predicted until 2030, with a peak of growth between 2021 and 2026. In 2012, the Brazilian Mortality Information System released 2,123 reports of deaths from malignant mesothelioma in the period from 2000 to 2010.<sup>4</sup>

Regarding the cancer disease problem in general, access and use of the health systems constitute a problem for the Brazilian population, and several factors may hinder the trajectory of the demand for cancer care, considering the waiting time and availability of the high complexity procedures.<sup>5</sup>

Mesothelioma is a rare, insidious cancer with a risk factor related to asbestos exposure.<sup>6</sup> This cancer affects mesothelial cells and cases are evident in the layers lining the lung (pleura)<sup>7</sup> peritoneum,<sup>8</sup> pericardium<sup>9</sup> and testicular vaginal tunic.<sup>10</sup> The most common type of mesothelioma is the pleura<sup>1</sup>, followed by the peritoneal.<sup>8</sup>

This cancer has peculiar characteristics with a high latency period.<sup>11</sup> It is usually diagnosed at an advanced stage, with ineffective treatment, and the survival from diagnosis is 12 to 17 months for pleural mesothelioma<sup>12</sup> and four to nine months for the peritoneal.<sup>8</sup>

Mesothelioma is a disease involving exposure to asbestos, also known as earth-flax, considered as the main cause. Asbestos is a mineral with a high carcinogenic potential. It is especially used in the fiber cement industry in the production of tiles and water tanks.<sup>2</sup> And, since mortality from fiber exposure is increasing, 55 countries opted to ban the use of asbestos;<sup>13</sup> however it is widely used mainly in Brazil, China and Russia.<sup>14</sup>

Under these conditions, the risk is documented and, even with knowledge of the harms of exposure, the WHO estimates that 125,000 people remain exposed to fiber in their workplace and, according to the International Labor Organization (ILO), about 19,000 people die each year from exposure.<sup>1</sup> It is noteworthy that the risk of contact goes beyond the occupational environment by easy fiber propagation by air and the risks extend to general population, since most Brazilian homes contain fiber cement products in their construction, which extends the danger.<sup>2</sup>

In this sense, when dealing with mesothelioma and predicting the possibility of this disease affecting the Brazilian population in the coming years, this study followed this research question: how did the therapeutic itinerary revealed by the family member of the person with mesothelioma occur? The objective was defined as follows: to describe the therapeutic itinerary of people with mesothelioma.

To understand the path taken by the individuals in the search for health care, this research was associated with the theoretical referential of the Health Care System,<sup>15</sup> proposed by psychiatrist and anthropologist Arthur Kleinman. This framework allowed understanding the therapeutic itineraries chosen by the people in health care.

The Health Care System is socially and culturally constructed and consists of the interaction of three distinct subsystems: the professional represented by the institutions formally legitimate for health care and the health professional; the folkloric characterized by healing specialists, but without official regulation such as folk healers, shamans, priests and others; and the popular represented by non-professional people who are close to the patient, such as neighbors, friends and family. Therefore,

the subsystems may have explanatory models about cause, treatment, evolution and prognosis of a given disease.<sup>15</sup>

In this respect, anthropology uses the term therapeutic itinerary, which compounds a complex particular dynamic.<sup>16</sup> The path taken to seek treatment comes from the way people view their health and disease process, and in the social and cultural context into which they are inserted.<sup>17</sup> The family is the essential structure for early health care. The decision to seek professional care is supported by the family and its interpretation of health/illness.<sup>15</sup>

## METHOD

The method used in this research is that of a multiple case study,<sup>18</sup> with a qualitative approach,<sup>19</sup> and the theoretical framework of the Health Care Systems,<sup>15</sup> held from January to July 2016. This study case consists in investigating a contemporary phenomenon - the case - as part of real world, especially when phenomenon and context are not clearly evident. This research method allows for the use of various data sources to incorporate evidences.<sup>18</sup> For the construction of the cases in the present research, two data sources were accessed: documentary records of the co-participant institution and family members' reports.

For selecting the participants - units of analysis/cases - records of a health institution specialized in cancer care, in the state of Paraná, Brazil, were used. Sixteen cases of people diagnosed with mesothelioma were identified from 1993 to 2013, of which six family members agreed to participate in the study. The first access to the families occurred through a telephone contact. Subsequently, an individual interview was conducted at a location determined by the family members, according to their availability, among the residence, the work place and public places. For the anonymity of the participants the following coding was used: the letter P representing the person with mesothelioma, followed by Arabic numerals, as they were incorporated into the research, and the letter F representing the family member (family member 1 corresponds to person 1 and thus sequentially in ascending order).

For data collection, the face-to-face interview technique was used, with a semi-structured script, and four central questions elaborated by the researchers: 1) Could you tell how the first symptoms of the disease occurred? 2) Could you tell how the disease was discovered? 3) How was the trajectory you went in searching for treatment? and 4) How did your family member (person with mesothelioma) proceed to take care of your health? The interviews were recorded in audio form, in a digital recorder. Afterwards, they were transcribed and sent to the family members for any necessary corrections. There was no return from the family members.

Data presentation was followed by the replication of the cases using the following stages: definition and planning; preparation, collection and analysis, with preparation of individual case report; analysis and conclusion with cross-case report<sup>18</sup> related to the Care Systems framework<sup>15</sup> and implications, hypotheses and conclusions were also developed.

For data analysis, comparative analysis was used, which analyzes data two or more times by comparing them to the descriptions or alternative explanations of the same case,<sup>18</sup> and categorical content analysis<sup>20</sup> following these stages: analysis organization, with pre-analysis, material exploration, treatment of results and interpretations; coding and categorization.

The present study followed the ethical precepts, according to the National Health Council Resolution number 466/12.

## RESULTS

The sociodemographic characterization and exposure data are described in Table 1. The individual cases and reports representing the units of analysis will be presented sequentially. Table 2 represents the clinical characterization of the units of analysis built to compose the case study.

**Table 1** – Sociodemographic characterization and exposure to risk factors of the six cases of mesothelioma. Curitiba, PR, Brazil, 2016

	Unit of analysis					
	P1	P2	P3	P4	P5	P6
Age	69	44	62	56	63	56
Gender	Female	Female	Male	Male	Male	Male
Race	White	White	White	White	White	White
Marital status	Widow	Single	Married	Married	Married	Married
No. of children	02	-	02	04	03	03
Religion	Catholic	Catholic	Catholic	Catholic	Catholic	Catholic
Schooling	High School	High School	High School	Elementary School	Elementary School	Elementary School
Profession	Retired Professor	Autonomous	Retired	Merchant	Autonomous	Merchant
Origin	Rio Grande do Sul/BR	Paraná/BR	Paraná/BR	Paraná/BR	Paraná/BR	Paraná/BR
Procedence	Paraná/BR	Paraná/BR	Paraná/BR	Paraná/BR	Paraná/BR	Paraná/BR
Comorbidities	No	No	Bipolar Disorder	No	No	No
Known exposure to asbestos	No	No	Yes	No	No	No
Exposure to known carcinogenic agents	No	Tobacco	Tobacco	Agrotoxic/ Occupational tobacco	Tobacco, ethylic alcohol Caustic soda and solvent/ occupational	Passive Smoker

**Table 2** – Clinical characterization of the units of analysis built in the study case. Curitiba, PR, Brazil, 2016

Variables	Units of analysis					
	P1	P2	P3	P4	P5	P6
Clinical diagnosis	Unresectable peritoneal mesothelioma	Pleural mesothelioma	Pleural mesothelioma	Pleural mesothelioma	Pleural mesothelioma.	Peritoneal mesothelioma
First symptoms	Back pain and feeling of gastric fullness	Back pain and fever	Stomachache and cough	Persistent cough	Vomiting with bleeding	Increased abdominal volume and weight loss
Examinations performed	Abdomen ultrasound	Chest CT Scam	Chest X-ray	Chest X-ray	Chest X-ray	Video laparoscopy followed by biopsy

**Table 2 – Cont.**

Variables	Units of analysis					
	P1	P2	P3	P4	P5	P6
Time between first symptoms and diagnosis	Three weeks before diagnosis	Five months before diagnosis	Nine months before diagnosis	Eight years before diagnosis	Three years before diagnosis	Three months before diagnosis
Access to Health Facility	Attended at three health institutions	Attended at six health institutions	Attended at five health institutions	Attended at four health institutions.	Attended at two health institutions	Attended at four health institutions
Time between diagnosis and death	Four months	Two years	Five months	Five years	A year and a month	One year and three months

The underlying disease is pleural mesothelioma in three men and one woman, and peritoneal in one man and one woman. Their age ranged from 44 to 69. The diagnosis occurred between 2005 and 2013. Only one case with occupational exposure to asbestos was confirmed by the family member and the data recorded in the medical record. All the cases were confirmed as mesothelioma after the biopsy, with a pathological examination. The survival rate after the diagnosis ranged from four months to five years. All were assisted at least in two and/or more health institutions since the beginning of investigation and treatment process.

The family members traced the therapeutic itinerary of the individuals with mesothelioma and the data were consolidated into seven thematic categories, presented below:

### Category 1 – Acknowledgment of the illness

To start the construction of the itinerary it is necessary to acknowledge the illness. This category presents the moment when family members reported the first manifestations of the disease, which included back pain, feeling of gastric fullness, fever, cough, vomiting with bleeding, weight loss and increased abdominal volume. Such symptoms are revealed by the family members as shown in the speeches from relatives 3 and 5.

*He started with a stomachache and weight loss. He lost pounds and lost weight very fast (F3).*

*He [person with mesothelioma] vomited pure blood, I saw a ball of blood falling. [...] he vomited about three liters of blood, and he lost weight (F5).*

### Category 2 – Popular care and the attempt to escape from the illness

In this category it is observed that people seek to solve their health problems with measures to alleviate discomfort. The speeches of the family members show the singular actions of the first health care practices, supported by common sense knowledge. One of the things done by the individuals, and guided by family and friends, was allopathic self-medication, with medications like paracetamol, omeprazole and the use of medicinal plants (herbal medicine), such as *Aloe Arborenses* popularly known as aloe, production of homemade syrups made from lemon, pineapple, bee honey and propolis. Such practices were performed before the diagnosis and understood as beneficial to health.

*Before my sister discovered the disease, she took medication on her own, just to relieve the symptoms of fever and pain, but on her own, no one prescribed it for her. She would come to the pharmacist and say: 'Give it to me!' And she bought it, and drank it (F2).*

*The aloe-based home remedy was made, and it helped my father a lot. My aunt searched in magazines and on the internet. It's been a long time since we know that aloe has benefits. I believe in natural medicine (F4).*

### **Category 3 – The family directs to the professional subsystem**

The family is the first reference of care for people diagnosed with mesothelioma and, when they identify the persistence of the symptoms and after the ineffectiveness of the care measures adopted, advise that it is essential to look for the professional subsystem to investigate and control the disease effectively, observed in the speeches from Family member 3 and Family member 5.

*I told him, let's do the exams, let's do other exams, and there was no result. His pain continued, and I took him to the pulmonologist, and said: Let's investigate (F3).*

*Watching him lose weight, it started to bother me. The doctor had the stomach checked and there was no results. One day he got up coughing, and I said: Look, please, you go to the doctor today. He went to the ER (F5).*

### **Category 4 – Professional subsystem: unraveling the mystery of the disease**

The professional subsystem has the challenge of confirming the diagnosis, with the pilgrimage in seeking answers. Between comings and goings, and with much insistence from the family members, the symptoms are interpreted and the cancer diagnosis is confirmed. In this unveiling, they involved the diagnosis's difficulty with the implication of constant returns to the professional subsystem, imaging (radiography, tomography, ultrasonography), laboratory and complementary practices (endoscopy, colonoscopy, video laparoscopy). How did Family member 5 and Family member 6 share the revelation of the cancer diagnosis?

*When he [person with mesothelioma] arrived at the hospital with a cough, the doctor said: let's do a lung x-ray to see it. The doctor was terrified, but said nothing to him about cancer, and then said: We'll have to hospitalize you! and he did several tests, and all detected the tumor (F5).*

*I [person with mesothelioma daughter] took him [person with mesothelioma] to the emergency room, and they did the exams. I followed everything, but nothing showed up on exams. And then they did a video laparoscopy; and the doctor said: Your father is full of lumps, his peritoneum has numerous lumps. And I was in shock (F6).*

### **Category 5 – Family: care supremacy**

Once the diagnosis of mesothelioma is confirmed, therapy is instituted and the family members played a fundamental role in the care provided to the sick person. In the following excerpts it is possible to exemplify them:

*He [person with mesothelioma] stayed lying in one position, and we had no waterbed. The nurse staff and the social worker from the basic health unit came once a week. I did the rest, and had to do the same, bath in the bed. And even my father was helping (F3).*

*She [person with mesothelioma] couldn't get out of bed, I had to carry her to bathroom. She had no strength in her legs to walk, and in this integral care was me and my daughter (F2).*

### **Category 6 – Religion: hope and encouragement**

The family members and the people with mesothelioma seek in spirituality/religiosity the strength to cope with the disease. And it can be understood as a source of maintaining life integrity. People found a hope for healing in faith.

Religion and religious practices are determining influences, and prayers and promises are attitudes that show encouragement, both to cope with the illness and to seek the cure. Thus, as the following speeches show, believing in the divine is the encouragement. And the promises made to achieve the cure are evidenced along the way.

*We had a lot of faith that she could make it, we prayed novenas. She had a lot of faith. In the parish in Copacabana there was a priest who died at 33 and my uncle brought a little piece of his clothes, and you cling to it, and as my uncle said: miracles are always possible (F1).*

*When his father became ill, he sought help from the Evangelical Assembly of God church. They visited us and we started to say a lot of prayers (F6).*

## **Category 7– The mesothelioma illness from the perspective of the family member**

The family members faced challenges in living with the person diagnosed with mesothelioma. Experiencing the illness with a low perspective of cure promoted reflections on the disease and on the care from the professional subsystem health. The difficulty in confirming the diagnosis, communicating the aggressiveness of the disease and the survival time was reported by the medical professional, as shown in the following interview excerpt:

*It has been found that he [person with mesothelioma] had malignant mesothelioma. The doctor called my aunt and we became aware of the situation. The doctor said: his case is serious, and if we perform surgery he will have a maximum of two months to live (F4).*

*When he [person with mesothelioma] went to the hospital he had no further treatment with good result. Few resources were offered to him. This disease is very ungrateful (F3).*

And from the family member's point of view, the pilgrimage through the professional subsystem results in suffering, as described by Family member 2.

*Difficulty dealing with the human being. You search and don't find an answer. She went to one, two doctors, and none could make a diagnosis. [...] she was still feverish. You go to a professional, look for another professional. You look for one health institution, look for another. I think this late diagnosis makes you suffer (F2).*

And Family member 3 confirming the importance of a more consistent investigative process.

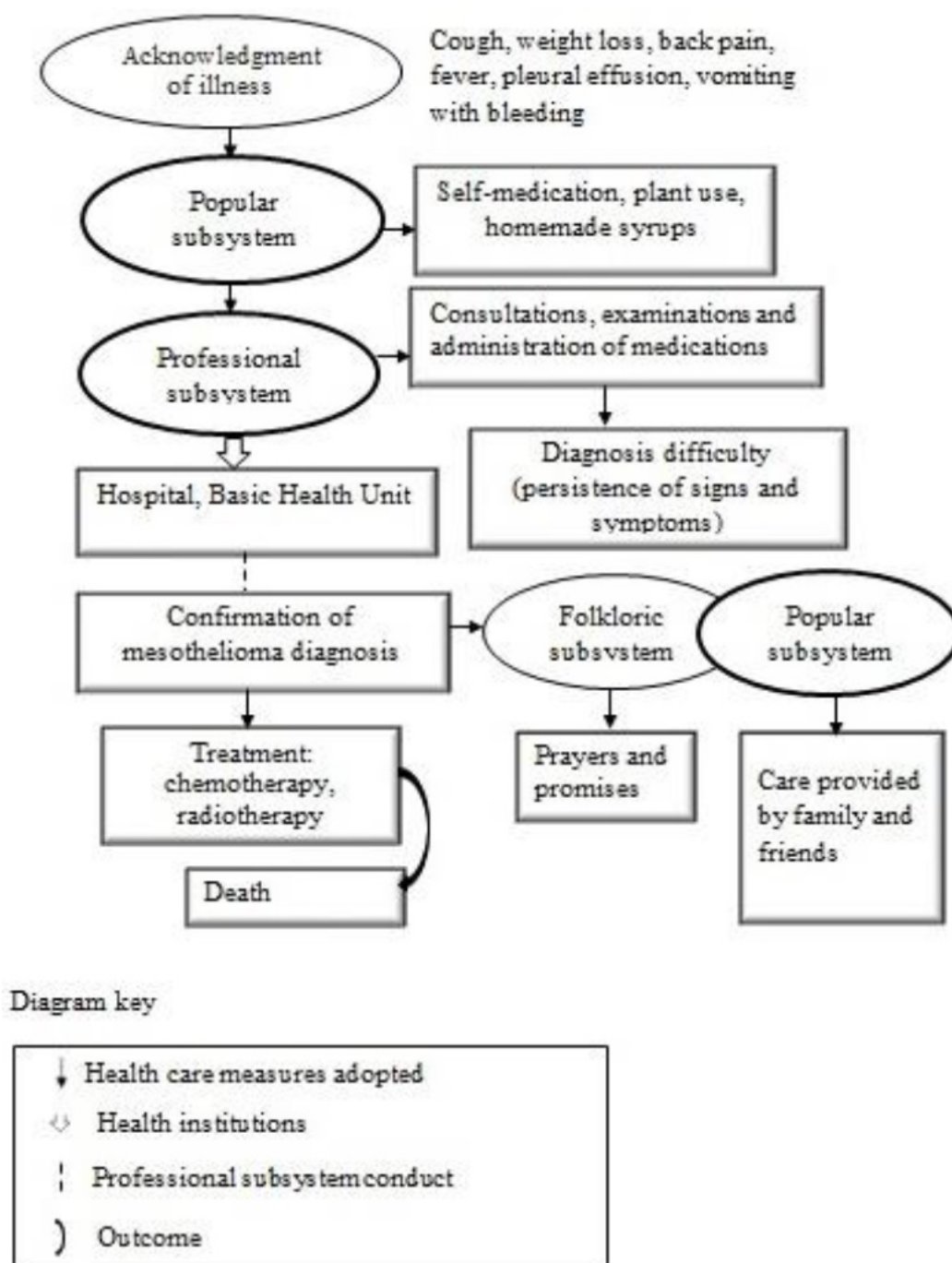
*It was a long time to find it out, and when discovered it was a big surprise. I believe that if you have a pain you need to investigate, and you can discard a more serious disease, or even treat the disease in the beginning. The first time he [person with mesothelioma] went for endoscopy they also did a blood test (F3).*

The categories present the construction of the therapeutic itinerary with identification of the three health care subsystems, according to the proposed theoretical framework. Figure 1 represents the trajectory taken by the individuals with mesothelioma according to the disclosure of the family member.

## **DISCUSSION**

The disease is a common phenomenon in people's lives, but the social, cultural and psychobiological aspects are crucial for coping with the disease.<sup>21</sup> In this study, the underlying disease was mesothelioma in two women and four men. The case in women under 55 suggests that the environmental exposure to asbestos may be one of the risk factors in the disease's development.<sup>22</sup> The causal link was not confirmed in this study because the family members did not have this information and there was no record in medical chart.

Regarding the age group, the individuals with mesothelioma were between 44 and 69 years old. The mean age of the people at diagnosis can range from 62<sup>23</sup> to 73 years old.<sup>24</sup> This is attributed



**Figure 1** – Diagram of the health care subsystems for individuals with mesothelioma.

to the latency period, so there are cases in which the disease takes a long time to manifest the first symptoms, especially those involved in the exposure to asbestos.<sup>25</sup>

The interpretation of health and disease is built on each person's experience. The family members built their way of living the first experiences with the person with mesothelioma and the signs and symptoms presented. Therefore, the acknowledgment of the illness happens from the moment the disease assumes its visible character. In the case of pleural mesothelioma, dyspnea, hemoptysis, pleural effusion, and chest pain are reported to be common.<sup>26</sup> And in the cases studied, other symptoms such as vomiting with bleeding and stomachache were reported. Pleural effusion is indicative of the disease and about 80% present this change before diagnosis.<sup>27</sup>

In cases of peritoneal mesothelioma, the first symptoms reported were abdominal distension, feeling of gastric fullness and back pain. The most peculiar symptoms of the disease are the following: formation of ascites, abdominal pain and odynophagia.<sup>26</sup> In this sense, recognizing the disease is fundamental for the beginning of treatment searching.

The popular subsystem is represented by family and friends, they are recognized as the first care unit during the health and disease process. One of the first practices adopted is self-medication. Brazil ranks first among the Latin American countries that use this alternative.<sup>28</sup> About 35% of medications consumed in the country are due to self-medication.<sup>29</sup> Another measure found in the popular subsystem was the use of the *aloe arborenses* (aloe) medicinal plant. This plant is widely used among cancer patients and also for the healing of skin lesions.<sup>30</sup> In this study, such practices were adopted before the individuals were diagnosed with mesothelioma.

The family is the support for the person during the illness process. This recognition is essential, as the professional subsystem needs to understand the importance of the family in the context of cancer care.<sup>31</sup> In this aspect, the family members drive the person to search for the professional subsystem. It is easily assumed that health care is indicated by the family members, and generally one of them takes the lead in care and decisions, determining the path to follow as soon as the symptoms are identified and persist.

In the context of the health care offered by the family members, all the individuals diagnosed with mesothelioma had the active follow-up of one or more family members and also the help of friends. They play a key role during treatment.<sup>32</sup> The family gives the necessary attention and care to the person.<sup>33</sup>

The family member has many responsibilities in caring for the person with cancer, such as personal hygiene and feeding.<sup>34</sup> In the reality of this study, people received care from the family members throughout the disease process, even though they were being assisted by the professional subsystem and receiving the conventional treatment such as chemotherapy and radiotherapy. Despite the targeted professional assistance, the family members face difficulties, especially when the person needs prolonged hospitalizations, causing changes in the family dynamics.<sup>35</sup>

In this study, the home was the place where the person spent most of the time during illness and treatment. The home residence is the ideal environment for the care of people with terminal diseases, since staying with the family is the way to maintain the ties with their origin.<sup>36</sup>

It is known that the professional subsystem carries the challenge of unraveling the disease and one of the problems that permeates the disease due to mesothelioma is the difficulty of early diagnosis reported by the family members. Such inferences can be found in studies on the general cancer landscape, where the cure rates are considerably reduced in cases of late diagnosis.<sup>37</sup>

The individuals with mesothelioma sought the professional subsystem during the onset of the first symptoms, and all sought at least two health institutions during the disease process to obtain the diagnosis. On the other hand, even with an early diagnosis there is no prospect of cure for mesothelioma. The survival time against the disease has not changed in recent years.<sup>38</sup>

Regarding the investigation process, most people were diagnosed in a chest X-ray, which is one of the first diagnostic interventions for finding mesothelioma, and one of the indications is the presence of pleural thickening.<sup>39</sup>

In parallel to the professional treatment, the individuals resorted to the folkloric subsystem, recognized for the beliefs about the divine and strongly linked to the popular. Clinging to religious beliefs is understood as a possibility of healing, and thus the actions involving religiosity are represented by prayer and promises. In this regard, it can be understood that the behavior of the Brazilians in relation to religiosity is a frequent practice. Approximately 89% say that religion is fundamental and 50% rely on some religious service.<sup>40</sup>

Not only in the healing sense, religion is considered as a support for coping with cancer and should be provided for the maintenance of human being's integrity.<sup>41</sup>

The understanding about cancer must overcome the biomedical model, the phenomenon of this disease significantly involves the family members, in relation to dynamics of care that need to be established, the adaptations of the person in relation to disease's limitations and living with a pathology that will surely culminate in death.<sup>42</sup> Searching for health care and the construction of a therapeutic plan go beyond the spheres of the professional subsystem and, concomitant to this context, there is a set of meanings associated with the disease process.<sup>43</sup> These meanings were constructed by the family members from the moment they recognized the severity, establishing actions for health care of the individuals with mesothelioma.

Regarding the limitations of this study, the difficulty in locating family members can be signaled, as well as the refusal to participate in the study, a fact that is related to the coping process that each family member has in relation to grief and to relive the suffering situation.

Still another identified limitation refers to the study case, as it does not allow generalizing the results obtained. The analyses and considerations are specific and not generic. Therefore, it was not intended to seek the construction of a generalizable knowledge, but of isolated discoveries, but which may be relevant and clarify the reality of this group of people who became ill and died of mesothelioma.

## CONCLUSION

This study allowed us to describe the itinerary of the individuals with mesothelioma from the identification of the symptoms, when the first common sense practices were adopted, such as the use of syrups, medicinal plants and self-medication. As central care unit, the family establishes the need to seek the professional subsystem due to the persistence of the symptoms and their worsening.

The professional subsystem has the challenge of unraveling the mystery of the disease with the difficulty of confirming the diagnosis. Religion is the source of hope during the illness process. The family carries the burden of facing the difficulties of the aggressiveness of the disease, from treatment until they choose to interrupt the professional system therapy. The delay in the investigation process proves to be a contributor to the evolution of the disease.

The whole disease process is seen as an ordeal; since it is an aggressive and incurable illness, the family members face an early mourning. Thus, it is expected that this research enables the understanding of factors, behaviors and actions that interfere in the care path, as well as the influence of the family member in this process.

Thus, for the health professionals, and especially those from the nursing area, it is important to emphasize the unprecedented nature of the study and the importance of research for planning the health actions to be promoted to the individuals with mesothelioma. The health care practices need to be rethought, from the process of research, diagnosis and treatment, to improve quality of care of the health services.

It is important to deepen the knowledge of the health care systems so that people exposed to asbestos in the workplace or out of work can be monitored, and that the diagnosis of mesothelioma is confirmed early, thus optimizing the health care offered to this population.

Reconstituting the therapeutic itinerary of the individual with mesothelioma provided the opportunity to know the experience of the disease through the perspective of the family members (popular subsystem) and to observe that each person carries a framework of sociocultural possibilities in which religion, popular and professional are interconnected during the whole process of seeking treatment for the disease.

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## NOTES

### ORIGIN OF THE ARTICLE

Extracted from the dissertation/thesis - O itinerário terapêutico revelado pelo familiar da pessoa com mesotelioma maligno: estudo de casos múltiplos, presented to the Graduate Nursing Program of the *Universidade Federal do Paraná*, in 2016.

### CONTRIBUTION OF AUTHORITY

study desing: Mercês NNA, Baran FDP.

Data collection: Baran FDP.

Analysis and interpretation of data: Baran FDP.

Discussion of the results: Baran FDP, Mercês NNA, Sarquis LMM, Rosa LM.

Writing and/or critical review of content: Mensi C, Sarquis LMM, Brey C, Baran FDP.

Review and final approval of the final version: Mercês NNA, Sarquis LMM, Rosa LM, Mensi C.

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### CONFLICT OF INTERESTS

There is no conflict of interest.

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