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Meanings of getting sick: what main caregivers of elderly with cancer think*

SIGNIFICADOS DO PROCESSO DE ADOECER: O QUE PENSAM CUIDADORAS PRINCIPAIS DE IDOSOS PORTADORES DE CÂNCER

SIGNIFICADO DEL PROCESO DE ENFERMAR: LA PERCEPCIÓN DE LAS PRINCIPALES CUIDADORAS DE ANCIANOS PORTADORES DE CÁNCER

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ABSTRACT

The goal of the study was to understand the social representations of the main caregivers about the process of a acquiring cancer and to relate them with their therapeutic choices when caring for an elderly bearer of this pathology at his home. Four main caretakers of elderly cancer patients participated in the study. Data collection occurred from March to November, 2005, using semi-structured interviews and participative observation. The data analysis was accomplished through the method of thematic analysis. The explanations for the disease found by the caretakers were opposite to the medical explanations, because they try to identify the mechanisms that led the elderly patients to acquire the disease in their lifestyle. The therapeutic practices at home are eminently cultural, considering socially-built beliefs and values. The need of recognizing the socio-cultural dimension of healthcare within the formal healthcare service was emphasized.

KEY WORDS

Caregivers.
Aged.
Neoplasms.
Home nursing.
Health of the elderly.

RESUMO

O objetivo do estudo foi conhecer as representações sociais da cuidadora principal sobre o processo de adoecer de câncer, e relacioná-las com suas escolhas terapêuticas ao cuidar de um idoso portador desta patologia no domicílio. Participaram do estudo quatro cuidadoras principais de idosos portadores de câncer. Os dados foram coletados no período de março a novembro de 2005, por meio de entrevistas semiestruturadas e observação participante. A análise dos dados foi realizada pelo método de análise temática. Constatou-se que as explicações encontradas pelas cuidadoras para a doença caminham na contramão das explicações do saber médico, pois elas procuram identificar na forma de vida e no contexto do idoso os mecanismos que o levaram a adoecer. As práticas terapêuticas no domicílio são eminentemente culturais, pois consideram crenças e valores socialmente construídos. Enfatizou-se a necessidade de reconhecer, dentro do sistema formal de saúde, a dimensão sociocultural do cuidado.

DESCRITORES

Cuidadores.
Idoso.
Neoplasias.
Assistência domiciliar.
Saúde do idoso.

RESUMEN

El objetivo fue conocer las representaciones sociales de la principal cuidadora, con respecto al proceso de enfermar de cáncer y de esta forma relacionarlas con las opciones terapéuticas para el anciano que cuidan en el domicilio. Participaron del estudio cuatro cuidadoras de ancianos con esta patología. Los datos fueron recolectados durante marzo a noviembre del 2005, a través de entrevistas semiestructuradas y observación participativa. El análisis fue realizado por medio del análisis temático. Se constató que las explicaciones encontradas por las cuidadoras para la enfermedad son contrarias a las del saber médico, pues ellas buscan identificar en la forma de vida y en el contexto del anciano mecanismo que le provocaron la enfermedad. Las prácticas terapéuticas domiciliarias son eminentemente culturales, pues consideran creencias y valores socialmente construidos. Se enfatizó la necesidad de reconocer, dentro del sistema de salud, la dimensión sociocultural del cuidado.

DESCRIPTORES

Cuidadores.
Anciano.
Neoplasias.
Atención domiciliaria de salud.
Salud del anciano.

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INTRODUCTION

The demographic transition, characterized by population aging and observed worldwide is followed by an epidemiologic transition, marked by the prevalence of chronic-degenerative diseases. Cancer is among them, with 60% of deaths by this disease occurring in the elderly population. In this age range, most tumor cases (80%) are diagnosed late, when the resources available for treatment are scarce. This situation limits the hope for life, contributes to the deterioration of the senior's self-image and supports the representation that cancer is an incurable disease(1).

In this perspective, the family is often surprised by the diagnosis and, almost at the same time, informed about the reserved prognosis, marked by the absence of therapeutic possibilities and the short lifetime. The family needs to bear the burden of the chronic extension of the disease and its sequelae, which includes the continuity of care at home, often without receiving enough clarifications about the care that needs to be performed, the characteristics and functions of the prescribed drugs and the situations that lead to the search for healthcare services.

Several studies have addressed the implications of the family assuming care for a relative with a chronic disease(2-4), even pointing to these families' need for professional orientation(3). At first, they have the illusion that they will receive support from the healthcare sector, but this feeling vanishes after the first intercurrences, because sometimes the attempts to hospitalize their loved ones are in vain. The insufficiency of hospital beds, associated with the condition of being *outside therapeutic possibilities*, constitutes an important setback when the family seeks help from the healthcare services(1).

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Hence, delivering care to an elderly family member with cancer is a unique experience for the family, which, by itself or with the support of the surrounding social network, builds its own way of caring day by day. The family, in general, has an explanative model of health-disease, constituted by values, beliefs, knowledge and practices that guide their actions in promoting the health of their members and the prevention and treatment of diseases(5).

The way individuals in a given society stand in relation to the disease, or how they perceive it, is fundamental in the determination of how this disease should be coped with. The same symptoms and diseases can be interpreted in completely different ways by individuals from different cultures, and health and the forms of recognizing and treating the disease are directly related to the subject's worldview, which is greatly influenced by culturally built beliefs, attitudes and values(6). These join popular and scientific reference systems, which are mutually different(7).

Understanding the disease as a social phenomenon makes treatment or coping actions to be interpreted as social and not individual constructs. Thus, social interactions play a leading role in the comprehension of the healthcare adopted in daily routine.

The cause for this is that actions adopted about the process of choosing a therapy are better understood when the individual is seen in his social relations network, because his perceptions, beliefs and actions are usually heterogeneous, complex and ambiguous and his knowledge and practices are built from several experiences, in determined biographical situations(8). Hence, both the experience of the disease and its related actions have intersubjective characteristics, integrating the individuals' subjective interpretations, permeated by certain cultural standards, into the process of social interaction(6).

Therefore, although it cannot be stated that all therapies adopted in the popular scope derive from a process of choice, the importance of them making sense for individuals should be taken into account. The adopted actions, therefore, are permeated by cultural habits and knowledge, several of which, although not apparently justifiable, build the way the world is understood by the individual and, what is more, how it is negotiated in social relations and supported by society(8).

The complexity involving daily life and coping with diseases in general is not part of the education of healthcare professionals, with a substantial difference between the elements that feed the reasoning of these professionals and of the many population groups, often causing difficulties for them to understand the attitudes of their patients, which may result in prejudiced and aloof relations. However, the perspective of integral healthcare recognizes the importance of the context, the cultural and family processes of the intersubjectivities, and takes into account the necessities and interests related to the daily routine of the involved subjects. All these aspects need to be considered in all individual care actions.

Therefore, one of the great challenges for healthcare professionals nowadays is how to articulate equality and difference, the common cultural basis and expressions of cultural and social plurality(7). In this perspective, delivering care to an elderly cancer patient at home transcends the biological aspects and covers the cultural dimension. This viewpoint evidences the role of the caregiver, which led us to define the study goal as getting to know the social representations of the main caregiver about the process of falling ill to cancer and relate them to their therapeutic choices when caring for an elder with this pathology.

METHOD

The theoretical methodological approach of social representations was used for the study(9), as we understand that the caregiver brings beliefs, positions and thoughts that characterize her way of seeing the world or analyzing facts, which reflect the social values of the context she is inserted in. Moreover, we consider that the characteristics of a given social representation are clearly revealed in periods of crisis, such as disease, when people are more willing to speak, the images and meanings are unveiled, collective memories are stimulated and behavior becomes more spontaneous(9).

Social Representations Theory (SRT) addresses the universe of common sense, understanding it as the group of opinions, knowledge, values and beliefs elaborated by the subject about a given social object (in this case, disease and care), which are shared by the social group and permeate cultural structures. There are three basic principles that form the basis of the SRT: The first is that people, by living in society, have a common way of life, in which values and ways of thinking are established about the daily reality; the second is that almost everything a person knows was learned from another – thus, the significant sources of knowledge and beliefs are interactions among people; and the third is that shared ideas and beliefs are rooted in social institutions, such as the church, the family and social movements(9).

Social relations direct behaviors and social practices, allow for the comprehension and explanation of reality, enable the protection of group specificity and interfere in socialization, due to the control exerted by the collectivity over its members; and, eventually, they allow people to explain and justify later their stands and actions in a given situation(9). This happens through two processes: objectivation and anchoring, which were both identified in this study. In objectivation, the caregivers acquire information and knowledge about falling ill from cancer in the elderly and build images and meanings around them; in anchoring, these images and meanings are integrated, in a cognitive way, to a pre-existent social thinking system. Therefore, what seemed strange becomes accessible to their comprehension, allowing them to develop care from an organized conceptual structure.

The study was performed with four caregivers of seniors with cancer. Data collection occurred from March to November 2005, daily, in alternating weeks (according to the researcher's availability), in observation sessions lasting from two to four hours. Semi-structured interviews and participative observations were used as strategies, in accordance with the anthropological tradition. The field journal was a fundamental procedure since, after each observation session, the impressions from the research environment were registered, including informal talks and notes for future encounters.

In participative observations, the social, affective and cognitive aspects involved in the caregiver's representation are focused on, about the process of falling ill from cancer and homecare actions for the elder with this pathology. These aspects were made evident in the discourse, gestures, attitudes, non-verbal communication and the main characteristics of the relationship between the caregiver and the elder. The semi-structured interviews were developed in the last phase of the participative observations, and the guiding questions were: *When you hear the word cancer, what do you think about? What images come to your mind?; What do you do to treat and care for Mr./Ms...?.* They were all recorded and integrally transcribed as soon as they had finished to avoid losing any details that contributed to their general understanding.

The study respondents are caregivers of elders registered in an oncology outpatient clinic integrated in the Single Health System in Guarapuava – PR. To be included in the study, they had to meet the following criteria: being the main caregiver of an elder with a confirmed cancer diagnosis; having no formal education in the healthcare area; working with the same elder for more than 30 days; residing in the same physical space as the elder; and finally, accepting to take part in the study by signing the term of consent. To guarantee their anonymity, the four caregivers were identified as Camomila, Cidreira, Hortelã and Malva.

Camomila was monitored in her home for almost six months, until data saturation was reached. The others were monitored for about a month and a half, when the monitoring was interrupted because the elder died.

The Thematic Analysis method(10) was used to analyze the data, by identifying the units of meaning contained in the main caregivers' testimonies and in the observation records. The method unfolds in three stages: *pre-analysis, material exploration and treatment of the results obtained* and *interpretation*. In pre-analysis, after several readings, the units of meaning, keywords or key phrases were identified, which showed the relevant thoughts and meanings for the caregiver. Those who had common central ideas were selected and grouped, and constituted the themes that outlined the study context. In the second phase, we analyzed the selections and established the rules to classify them; and, in the third, they were categorized, which allowed us to define the social representations of the main caregiver about the elder's process of falling ill from cancer, which were related with the homecare therapeutic practices. Two themes (in bold) were identified with their respective categories (in italics): **the elder's process of falling ill from cancer according to etiologic conceptions**, which included three categories: *religious representations, representations related with the conditions of life and humanistic representations about cancer;* and the **elder's process of falling ill from cancer according to the meanings attributed to it**, which covers five categories: *representation of cancer as a threat of death; as a symbol of human fragility; as the announcement of cumulative losses; as aggression and as expression of the person's desires.*

The study development complied with the ethical guidelines set by Resolution 196/96 of the Ministry of Health, and the research project was approved by the Ethic Committee of Universidade Estadual de Maringá (File #277/2005).

RESULTS AND DISCUSSION

Camomile (36 years old) was married for 16 years, had two children and took care of her mother, 68, struck with multiple myeloma for a year; she had a distant brother. Cidreira (52 years old) was divorced for 20 years and lived in Santa Catarina. By request of her son, who is a preacher at an evangelic church, she was taking care of her ex-husband (63 years old), sick with liver cancer diagnosed three months earlier. Hortelã (25 years old) was single and the youngest of five sisters; she took care of her mother, who was 62 and had had lymphoma for three years. Malva (38 years old) was married, had three young children and took care of her 61-year old mother-in-law, a faith healer, who was very respected in her community and had had hypopharynx cancer for nine months. The social conditions, the income, the fact of living in peripheral areas of the city, the restricted access to services and goods characterized these caregivers as poor working-class women.

The elder's process of falling ill from cancer according to etiologic conceptions

Data interpretation permitted verifying that the main caregivers of seniors with cancer have peculiar ways of explaining the process of falling ill: they start with etiological conceptions and admit supernatural, biological, personal and social causes. These conceptions orient the therapeutic procedures adopted in their daily routine, which can be identified from the observations.

Religious representations of cancer

In this category, the caregivers revealed that the process of falling ill is seen as the manifestation of God's will, with a strong relationship with sin and the opportunity of conversion. These representations lead them to base healthcare particularly on ritual therapies to expunge the evil symbolically and provide protection grounded on faith and trust in God:

> That's God's punishment for what he did in life, all I did was suffer, what this man did to me [...] that is, to pay for his sins. I'm also paying for my sins (Cidreira).

This caregiver would frequently ask her son, who was a preacher, to pray for the elder. Sorrow and regret were perceived in her words due to all the suffering endured with the alcoholic husband. However, in her care practices, she made efforts to allow him to find values and beliefs that she considered essential. It was observed that this caregiver has a moral/religious connotation of cancer, which she considers a punitive and deadly disease(11).

For Camomila, cancer is an enemy that spreads out silently, causing damage that is impossible to control only with the treatment available, needing divine intervention:

> This is a disease with several types, and there's one that's really serious, when the person feels it, it has taken him all over, and only God's grace will make her feel better (Camomila).

Hortelã conceived cancer as the image of a situation of unhappiness, where the disease took over her mother's life. Her care practices aimed at offensively opposing this reality and, for that, she needed to be sure that she was acting correctly. Therefore, she strictly complied with the medical treatment and reproached her mother's interest in popular practices related to healers, although she regarded the catholic religious practices highly:

> This disease causes lots of suffering [...] you have to do everything right, as the doctor tells you to, I don't do things on my own. She wanted to get a healer, those men who mix stuff in bottles, but I didn't let her [...] At the weekend, we took her to the sanctuary at Morro da Divina Ternura and the sanctuary of Santa Rita; but I'm against doing it only sometimes (novenas and prayer chains), you have to do it all the time, to be strong when things turn difficult (Hortelã).

For Malva, her mother-in-law's cancer was something undesirable, but it was represented as a symbolic element, through which God himself would have made his presence known in her family group, leading them to reevaluate their values, social choices, forms of living and relating:

> Malva considers that things were not going well in her family. Her husband had faced alcoholism, one of her brothers-in-law had impregnated a teenage girl and the other was very rude. She considers that, when the senior had her cancer diagnosed, even being a difficult situation that nobody desired, God spoke through her, since it contributed for everyone to rethink their actions and several aspects had already changed in the family relations (Field journal, October 22, 2005).

It was observed that, for Malva, suffering was accepted and transformed into an opportunity of family growth. Cancer affected her mother-in-law, but its repercussions and importance occurred beyond the corporeal space, covering the social and family environments the elder was inserted in. The therapeutic practices of this caregiver, aiming at divine protection through a priest or healer, were frequently observed during the whole study period.

The connotation these women give to cancer leads them to try to find support in religion, through ritual practices or invocations upon God. These strategies are accessible because the urban popular context makes several religious services available(12). Therefore, requests acquiesced to by God confirm and concretize the *bargain* and promote *faith* and hope, with faith often being presented as support for coping with difficulties and suffering, helping them and providing strength to overcome problems(2). Besides, it is common for people to report welcoming and concerns by their religious peers, so that the family and religious practices become parts of social networks that provide particularly cognitive, normative and affective support(2,12).

All in all, it is important to note that religious pursuits should not be understood as a way of escaping reality. Culturally, it performs several functions: it creates a cohesive identity between people, provides new strength in the struggle for survival and reinforces a cultural resistance that, by itself, also strengthens religious pursuit as a solution(13).

Representations related with life conditions

The caregivers attributed the cancer etiology to factors originated in the process of falling ill. According to this representation, there is continuity between the healthy state and falling ill from cancer, since these are not understood as different conditions but as consequences of concrete changes that unbalance the senior's quality of life and end up causing physiological disorders as well. Therefore, the process of falling ill from cancer was represented as the consequence of adverse conditions, external situations that interfered persistently and negatively through the whole life of the elderly:

> She has been complaining about her denture for four years, maybe she got sick because of the denture (Malva).

Identifying the denture as an etiological factor of the process of falling ill from cancer, Malva chose to restrict its use. Thus, she would not allow the elder to use it constantly, and both reached a consensus of using it only when they had visitors.

The working conditions, when represented as aggressive, are also related with the losses and deterioration of the elder's life:

> She worked a lot since she was young, she suffered a lot when she worked in the fields […] now she lost her strength, lost weight, lost the willingness to go out (Camomila).

This comprehension of the process of falling ill based the compliance with care practices that added benefits to the life of the seniors: alimentary restitution treatments, medical interventions materialized in medications, which were added to procedures and encouragement to participate in the informal network, represented by providing emotional and social support.

It is interesting to observe that, before the person sought professional help, she had already built a personal narrative about her health problem, which can be directly related with the acceptance of the therapy, since it indicates the interpretations the patient has already formulated about the problem, which may coincide with those proposed by the physician(14).

Humanistic representations of cancer

The causes of the disease are identified in the senior's life as a whole, in her personal, family and social pathways:

> He has brothers and a mother, but they never helped him, because he's not in good terms with anyone; he's like this today because of his meanness. After the divorce, his life got worse. He was not so young and he ended up lonelier and lonelier, to the point of not having anyone with him. Even his brothers moved away. He spent his days on the streets, didn't eat, just drinking. My son took pity on him and took him home, but he didn't stay there, he's stubborn. He was always told that if he didn't quit drinking he'd end up dying. It was his choice, and it's just a matter of time now (Cidreira).

In this representation, cancer is not considered a wholly strange *being* that took over the elder. It is the consequence of personal choices and the values that guided his life. This comprehension is expressed when the caregiver relates cancer with the elder's temper, with his terrible family and social relations, and identifies the abuse of alcohol as an etiological agent, which supposedly caused a general unbalance, affecting his health as well. The care practices developed aimed at contributing to balance and harmony in the household scope, covering the organization and cleaning of the house. Regarding the elder, the greatest concerns were his hygiene and diet; besides, there were attempts to mend family ties, facilitating the elder's contact with his sisters, who were not receptive.

Camomila attributes the aggravation of her mother's health to the family relations, more precisely to the conflicting relation of the elder with her son after his divorce, because she felt that important family values were not being well regarded anymore. Since then, she started to present recurrent episodes of depression, becoming reserved, and the son moved away from her:

> She had a huge relapse when her son divorced, because she doesn't accept that. Because a person with cancer cannot become emotional or disappointed. Then I put myself in her places and think about how much she suffers because her only son, to whom she gave life and was deprived of many things for, does something like that and doesn't show up (Camomila).

Depression can be the background of the immunodepression processes that caused tumor development. Therefore, although the representation that Camomila uses to explain her mother's process of falling ill is not valued in the formal system, it has a scientific basis and would justify a medical approach beyond the biologistic perspective(15).

Cidreira and Camomila have different explanations for the process of falling ill from cancer and, at the same time, they share the representation that the origin of cancer does not lie only in the individual's environment, either organic or psychological, but also in the scope of the social relations. Such representation rejects the dominant trend of the biomedical model, limited to treating the body or, more specifically, the diseased organ. The caregivers understand that it is necessary to go beyond, aiming at restoring the elder's life and relationships. This explains why they regard family support, demonstrations of solidarity and religious practices so well.

Thus, religion relieves suffering as it allows for changes in the subjective perspective in which the patient and the community perceive the context of the grave disease(11).

The elder's process of falling ill from cancer according to the meanings attributed to it

The main caregivers need to symbolize the situation they are experiencing in an acceptable way, so that they can overcome the day-to-day obstacles. Then, they build a series of meanings about the diagnosis, struggle to provide meaning to the symptoms, the changes and the deterioration the disease causes in the senior. The meanings attributed to the process of falling ill from cancer are related to the form in which it is experienced and perceived, and contains the social senses that allow the caregiver to address it as something understandable and manageable.

Representation of cancer as a threat of death

This category is characterized by a strong negative connotation, since this pathology is considered a source of distress and suffering, and provokes the awareness of finitude. At the same time, it mobilizes fraternal feelings in the caregiver, such as solidarity and compassion for the patient.

The four caregivers experienced and faced the imminence of death daily. Malva stopped sleeping with her husband to take a bed beside her mother-in-law's, because she was afraid that *something bad would happen* during the night and, if she were not there, it would be very sad for her mother-in-law to die alone. Hortelã mentioned not being able to imagine life without her mother, since, although they argue a lot, *one does not live without the other*. Cidreira would be desperate when the health of the senior worsened, demanding him to be hospitalized, and saying *I don't want him to die on me*. This caused several conflicts with the physician, who would tell her that the elder should stay at home, that the only possible intervention was pain relief, which was already being accomplished at home. Indeed, the family members tend to take the moment of death away from the context of care, clearly choosing for death to occur at a hospital, even when they want to provide care at home(15). On the other hand, the decision to keep the patient at home or at the hospital is a dynamic process, in which the best option today may not be the best for tomorrow, and this depends on how the patient's organism responds to the treatment(16).

Camomila, in turn, cried a lot when she manifested the fear of losing her mother

> For anyone, cancer is a torment, the word itself is heavy, isn't it? When the person knows she has cancer she goes into a depression, and the whole family wants to avoid that. It's very difficult, it's horrible, especially because so many of her sisters died of cancer […] when we think about cancer, we soon think about death (Camomila).

Death is part of the human condition, but little is said about that, which makes it difficult to cope with. This is a difficult issue for the caregivers and, although they consider death a natural process in old age, the possibility of death occurring at an unexpected moment is a reason for great distress. Besides, even when they strongly associate cancer to the possibility of death, the caregivers keep hope as something far greater and seek resources to deal with suffering, as identified in other studies(11). On several opportunities, we heard the caregivers talk to the elders with hopeful expressions, valuating every small achievement and helping them to live with their limitations.

Representations of cancer as a symbol of human condition

This representation is built from the traditional religious perspective, according to which the disease represents the being's state of degradation. Physical deterioration is the outer manifestation and reflection of the distance that separates the human being from perfection:

> I know that it's like this, we all die because of something, nobody is eternal […] all I want is that she lives well in the time she still has (Malva).

As Hortelã perceived her mother's deterioration, she compared it with her physical and emotional state before the diagnosis, revealing her fragility:

> She always had a commanding voice, she was the one who would decide and do everything here, now it's difficult to believe that she fell (Hortelã).

The senior's vulnerability was another source of suffering for Camomile, who felt powerless in view of the limitations imposed by the aggravation of the symptoms. The representation of cancer as a symbol of human fragility was related to the importance of the protective function of the family:

> You have to treat it adequately from the start, using everything there is and being well-supported by the family. If the person has no support, she becomes more and more nervous and goes more and more backwards. The person with this disease needs a lot of care and affection (Camomila).

This representation based the compliance with treatments that they considered effective, such as the use of herbs and sunbathing, because they did not have side effects that would cause greater discomforts, and mobilized strategies like leisure, contact with nature and social and family interaction to restore the joy of living to the seniors and contribute to their welfare.

> I try to make her leave the house and visit the neighbors or her grandchildren. It's nearby, you have to be patient because she walks slowly. She also likes to take care of her plants, and I encourage her to go to the garden. We do everything we can to help her (Malva).

Representation of cancer as the announcement of cumulative losses

Cancer not only symbolizes the loss of physical capacity, but also of ties, family structure, future and control.

The process of falling ill causes a possibility of rupture, as *normal life* is changed:

> At the start of the disease, I thought I could keep on working and take care of her, but as time went by, she got weaker and needed me more, I have to do everything, bathing, cooking, medication, bring her to and from the hospital […] I had to stop working and with that the money is never enough […] I had to leave many things behind (Camomila).

For this caregiver, leaving her job meant an important financial loss, which reflected in the family's quality of life. Cidreira, in turn, perceived that, after the cancer diagnosis, the loss of social ties with her husband increased, and she states that he is alone, counting only on her for support. Malva *breaks* the usual relationship with her husband and children *transitorily*, and dedicates most of her time to care for her mother-in-law.

We noticed that cancer represents a threat to the sense of security built throughout life, and it causes anxiety. It is a very particular strange body: it is born and develops through a process of invasion and inner consumption, causing progressive losses, which cover the person's family and social spaces(17).

As a consequence, the main caregivers mobilize and integrate formal, informal and popular resources that allow them to manage this situation. We observed that there are important investments to maintain habits of the elder's existence, including the maintenance of principles of family life, religion, leisure and social and family interaction. Cultural characteristics that are part of these practices can be changed or adapted by the caregiver to meet the changes in the elder's conditions of life. For example, Camomila encourages her mother's participation in a prayer group, of which the senior has been a member for years, by organizing meetings at her home.

Representation of cancer as aggression

By referring to cancer and treatment, the most usual expressions used by the main caregivers were: *We will do everything to get rid of this disease; We're struggling; Why did this come to affect her?.* These words reveal a representation of cancer as something that is not part of the body. The tumor is a *being* that conspires against the senior, bringing misery and acting as an enemy, coming against the desire of seeing him participate actively in family and community life and developing even the simplest activities of everyday life:

> The disease is slowly killing her, she lost weight, she feels a lot of pain, she can't eat, she vomits too much and can't sleep, she doesn't speak, doesn't want the neighbors to see her (Camomila).

Malva, after a chemotherapy session in which her mother-in-law presented incontrollable vomiting, said:

> This disease causes too much misery. It's not the only one to attack, the treatment also attacks the patient.

The words reveal that, by seeing cancer as an aggression, the caregiver believes that the elder is not responsible for what happens to her, that the disease develops in her body against her will, imposing limits:

> This thing doesn't let her live, causes too much pain to move, forces her to lie down, we have to put diapers on her, she doesn't feel like going out, talking […] it's difficult! (Camomila).

Hortelã worries about identifying the nature and extension of the aggression caused by cancer in her mother's life:

> She does what the disease lets her. At night she doesn't sleep much, and she is too weak to go to the bathroom by herself. I encourage her to walk, but she can't do it without help (Hortelã).

Therefore, for these caregivers, cancer is an unfriendly entity that saps the physical strength and good mood, and torments the elder day and night, both physically and emotionally. In view of this situation, the caregivers make efforts to improve their conditions of life and, by considering the process of falling ill as something completely alien to their person, they believe that a cure can only be expected from outside, through either formal or popular resources. Therefore, the option of complying with the chemotherapy is related with the representation of this treatment as something very aggressive and, as such, adequate to face a disease considered as an enemy and evil.

> I think it's good that she vomits, she's getting everything outside her, she's cleaning from within. This is a sign that the chemicals are working, and this is good, because she has to cut this evil at the root. You can't let this disease spread, you have to struggle (Camomila).

For Camomila, the side effects that the chemotherapy provokes show its efficacy, the vomiting is a sign that the disease is being purged and the elder is becoming *clean inside*, as found in other studies(18). Thus, culture offers a way of understanding the body and its inner working to organize the information available and give it coherence, *making sense*, i.e. the congruence between the subject's cultural basis and the process developed for a healthcare action. This process of individual choice is based on the cognitive theories that seek to explain the several therapeutic itineraries(8).

The starting point for the meanings of the representation of the disease as something that attacks, causing the problem and the imbalances, is the perception of the human being as someone who naturally contains therapeutic processes, capable of defending himself and the will to live, and this nature is abused by harmful powers that attack it; in these conditions, the patient can only be considered a victim(17).

Representation of cancer as an expression of the person's desires

Cancer is also represented as a symbol of the inner reality, much more truant that the symptoms themselves. Cidreira, for instance, considers that the elder's cancer is just one more sign of an old evil that has already destroyed his marriage and the family unity. In this sense, the elder is considered *guilty* for his disease:

> He has the disease he deserves, he wanted it this way. If he were different, this disease wouldn't have come up. He's weak, and the drinking took over. He drank all his life, pushed his family away, and now that's how he is. He wanted it, I'm here because my son asked me to. I think it's good that he feels that our son forgave him (Cidreira).

In the representation of this caregiver, her husband, by acquiring cancer, did not fall ill at that moment, since he had been an alcoholic for 50 years. This diagnosis was the end of a process of self-destruction, the reflection of his own life. Therefore, when delivering care, her attention is not only focused on the physical condition of the elder. She also attempts to rebuild ties that were significant for his life, especially bringing him closer to his son.

Cancer is revealed in Camomile's testimony as the fruit of personal attitude: the intransigence of her mother in view of the son's decision to divorce resulted in the rupture of harmony in family relations, who were relevant for the elder, leaving her subject to her own weakness:

> She got sick because of her son. He divorced, left his family for another woman, she suffers so much because of that, not only because of her grandchildren, but also because she is very religious and thinks this is not right. Since that happened, she hasn't been the same, she ended up getting sick (Camomila).

For common sense, personal choices can make physiological functions stray from their normal course, making the individual's health more chaotic. The changes in personal and social life are translated in body alterations that end up leading to death.

It is interesting to observe that the representation of cancer as a strange entity that attacks the elder unexpectedly, without him having done anything to deserve that, i.e. without being responsible for the situation, is less elaborate than the representation that the elder creates his disease. To reach this meaning, it is necessary to further the notion of individuality and recognize that the person is able to cause his/her own deterioration.

FINAL CONSIDERATIONS

The main caregivers of elders with cancer revealed that, in the commonsense perspective, the process of falling ill is not an individual event, since it not only covers the corporeal dimension, but also the family and social relations. According to them, cancer causes imbalances that go beyond the corporeal aspect of the elder, demanding reorganization in different dimensions of the life of the main caregiver and her family. We verified that the explanations the caregivers found for the disease often flowed against the biomedical biologistic explanations, because they attempt to identify the processes that led the elder to fall ill from cancer in his life and context, and find the meanings of this process in divine will.

The etiological identification of cancer was shown to be closely related with the care practices adopted at home: when cancer is considered an enemy that invades the elder's body, affecting his physical, spiritual and social life, it is believed that formal interventions are not enough, and divine intervention is expected and sought. When understood as the consequence of a dysfunction that is not only organic but also subjective, family and social, the caregiver tries to help him retrieve and maintain lifestyle habits that can help to protect him from whatever is destroying him.

In the daily routine of the main caregivers, we noticed that there are great concerns with the changes the disease can cause, which are translated in physical, emotional and social symptoms. Hence, the meanings around the disease and the possibility of loss are not centered only on organic damage, but also on the elderly person and the possibility of losing a loved one, which leads them to implement care that values a good life and welfare of the senior.

These results point to the need for healthcare professionals to make efforts to understand the complexity involving the daily life and ways of coping with diseases in general, because such aspects are shown to be fundamental for improvements in the healthcare quality that is provided both to the elder with cancer and his caregiver, by improving not only technical interventions but also the valuation of individual care and the symbolic and affective dimension involving this care. Therefore, it is necessary to use a care process where the caregivers are not forgotten in their vicissitudes, but inserted in the process, establishing goals and exchanging experiences with the team.

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