

THE MESOTHELIOMA DISEASE IN THE PERSPECTIVE OF THE FAMILY CAREGIVER¹

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ABSTRACT

Mesothelioma is an aggressive type of cancer with no prospects of cure. This study aimed to know and to describe the illness due to mesothelioma from the first symptoms at death from the perspective of the familiar caregiver. This is an exploratory study with a qualitative approach. The data were collected from January to July, 2016, in the city of Curitiba, Paraná, through an interview with family members who followed the process of illness from 1993 to 2013, and after the analysis of categorical content. From the six participants, five ones are female and all of them live with the sick family member. From the analysis four categories have emerged: Discovery of the disease; Conviviality with an incurable disease; The transformations; The decision to let them go. The family member's experience in living with the person who has mesothelioma goes through denial of accepting cancer, living with physical and emotional changes in daily routine, and spirituality, which provides a foundation for the relief of pain and anticipatory grief. It is concluded that mesothelioma illness from the family perspective points to confrontations and overcoming during the living and the care offered to the sick person.

Keywords: Caregivers; Family Relations; Mesothelioma; Qualitative Research.

INTRODUCTION

Mesothelioma is a type of cancer that has few prospects for cure. It occurs with the involvement of the mesothelial cells, layer that covers the lung, peritoneum, pericardial and testicular vaginal tunic⁽¹⁾. This cancer has peculiar characteristics, such as difficulty in obtaining an early diagnosis, tumor aggressiveness, limited therapeutic management, low survival and limiting quality of life after confirmation of diagnosis⁽²⁾. One of the factors attributed to the causal nexus for mesothelioma is exposure to asbestos, especially in the occupational environment. According to the World Health Organization (WHO), it is estimated that 125,000 people remain exposed to asbestos, from them 100,000 will die every year⁽³⁾.

A multicenter study conducted in 83 countries from 1994 to 2008 showed that 92,253 mesothelioma deaths occurred during this period. Pleural involvement accounted for 41.3% of the cases; the peritoneum, 4.5%; and unspecified sites, 43.1%⁽⁴⁾. However, one of the problems found in Brazil is the inconsistency of hospital records of mesothelioma cases, due to the difficulty of confirming the diagnosis⁽⁵⁾. Data from the Mortality Information System (SIM) from 2000 to 2012 indicated that there

was underreporting of mesothelioma cases, so there is a lack of consistent data regarding the situation in the country in relation to the disease⁽⁶⁾.

In the context of mesothelioma illness, as well as other types of cancer, the person goes a long way to the diagnosis, marked by uncertainties, especially by the stigma of death. It is in the family structure that the first care is performed; the family experiences the stages of illness with the person, with the attention focused on coping with the difficulties that develop throughout the illness⁽⁷⁾.

Illness due to cancer alters family relationships, with increasing demands on the sick person, and the need for remodeling of daily activities⁽⁸⁾. Family members are directly involved in the practice of care, but it is necessary to understand that they have the experience of caring in a different way, either in the structural dynamics established for the care, or in the feelings they experience, in facing cancer illness⁽⁷⁾.

In Paraná, prospectively, mesothelioma illness presents a tendency to increase for the next decades, mainly in relation to the use of asbestos in the state⁽⁵⁾. Therefore, the knowledge about the subject can contribute to the understanding of the particularities of the disease and instigate the advance of the policies of attention to specific cancer care. Thus, this study

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aims to know and to describe, from the perspective of the family caregiver, the illness due to mesothelioma from the first symptoms until death.

METHODOLOGY

A qualitative study was carried out between January and April 2016, with six relatives of people diagnosed with mesothelioma, who were assisted in an oncology hospital located in the State of Paraná. The inclusion criteria were: to be a family member and primary caregiver; to have accompanied the process of illness of the person with mesothelioma, from the first symptoms to death. The exclusion criterion was: impossibility of contact, by telephone and correspondence.

For the recruitment of the participants, we searched the cases of mesothelioma that were registered at the participating institution that comprised the period from 1993 to 2013. We identified 16 cases and, when the relatives were contacted, only six accepted to participate in the study. The reasons for the refusal were: lack of time for the meeting with the researcher, showing disinterest in the study (3); do not want to remember the process of illness (3); also deceased family caregiver (2); and impossibility of contact (2).

Data collection was performed using the interview technique, with open questions elaborated by the researchers, and there was no need to repeat the interviews. The places for the realization were: residence, work environment, public place, which were chosen by the participants. The content of the interviews was recorded by tape recorder and lasted between 18 min. and 1 h, and field notes were also made before and after the interviews. The material obtained from the interviews was returned to the

participants by e-mail so they could listen and add comments or request corrections, but there was no return.

The data were organized and analyzed according to the steps defined for the analysis of category content⁽⁹⁾, as described: transcription of the interviews, pre-analysis of the text, dismemberment in units for coding, accomplishment of clippings and aggregation into categories according to similitude, realization of inferences and interpretations. At the end, the categories were defined, which correspond to the family's perspective on the process of mesothelioma illness, from the first symptoms to the death.

The research was approved by the Research Ethics Committee of the Federal University of Paraná and the participating institution, by Opinion number 677.015 / 2014. To preserve the participants' anonymity, the word "familiar" was used followed by increasing Arabic numerals, according to inclusion in the study.

RESULTS AND DISCUSSION

Six family caregivers participated of the study; from them five are female. The age varied from 27 to 63 years-old, being three daughters, two wives and one brother. Regarding occupation, two participants are housewives; one housekeeper; two, shopkeeper; and one, prosthetic. Five participants mentioned that their religion is Catholicism and one [,] protestant. About the current residence [,] five live in the State of Paraná and one [,] in Santa Catarina.

From the content analysis, four categories were presented in Figure 1 and described below, with excerpts from the relatives' testimonies.

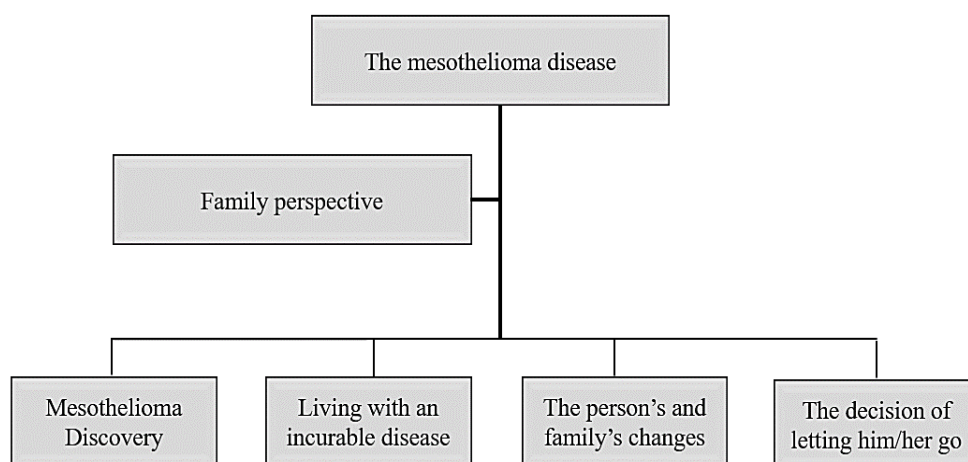


Figure 1. Study categories - Illness due to mesothelioma from the perspective of the family caregiver

Detection of mesothelioma

This category demonstrates the timing of cancer discovery. The suspicion of all the familiar caregivers happened by the recognition of the first signs and symptoms. This was the moment when the disease took on the visible character, and indicated an aggravation to health.

Speeches extracted from the interviews show the signs and symptoms highlighted by family caregivers, being: pain, weight loss, fever, unpleasant sensation during and after meals.

She felt pain, it was pain in the back, and she complained that what she ate was bad for the stomach (F1- Daughter)

Her symptoms were constant fever and back pain, these were the first symptoms, and she stayed about four or five months like this. (F2- Brother)

He lost weight, he lost pounds, he was losing weight very fast. (F5- Wife)

Some types of cancer may be delayed to be diagnosed, just as in the case of mesothelioma, where the initial signs and symptoms do not clearly show the severity of the disease⁽¹⁾. It was not also possible to relate to the cancer initially, since these symptoms may be related to a series of health deviations. This characteristic can also be added to the difficulty of access to health care, to disinformation and to the culture of not seeking professional assistance at the beginning of the symptomatology, facts that may predispose to the progression of the disease and the late diagnosis.

The study points out that the potential risk factors for advanced cancer diagnosis are related to access to health services, which includes from distance or time of travel to the professional health system, as well as the scheduling of the first care in the services social and demographic factors, as well as race and cultural disparities⁽¹⁰⁾.

From the perspective of the cancer discovery, the family caregivers motivated the search for professional health care when they realized that the signs and symptoms did not disappear, and, from the investigations, it was possible to have the diagnosis of cancer, which occurred through the result of the biopsy. And then they received the information from the medical team that it was an aggressive cancer.

When they did the biopsy, the result came, which was a malignant tumor and was very aggressive, and when

they moved (tumor) it (tumor) it began to evolve very fast. [...] Everything was scattered! (F1- Daughter)

The doctor came and called me when the result of the biopsy arrived, he said it was malignant. Wow! I was incredulous, and I thought: Oh my God, I cannot believe it! (F6- Daughter)

Receiving the diagnosis of cancer is a difficult time, and the person with mesothelioma and their family members realize the severity of the disease. When the diagnosis was confirmed to the relatives by the medical professional, it was already a cancer with no possibility of cure, with estimated life time oscillating between 45 and 60 days.

When the doctor discovered, he (the doctor) said, "Look, she (person with mesothelioma) has 45 days to a maximum of two months of life." (F1- Daughter)

The biopsy was performed, and he found that he had cancer, malignant mesothelioma, doctors called me and my aunt, and we became aware of the situation, the doctor said that the case was very serious, and even if he was to do the surgery he (person with mesothelioma) would have at most two months of life. (F4- Daughter)

Mesothelioma sickness is extremely aggressive, its evolution is rapid. When the person is diagnosed, the average survival for peritoneal involvement usually does not exceed nine months⁽¹¹⁾. In cases of pleural mesothelioma, survival may vary from 12 to 17 months, and in some cases from 4 to 8 months⁽¹²⁾.

Faced with a diagnosis without possibilities of cure, several situations are experienced. Descriptive research carried out in the outpatient setting had the objective of knowing the experience of 12 family members and 10 patients facing cancer illness. The study revealed, through thematic categories, the impact of receiving diagnosis and the feelings originated in the confirmation. Both family members and patients present various reactions and experience unpleasant feelings, especially fear and distress⁽¹³⁾.

Living with incurable disease

This category is based on the coexistence with a person diagnosed with cancer without a cure perspective, and the coping strategies adopted for living with the person. The relatives revealed in some testimonies they hadn't believed that their family member had an incurable disease, and they had to be faithful as a form of support for the moment they were experiencing. The existence of an incurable disease involves several questions, especially understanding the origin of the disease, the family

members asked about the origin of the cancer, and these questions happen after the diagnosis:

In my mother's family, there are no cases of cancer until now, until two years before she became ill. There was an uncle of mine, who was almost 80 years-old, with cancer, but I also believe that, in his case, it is a little because of his age. But no more, in her family (the person with mesothelioma) there is no one, no case, so I do not know where it came from, all of which made us very, very afraid of what would come. (F1- Daughter)

Denial is the defense mechanism found in the interviews and presented by one of the relatives. The same highlighted the non-acceptance of the disease and the death of the person.

He (doctor) said, "Your father has three months of living." And I said: "Never! I do not accept that". [...] I did not accept this disease; I never accepted it, until now I do not accept his death. (F6- Daughter)

In this sense, one of the ways to face the diagnosis is denial and many relatives choose not to comment on the disease; this action can be considered as a coping mechanism to protect oneself and to alleviate the suffering experienced⁽¹³⁾.

Another important aspect highlighted in this category is the belief, represented by spirituality and faith in the divine. From the moment they knew the diagnosis, the support of religion was constant. All the family caregivers reported that they belonged to a religion, often the same religion that the person with mesothelioma followed, and seeking relief through faith was a way of facing illness, both to gain strength and believe in the possibility of a miracle, and to stay beside the person during treatment, and accept the possibility of death. All family members were informed in advance of the imminent risk of death.

The acts that represent the faith were the prayers, which directed the family and the people in various senses, either to accept the illness, the hope of healing and/or the relief of suffering. The practice of prayers was carried out with the person, with relatives, and also counted on the members of the church (s) of which one (s) participated.

We always prayed, I prayed a lot with her (a person with mesothelioma) and when we pray, it gives us relief, even if the person remains ill, it gives a relief to you (referring to her) and to the person as well. (F1- Daughter)

He had a lot of faith that was going to be healed, the whole church started going there at my house to make a prayer campaign for him. [...] And I believed it was just asking for God's help. (F5- Wife)

In order to face illness, some strategies are adopted to alleviate suffering; faith is interpreted as the foundation, believing in divine power represents encouragement in the face of the moment they live. A phenomenological study carried out in the city of Barretos (São Paulo), in a specific unit for the care of people in palliative care, showed the importance of the spiritual context of people with terminal illnesses, as well as family members⁽¹⁴⁾.

A study conducted in 2017 to compare quality of life and religious support found that in the 192 participants, 96 of whom had no diagnosed disease and 96 in palliative care, Catholics, regardless of the study group, had a high quality of life. It is suggested that this coping strategy may be more stimulated in palliative care patients⁽¹⁵⁾.

Despite the difficulties, hope is the faithful companion of people with mesothelioma and their families, because it gives meaning to the days of people with illness and strengthens living, even in the face of the difficulties imposed by the course of the disease and its treatment. Hope becomes a feeling capable of motivating the human being to envision a horizon of life with new perspectives, never before thought⁽¹⁶⁾.

So, in this journey, which involves cancer sickness and certainty of death, but without a certain date to happen, feelings are often confused⁽⁸⁾. Suffering and anticipated mourning are confronted, with the need to make the day of the loved one the best possible. It can be said that it is the struggle for the good to live; not counting the time that can last.

The person's and the family's changes

This category is characterized by changes in the disease. Living with the person and being the main caregiver has modified the emotional structure and daily dynamics of the family members. A remarkable moment was reported to face the person with the chemotherapy treatment, the relatives realized the physical changes, such as the physical weakness and the malaise coming from the therapeutics, these changes have become apparent. An important aspect, pointed out by one of the relatives, permeates the side effects of chemotherapy. One of the relatives revealed that he had knowledge about the effects that the treatment might entail but believed that the person would go through the treatment differently. Gradually they arose aggressively and this was interpreted as a form of suffering.

The doctor said that the chemotherapy was enough to sacrifice the patient, but we do not believe it, and I would say: Ah [...] no, it's going to be okay! We had already listened about it, but we had never imagined that [...] until we see what it is. (F1- Daughter)

He did a chemotherapy session, but it weakened him a lot. [...] In the final stage he became very weak [...] (F4- Daughter)(.)

He started having chemotherapy, but he was very ill, when he returned from the hospital (after the sessions) he was exhausted. (F5- Wife)

As for treatment, chemotherapy was recognized as aggressive. Common side effects that occur during treatment are alopecia, fatigue, nausea and vomiting⁽¹⁷⁾. Another issue is how the person faces the treatment; the impotence and negativity are frequent feelings. When the disease has a prospect of cure, it is assumed a posture motivated for the continuity of treatment, in this study, the consequences of the treatment weakened considerably people with mesothelioma, and they obtained no benefits.

In this context, the disinformation about the disease and the side effects of the treatment are related, chemotherapy is often seen as an enemy, considering its toxicity, side effects and low response in cases of mesothelioma. Therefore, the health team and the person with mesothelioma need to make choices together, aiming at quality of life. The goal of effective disease control is limited to this aggressive cancer and it takes time to process illness and death.

The daily activities also changed, the moment of preparation of the meals needed changes, due to the limitations of the person regarding the smell of the food and the difficulty of rest due to the pain. Family members needed to be reshaped to the needs of the person, especially in the activities performed at home, as well as in the family organization for the insertion of other family members to assist in care.

I couldn't cook at home, I had to cook at my sister's house because of the smell, he could not smell any (food) (F3- Wife)

During this time he suffered a lot, he suffered too much, he had a lot of pain, he did not sleep anymore and I stayed with him all the time. [...] and we used to live with people's help, sometimes I had to leave him and go to work and my 14 year old son had to take care of him. (F5- Wife)

It is emphasized that caring for a person with an advanced disease often gives rise to a series of

changes in daily life, as changes in the well-being, in the professional life, diminish the self-esteem, the confidence and compromise the quality of life of the relatives⁽¹⁸⁾. And there are physical transformations of the person's image with mesothelioma; one of the relatives reported the impact and suffering of the person when he perceived the transformations in the body, when seeing himself with the disease and with the alterations coming from it.

This disease is very hard, huh? [...] He always knew he had this disease, because he looked at himself in the mirror and said he was turning a skull, and he turned a skull, it was skin on the bone. (F3- Wife)

The changes mentioned show several faces of the disease process. Effective care at the end of life, from the perspective of family members, is to carry out actions that may contribute to the person's well-being, including daily activities for the maintenance of basic human needs, such as food and hygiene, and the essential, of comfort and love⁽¹⁸⁾.

The decision to let go

This category shows the moments that preceded the death, and the decision of the relatives in agreement with the health team that assisted the person to stop the treatment. When the attempts to recover health, control the disease, with the curative treatment did not present benefits, and this generated extreme suffering, the time has come when the family member agrees with the medical team to stop the chemotherapy treatment. And they revealed the moment of that decision.

You learn what love is, it is hard to lose someone you love. [...] I went to the doctor and I said: I cannot see my sister like this anymore, you can sedate her, I do not want her to go through this anymore. The doctor had an amazing reaction, she smiled at me and I do not forget until today, and she said: "At last you asked!". (cry)

The doctor called me and told me that the chemotherapy was not working, I remember she told me, "Look, it's not working, we'll call the medical team next to you to decide to continue (the treatment) or not.". And I answered her (doctor): Well, if it's not working, why should we make him suffer more?

One of the points observed is the authority granted to family members to decide to sedate or to discontinue treatment. In this sense, it should be emphasized that one of the principles of palliative care is to provide effective communication between family members, patients and professionals involved

in care, so that the decision is directed to provide a better quality of life and comfort to the person. Having the follow-up of a palliative care team provides well-being to patients and their families⁽¹⁹⁾. From the six relatives, only one mentioned having received follow-up from this specific service.

After death, living the mourning period is a conflicting moment reported by family members. In this process, the caregiver resumed his life without the person, with the restructuring of the material context. The places, objects that recall memories of difficult times were replaced by others, this was the way the familiar found to face the absence and resume life after death.

Longing will stay. [...] I had a house on my mother's estate, but that was where he died, I could not stand being in that house anymore, I sold my house. [...] I left all my things there in the house, I wanted everything different [...] I got rid of all the things that we bought together. And when he was sick, especially the couch, he used to lay on the couch, and I could not look at that couch [...] so I got rid of him [...] (F5- Wife)

It would be fundamental that family members who care for people with terminal illnesses could have adequate physical structure for the needs of this nucleus - person with mesothelioma and family members - as well as with emotional support. Palliative care teams are allied in this process of coping with terminal illness; there is an imminent need for support in home care⁽¹⁹⁾. In this study, according to family members' reports, there was no follow-up.

With these reports, it was possible to know the feelings expressed before the death of a family member with cancer, the temporalities and the anguish. The individual discovers and rethinks finitude and experiences the fact of being mourned. Regarding strategies for coping with mourning, a study by psychologists showed that spirituality was highlighted in the confrontation with family members⁽²⁰⁾.

FINAL CONSIDERATIONS

THE MESOTHELIOMA DISEASE IN THE PERSPECTIVE OF THE FAMILY CAREGIVER

ABSTRACT

Mesothelioma is an aggressive type of cancer with no prospects of cure. This study aimed to know and to describe the illness due to mesothelioma from the first symptoms at death from the perspective of the familiar caregiver. This is an exploratory study with a qualitative approach. The data were collected from January to July, 2016, in the city of Curitiba, Paraná, through an interview with family members who followed the process of illness from 1993 to 2013, and after the analysis of categorical content. From the six participants, five ones are female and all of them live with the sick family member. From the analysis four categories have emerged: Discovery of the disease; Conviviality with an incurable disease; The transformations; The decision to let them go. The family member's experience in living with the person who has mesothelioma goes through denial of accepting cancer, living with physical and emotional changes in daily routine, and spirituality, which provides a foundation for

Interviews with family members showed mesothelioma illness from the family perspective. These have gone through many moments; the analysis full of meanings shows how people build in similar and dissimilar ways the experience of the phenomenon of illness. It allowed to know the feelings and the practices adopted for the confrontation, strategies of denial, the foundation of spirituality culminating for the relief of the suffering and the anticipated mourning, thus allowing the acceptance of the disease, to live with the physical and emotional changes resulting from the chemotherapeutic treatment and daily routine, which were the main changes experienced by family caregivers. The decision to let go is a difficult time, this action is directed exclusively to the family.

Health professionals, especially nursing professionals, need to know the subjectivity of the different stages through which the family goes through the process of becoming ill and caring. A look at families is a challenging proposition, each one bringing diverse perspectives, moments of pain, suffering and confrontation. The family is the elemental structure in support of the person, and especially the family member who carried out the care.

The study is not intended to make generalizations due to the qualitative nature. There are still few studies on the subject of mesothelioma that address the subjective dimension of family members, so this knowledge may provide subsidies to health and nursing professionals to direct attention to the sick person and optimize the quality of care to be offered to the person and to the family, in the phenomena of mesothelioma illness.

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the relief of pain and anticipatory grief. It is concluded that mesothelioma illness from the family perspective points to confrontations and overcoming during the living and the care offered to the sick person..

Keywords: Caregivers. Family Relations. Mesothelioma. Qualitative Research.

LA ENFERMEDAD POR MESOTELIOMA EN EL PUNTO DE VISTA DEL FAMILIAR CUIDADOR RESUMEN

El mesotelioma es un tipo de cáncer agresivo y sin perspectivas de cura. Este estudio tuvo por objetivo conocer y describir la enfermedad por mesotelioma de los primeros síntomas al óbito en el punto de vista del familiar cuidador. Se trata de un estudio exploratorio con abordaje cualitativo. Los datos fueron recolectados en el período de enero a julio de 2016, en la ciudad de Curitiba, en Paraná-Brasil, por medio de entrevista junto a familiares que acompañaron el proceso de enfermedad en el período de 1993 a 2013, y después sometidos al análisis de contenido categorial. De los seis participantes, cinco eran del sexo femenino y todos convivían en tiempo integral con el familiar enfermo. Del análisis surgieron cuatro categorías: Descubrimiento de la enfermedad; Convivio con una enfermedad incurable; Las transformaciones; La decisión de dejar partirse. La experiencia del familiar en convivir con la persona que tiene mesotelioma pasa por la negación en aceptar el cáncer, el convivir con las alteraciones físicas y emocionales en la rutina diaria, y la espiritualidad, que configura una base para el alivio del dolor y del luto precoz. Se concluyó que la enfermedad por mesotelioma en el punto de vista del familiar señala enfrentamientos y superaciones durante el convivio y en los cuidados ofrecidos a la persona enferma.

Palabras clave: Cuidadores; Relaciones Familiares; Mesotelioma; Investigación Cualitativa.

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