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## RESEARCH

### O câncer nas representações sociais de cuidadores: implicações para o cuidado

Cancer in the social representations of caregivers: implications for care

Cáncer en las representaciones sociales de los cuidadores: implicaciones para la atención

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#### ABSTRACT

**Objective:** Identify the social representations of caregivers of cancer for patients with no chance of cure and analyze their implications for care. **Method:** This is a qualitative research based on the Theory of Representations. **Results:** In thematic content analysis fell into two categories: The discovery of the other necessary care and generating two subunits: Limitations and Dependencies of the patient and participation in care; The relationship care, caregiver and patient that generated two subunits: The suffering of caregivers and support, the comfort and hope the caregiver. **Conclusion:** Is necessary that the nurse promotes strategies that facilitate the involvement of caregivers and the family in caring. **Descriptors:** Nursing care, hospice care, psychology social.

#### RESUMO

**Objetivo:** Identificar as representações sociais do câncer para cuidadores de pacientes fora de possibilidade de cura e analisar as implicações destas para o cuidado. **Método:** Trata-se de uma pesquisa qualitativa com base na Teoria das Representações Sociais. **Resultados:** Na análise de conteúdo temática emergiram duas categorias: A descoberta do outro e o cuidado necessário que gerou duas subunidades: Limitações e dependências do doente e a Participação no cuidado; A relação cuidado/cuidador e paciente que gerou duas subunidades: O sofrer do cuidador e o suporte, O conforto e a esperança do cuidador. **Conclusão:** É necessário que o enfermeiro promova estratégias que possibilitem o envolvimento dos cuidadores e de toda a família no ato de cuidar. **Descritores:** Cuidados de enfermagem, cuidados paliativos, psicologia social.

#### RESUMEN

**Objetivo:** Identificar las representaciones sociales de los cuidadores de pacientes con cáncer para ninguna posibilidad de curar y analizar sus implicaciones para la atención. **Método:** Esta es una investigación cualitativa basada en la Teoría de las Representaciones. **Resultados:** En el análisis de contenido temático se dividían en dos categorías: El descubrimiento de la atención que sea necesaria y la generación de dos subunidades: Limitaciones y dependencias de la paciente y la participación en el cuidado, la atención de la relación, el cuidador y el paciente que ha generado dos subunidades: El sufrimiento de los cuidadores y de apoyo, el consuelo y la esperanza del cuidador. **Conclusión:** Es necesario que la enfermera promueve estrategias que faciliten la participación de los cuidadores y la familia en el cuidado. **Descriptor:** Atención de enfermería, cuidados paliativos, psicología social.

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## INTRODUCTION

**T**he cancer and its chronicity when present in the individual, can lead to a number of events not previously experienced by family members, such as anxiety, fear, anguish and suffering.<sup>1</sup> In most cases, the family caregiver is responsible for the direct care to be, being responsible for numerous care from hospitalization, medication schedules, events, even outpatient care. The disease, on this view, brings its countless consequences for the social roles of family caregivers, directly reflecting on their lives and care.<sup>2</sup>

When curative treatment for cancer is no longer an option, but a tie for maintaining the life of the patient, the family caregiver faces major challenges, such as establishing measures for the control of pain and other symptoms, in order to seek a better quality of life.<sup>2</sup>

Most of the time, while searching for this quality, the caregiver is not prepared to engage in the practice of patient care, because I had never expected to assume such responsibility,<sup>3</sup> thus encounter something strange in their lives because not family, which depending on the way that they envisage such a reality, directly reflect the care directed to another.

Carers living in different socio-cultural contexts, experiencing various contingencies in their relationships, be they social, family, emotional, among others; have ages, genders, education levels, income, experience and own livings and suddenly find themselves faced with a task, most often, arduous and requires some degree of sacrifice and deprivation.<sup>4</sup> The daily care and interference in the activities and life of the caregiver bring an overload that can take different degrees according to the variables involved in the relationship caregiver/patient.<sup>5</sup>

Studies show that this relationship when disharmonious, can affect both the social network and the networks of support for the caregiver. The social support networks of caregivers, mostly consist of relatives and friends, and many caregivers do not receive help from anyone<sup>6</sup> or have few people to share their care activities, compared with the number who thought count within their social network.<sup>7</sup>

Cancer causes a disruption in the organization of family dynamics, making the sick person and their caregivers to rethink their daily activities, roles and concepts.<sup>8</sup> At this point recurs that caregivers struggle with situations not yet experienced, leading to a reorganization of ways of thinking, feeling and acting.

However, when faced with a situation not familiar, the subject worth of knowledge and experience previously acquired and shared with the social group in which it is inserted. In this sense, social representations are presented as forms of knowledge, oriented to communication and understanding of the social context, being socially elaborated and shared.<sup>9</sup> These representations are built daily by caregivers, are closely linked to

communication, language and social practices: dialogue, discourse, media, and all that belongs to culture,<sup>10</sup> individual it carries on the role of social mediator, thus making no familiar family.

A social representation is an organized structure of knowledge, and above all a mental activity, on which carers make intelligible the physical and social reality, ie, guide their activities and attitudes to the real world, being present in the group sharing or a connection to everyday knowledge exchange.<sup>11</sup>

In this context, the social representations help to clarify the phenomena of the universe consensual knowledge of the subjects and their practices related to caring for others. Thus the social representations apply to this study that proposes access the common sense knowledge of caregivers of people with cancer are beyond healing, considering that they are a form of knowledge appropriate to the understanding of phenomena that appear relevant in the social web.<sup>12</sup>

So, knowing the representations given by family caregivers of people with cancer are beyond healing of cancer is very important so that they can adopt strategies that consider the health singularities, biographies and cultural roots of these subjects, thereby unveil more specific care to respect the individuality of the subjects in their social support network and encourage more and more caregivers to care.

However, there are few studies that evaluate the concepts of caregivers about the care provided to the patient are beyond healing. Thus, this article aims to identify the social representations of family caregivers of cancer patients are beyond cure on cancer and analyze the implications of these representations for care.

## METHOD

It is a research-type exploratory, descriptive qualitative approach. To work out the contents of the reports of caregivers was used social representations theory, which allows the theoretical knowledge to obtain indications about the way of thinking and acting in the patient care in the terminal phase, so we sought to understand the relationship established by the population with this consensual act, as well as its influence on the values, attitudes, opinions and behaviors.<sup>10</sup>

The subjects were 30 family caregivers who accompanied their relatives admitted to the hospice in Ophir Loyola Hospital in Belém do Pará, and expressed their willingness and interest in participating in the study, after the knowledge of the objectives and signing the informed consent and clarified.

Data were collected through semi-structured interviews and analysis of the collected material was used the technique of thematic content analysis, which can be understood as the expression most commonly used to represent the processing of qualitative research,<sup>13</sup> which unfolds in the following steps: 1- Pre-analysis is the first contact with the contents to be analyzed, favors the organization of the material and read the interviews so there

impregnation of the ideas that emerge. At this stage, follows on the initial objectives, reformulating them or operationalizing them against the collected material. 2 - Exploration of the material: It consists essentially in the encoding operation. This takes place in the transformation of the raw data, in order to reach the core of understanding the text. Subsequently, it chooses counting rules that allow quantification. And lastly, ranks and aggregates the data by choosing empirical or theoretical categories that commanded the specification of subjects.

Proceeded raising significant issues from reports by caregivers counted, corresponding to the texts produced. Then we started to translate each statement in a speech prepared, in short, is believed to express the social representations of family caregivers.

After the initial reading of the texts produced, the units of analysis emerged were grouped and then subjected to a farm to better understanding of the research object by content deemed most significant in each text,<sup>13</sup> in order to consolidate into two main thematic units, as shown in Table 1.

The study was submitted to the Ethics Committee on Human Research of the School of Nursing "Magalhães Barata" State University of Pará, protocol-CAAE 0048.0.321.000.11 according to the precepts of Resolution No. 196/96/CNS / MS.

## RESULTS AND DISCUSSION

**Table 1:** Categories of analysis of social representations of family caregivers of patients not amenable to cure.

Category of analysis	Subcategory	Contexts of Meaning
1) the discovery of another and the due diligence	Limitations and dependencies of the sick	Limitation to promoting self-care; Reliance on third parties to handle.
	The participation in the care	The implementation of care activities; Exhaustion, tiredness in the realization of care.
2) the relationship care, caregiver and patient	The suffering of the caregiver	Gift of self to be careful; Impotence in not knowing how to take care; Suffering for empathy.
	The support, comfort and hope from the caregiver	The projection of the cure on divine entity.

### Category Analysis 1: The discovery of another and necessary care

#### *Subcategory 1: Limitations and reliance on patient*

Before providing care, it is essential that the caregiver knows the subject to be taken care of their needs, limitations and dependencies, as from the understanding, vision focused on the other you can access as caregivers comes the need for your contributions

their participation in caring for each other. Thus, the caregivers were asked what comes in your mind when you talk to your family with terminal cancer, 70% reported the following speeches.

*"I think at this point better, because when she was at home vomited a lot, did not effect the medication. Today she has limitations, not walking, bathing in bed, depends on us to do everything. Always need of our care. "(E12)*

*"It was very bad, not mobilized. (look of distress) All we have to do, to help [...] very bad state she was. The doctor said the disease has already taken care of it. This disease each person gets different symptoms. She now relies heavily on the people. "(E14)*

*"Before the disease she has always been independent, did things alone. (look seasick, sobbing) But now it has become dependent on us. Make the necessary care because she needs more now. We know that there is more healing. "(E22)*

*"Today she does not do anything alone. It depends on other people. Now it's useless, has limitations. Always need the help of others. "(E28)*

The presence of a disability, determined by advanced cancer involves the interference with the ability to perform certain activities, and can be caused by intrinsic or extrinsic, ie, it can be determined by factors inherent in the physical state of the patient, or it can be determined by social and cultural factors, and above all directly related to the way that caregivers come to be care and their contributions to the rehabilitation of it.

### **Subcategory 2: Participation in care**

Despite the existence of the possibility of healing and biotechnological progress achieved in recent years, cancer is still a silent disease and healing prognosis uncertain. The gesticulations of fatigue and speed in lecture elements that characterize their involvement in caring for others, features that caregivers make the activity a caring present moment in their daily, often labeled as a phenomenon of delivery, search the additional needs the other, as seen in 100% of speeches.

*"I participate at bath time, feeding, change serum, because I've learned; I'm careful with medications, participate in the hour of hygiene, combing hair, leaving it looking clean." (E1)*

*"Ah! I take him in the bath, I feed. (vocal intonation fatigue) Every day they have to bathe, change clothes, water, urinating. I just do everything. "(E9)*

*"Ah! The care, I look to see if there is crappy, with fever, cold [...] help at bath time, cut nails, shot his beard, cut his hair. I worry about feeding and hygiene him. If it's done 'pee'. "(E10)*

*"So [...] care at the time of feeding, hygiene, bath time. I'm always on the alert with the care that health professionals have guided me to do, like gymnastics and physiotherapy feet. We have to be careful because sometimes she does not want to eat, this is our very tiring."(E21)*

In most of the interviewees, the lack of financial resources that would allow the hiring of specialized caregivers in the home environment, was not present, such care then

proceeded to be performed by a family member, which is dedicated to promoting actions prevention and rehabilitation of the family with cancer.

### **Category 2 review: The relationship care, caregiver and patient**

#### ***Subcategory 1: The suffering of the caregiver***

The disease, worsening of the patient care directed and expect healing characteristics are common in everyday caregivers are often perceived as mechanisms proponents of suffering and pain. Many of the caregivers (80%) during the exposure of their reports were presented tearful, tense and frightened while reflecting on the future of their loved care, such behavior may imply that caregivers suffer psychologically, and becomes a being as hopeless a positive reaction in the improvement of the family, and its shares are sometimes threatened by synesthesia between pain, suffering and helplessness, as represented in the speeches that follow.

*"Early on it was hard, I suffered when I saw her situation very weak (crying). But then when I see her surrender, I know not help, I'm sad, I do everything, just me by it. "(E8)*

*"I feel very bad, (shaking hands) is very sad because you see a person suffer and not being able to do anything, mainly because I'm just to take care of her. It is very sad to see the same person suffer. "(E14)*

*"I feel helpless. (four minutes of silence) I would take the pain it put to me, as I do to him next. I feel sad helplessly. "(E20)*

*"It is very sad to see my son as well, a young [...] and I cannot do anything (cry). Just take care of the best, the most, for only myself. "(E29)*

The family members interviewed also expressed feelings of discomfort and loneliness by lack of support from family, creating a crisis in their performance, in which the usual relationship of affection and reciprocity was added to a list of urgent need to do for the other, and this do often embargoed by the evolution of the disease, which then leading them to uncover feelings of helplessness and suffering.

#### ***Subcategory 2: The support, comfort and hope of the caregiver***

When facing a chronic, degenerative disease like cancer, caregivers showed up sad and powerless in the face of pain and suffering of others, bringing you such feelings. With looks distressed and trembling voices 60% of respondents reported seeking overcoming suffering from assisting others in designing religious faith hope of improvement of their loved one, making it, in a holder that allows to establish a comfort where they find the strength to continue their duties of care, as evidenced in the following discourses:

*"It's very difficult to see this situation here. Has suffered much. I read a lot bible, ask God to comfort me. I left my husband my children to take care of her. "(E11)*

*"What I feel is lacking in conversation with psychologist with my sisters to understand (facial numbness). My sisters cry. Seeking help in the church, pray a lot. "(E15)*

*"I've gotten used to it. Only because I take care of him. I believe from the beginning that he will heal. I read the bible, internet access; I try to distract myself to give him strength. "(E20)*

*"Today I feel calmer accepting and trusting in God that this will pass. Before it was hopeless, but not until today. (sigh of relief) is a disease that when we believe in God it can be destroyed." (E30)*

Caregivers face of difficulties and disappointments encountered in caring for the patient in the terminal phase, anchor their hopes on other types of aid not only doctors, religiosity has been intricately associated with curing cancer, with a transit sentimental comfort that allow overcoming moments of suffering and continue to be careful.

Through social representations assigned to the subject with cancer caregivers, one can understand that the terminally ill patient is being undermined, not only by the stigma of their disease, but also by how their care agents represent them in their lives as a being anchored dependencies and constraints.

Understand that your deceased family can no longer perform their activities as before, be active in charge of the home and of his own life, is to go against a hidden liability in this system of family relationships, which appears whenever a family member sick, ie, designation of who will be the provider of care, and how to render that care, if it will be shared among the remaining members or will only focus on the figure of a single caregiver.<sup>14</sup>

During the choice of who this guy is, is not always the one who has greater feelings of love and affection for the other, sometimes that choice is processed in figure who is closest or even those who have more time available. It is believed that, when caring for a patient beyond cure, and if the choice of caregiver was based on feelings of moral obligation will require a greater effort caregiver to reframe their relationship with the patient and develop strategies to deal with the finiteness of life.<sup>15</sup>

The relationship with the patient at the end of life is extremely important, because palliative care to improve the quality of life even at the maximum of its possible functions, thus the choice of who will be the provider of care is directly related to the social representations that it will direct to be careful because these are social representations of knowledge created in the social environment in which caregivers belong, being shared through language among its members and restructured through the life stories of each, present in their daily guiding their actions, their choices and their real world of care to another.<sup>10</sup>

Thus, when caregivers reveal that being careful is dependent and limited also reveal through their social representations, that their relationship to it is full of care actions, since being is not an active agent of self and thus needs the other, these actions marked the speeches prepared by the interviewees as being a phenomenon full delivery of effort to complete each other's needs.

Given this scenario, if the caregiver who is assigned to care even aware of the limitations and dependencies, represent the subject as predisposed to improvements and health gains can positively encourage the realization of practical care, untying the same objectification reported by caregivers as synonymous proponent of fatigue and exhaustion.

Participation in care/care should be positive, even after a lot of commitment and effort, because the health care of a terminally ill be a social requirement of perfection and

omnipotence remain in day-to-day caregivers to cope with patients.<sup>16</sup> The suffering of the caregiver in these circumstances, as reported by the group, is extreme.

However, the caregiver, dealing with grief, fear and despair on the other, and this leads often to relive personal moments of suffering too. So the group through their personal realities and experiences shared in common creates representations, suffering and helplessness on the other led them to identify with the person suffering at end of life, since the process of empathy implicit in some speeches, guided them to reflect that all care even when expressed in the best way possible will not be sufficient to prevent the inevitable factors of cancer evolution.

In these circumstances, caregivers emanated suffering, crying and nervousness to sift through their minds and realize your family in a situation of imminent death, so the fear of losing it and helplessness of not knowing how to help lead them to an apparent frustration and a delivery of always wanting to give their best to compensate for the other .

However , when we observe this behavior and delivery of suffering on the lens of the health/disease process, we realize that participation in care is the resulting set of " impressions" and experiences gained through the divisions of this process with the group of caregivers,<sup>17</sup> where sometimes the subjects take different dialogues, but with similar contexts, which allowed us to decode a parallel reality to care, the presence of the projection of healing and overcoming suffering in social media groups as caregivers and divine entities.

Social representations now present themselves as a tool for social support, allowing caregivers to organize themselves socially forming a network of interpersonal ties, forming groups and enabling interaction among individuals, providing a sense of support and protection to caregivers involved in form that enables them to overcome the suffering, fear and helplessness of caring for others.<sup>18</sup>

Regarding social support, concerns a reciprocal process regarding any information or assistance offered by people or groups to which caregivers usually maintain contacts and produces a positive effect on the practices of the recipient or the care giver. It is having someone to count on in difficult situations to receive, for example, material assistance, and emotional or affective furthermore relates to realize valued in groups of caregivers to which they belong.<sup>6</sup>

Social representations assume this role with caregivers through the act of re - presentation of knowledge, which is in the midst of which the subject of care through dialogue with other members of their group membership transfer what disturbs you, what threatens their relations to take care from the outside to the inside, ie, its reality for your thoughts.<sup>10</sup> Thus, the concepts and perceptions emanating about their experiences intertwined with the placement of the context of care for the terminally ill patient presents on decoding which makes what was unusual in common, in the unknown known.<sup>19</sup>

The social support offered by social representations as noted in the speeches of caregivers seems to increase the capacity of the same in dealing with situations of care and stress and suffering by caring , by modifying the way they perceive and face care for terminally ill family, a fact observed in the expressions of relief and hope represented during interviews. We believe therefore that the base of this strengthening, this hope is to

increase the confidence and the perception that social representations as provide support in coping with problems.

Social representations behave this way because they are socially produced forms of knowledge, constructed through social interactions with the world, with care and with the subject, from the grouping of sets of meanings that make sense to allow facts new or unknown found in the day-to-day, as care, thus forming a shared knowledge, general and functional for caregivers.<sup>20</sup>

## CONCLUSION

The care of terminally ill individual was represented as a chore, since the representations assigned by the carers interviewed were anchored with the idea of exhaustion, which confirms that the care was provided in a few moments with the requirement that there is then the ideal concept care, which is to meet each other's needs and satisfaction with care domain.

Caregivers also represented his assistance associated with a feeling of anguish, the suffering is with the object of his care, or dependency on other has for you, and powerlessness that the caregiver feels when something exceeds your ability to watch your receiver care, seeking social support social representations reveal the support for planning a more informational and empowering this care.

The caregiver in this approach must respect the uniqueness and complexity of each subject, and that is humane and holistic care, it becomes essential to use various means of communication (verbal and nonverbal) between the caregiver and the care receiver, so that fosters the emergence of social representations about the positive act of care among caregivers, so that the perception and understanding of being terminally ill is full.

The nurse in this scenario should take ownership of such representations, because these enable the professional to have access to a vast field for research to understand the various relationships established in the area of care to the individual, such as those that are built on individual and collective experiences of family caregivers of individuals suffering from terminal cancer.

It is valid to point out that to guide the individual to take care of another need not neglect taking care of themselves and who meet the other is an act of giving and not compulsion, for when it becomes the present, in addition to being characterized as a burden, foster caregiver in a variety of illnesses, such as fatigue and stress, which ultimately implying a reduction in the act of providing care, thus disharmonizing assistance.

Considering this fact and knowing that caregivers will assume care, it is necessary that nursing promotes strategies that facilitate the involvement of health care providers, family and patient in preparation for discharge and home care, and the development of holistic care centered on beneficence and promoting autonomy and independence of being.

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