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SOCIAL REPRESENTATIONS OF THE FAMILY CAREGIVER ABOUT PALLIATIVE CARE IN TERMINAL PATIENTS

*Representações sociais do cuidador familiar sobre cuidados paliativos em paciente terminal**Representaciones sociales del cuidador familiar sobre cuidados paliativos en pacientes terminales*Sílvio Éder Dias da Silva¹ Márcia Aparecida Ferreira de Oliveira² Jaqueline Alves Ferreira³ Jeferson Santos Araújo⁴ Diego Pereira Rodrigues⁵ Diana Madeira Rodrigues⁶ 

ABSTRACT

Objective: to analyze the social representations of family caregivers about palliative care in terminally ill patients. **Method:** the study was descriptive, using a qualitative approach. For the interpretation of the results, the Theory of Social Representations, created by Serge Moscovici and Denise Jodelet, will be used as a theoretical contribution. The research was carried out with 30 family caregivers of patients with end-stage cancer. Data collection was carried out through semi-structured interviews and thematic analysis technique.

Result: after data collection, the dimension of the family caregiver and the inserted environment of social representations were observed. **Discussion:** The theory of social representations, linked to the area of family caregiver health. **Final considerations:** the social representations of the family caregiver made it possible to identify the true extent of daily issues in the professional routine.

DESCRIPTORS: Cancer; Palliative care; caregivers; Social representations; Oncology patients;

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RESUMO

Objetivo: analisar as representações sociais dos cuidadores familiares sobre os cuidados paliativos em paciente terminal. **Método:** o estudo foi do tipo descritivo, utilizando abordagem qualitativa. Para a interpretação dos resultados será empregado como aporte teórico a Teoria das Representações Sociais, criada por Serge Moscovici e Denise Jodelet. A pesquisa foi realizada com 30 cuidadores familiares de pacientes com câncer em estágio final. A coleta foi feita por meio da entrevista semiestruturada e a técnica de análise a temática. **Resultado:** após a coleta de dados, observou-se a dimensão do cuidador familiar e o meio inserido das representações sociais. **Discussão:** a teoria das representações sociais, vinculada a área da saúde do cuidador familiar. **Considerações finais:** as representações sociais do cuidador familiar possibilitaram identificar a verdadeira extensão das questões diárias no cotidiano profissional.

DESCRIPTORIOS: Câncer; Cuidados paliativos; Cuidadores; Representações sociais; Pacientes oncológicos;

RESUMEN

Objetivos: analizar las representaciones sociales de los cuidadores familiares sobre los cuidados paliativos en pacientes terminales. **Método:** estudio descriptivo con enfoque cualitativo. Para la interpretación de los resultados se utilizó como aporte teórico la Teoría de las Representaciones Sociales. La investigación se llevó a cabo con 30 cuidadores familiares de pacientes con cáncer en etapa terminal. **Resultado:** se observó la dimensión del cuidador familiar y el ambiente inserto de las representaciones sociales. El cuidador no es un simple miembro de la familia, sino alguien que sufre junto con el paciente, especialmente aquellos con cáncer terminal, y por lo tanto también necesita orientación para su cuidado físico y emocional. **Discusión:** La teoría de las representaciones sociales, vinculada al área de la salud del cuidador familiar. **Consideraciones finales:** las representaciones sociales del cuidador familiar permitieron identificar la verdadera extensión de las cuestiones cotidianas en el cotidiano profesional.

DESCRIPTORIOS: Cáncer; Cuidados paliativos; cuidadores; Representaciones sociales; Pacientes oncológicos.

INTRODUCTION

Worldwide estimates show that in 2012 there were 14.1 million new cases of cancer and 8.2 million deaths. There was a slight male predominance in both incidence (53%) and mortality (57%). In Brazil, the estimates for 2014, which are also valid for 2015, are 576,000 new cases and according to the World Health Organization's projection, 27 million new cases are expected in the world population by 2030. This pathology is characterized by the abnormal growth of cells in the body, which can affect various organs and tissues and generally evolves slowly and chronically.¹

Thus, having a life-threatening disease can result in a slow death, with a lot of physical, mental, social and emotional suffering. In cases where the pathology is at an advanced stage, in which curative treatment modalities no longer produce the desired efficacy, the therapy to be instituted is palliative care. Palliative care is not based on protocols, but on principles, one of which consists of offering a support system to the family, since the family not only actively participates in the care process, but also deserves to have its needs met.²

Palliative care is not based on protocols, but on principles. We no longer talk about terminality, but about life-threatening illness. Care is indicated from the moment of diagnosis, expanding our field of action. It also doesn't talk about the impossibility of a cure, but about the possibility or otherwise of disease-modifying treatment, thus dispelling the idea of "nothing more to be done". For the first time, an approach includes spirituality among the dimensions of the human being. The family is remembered, and therefore assisted, even after the patient's death, during the mourning period.³

Thus, according to Moscovici, Social Representations consist of a form of guided recognition that allows us to understand a given social context, created by social actors belonging to a group,

considering reality through cultural, social and historical aspects, making it possible to understand their behavior. In this context, the Theory of Social Representations (TSR) allows for the understanding and analysis of common sense, in which the opinions, precepts and beliefs that permeate the caregivers of cancer patients in palliative care are understood, being essential to know the behavior exercised and the adversities faced by these people.⁴

Palliative care offers a support system that enables the patient to live as actively as possible until the moment of death, assists family members during the patient's illness and helps them cope with bereavement. It should be started as early as possible, along with other life-prolonging measures such as chemotherapy and radiotherapy, and include all the necessary investigations to better understand and control stressful clinical situations.²

Therefore, the dissemination of information and knowledge about the issue and problem of caring for cancer patients in palliative care is essential. It is up to the professionals in the multi-professional team to know how to deal with the needs of each patient, as well as their family members, who often need more help from the team than the patient themselves. In this context, the aim was to analyze family caregivers' social representations of palliative care for terminal patients.

METHODS

The study was descriptive, using a qualitative approach. In order to interpret the results, the Theory of Social Representations, created by Serge Moscovici, will be used as a theoretical contribution. This theory is defined as the knowledge that individuals have about a certain subject and based on this, they

build their daily practices, sharing them with the group to which they belong. This theory works with the cognitive aspects of the subject and their interaction in the social environment, acting to transform them, showing how they represent themselves and construct their reality in relation to something.⁴

The qualitative approach objectively analyzes the phenomenon studied and when it comes to the field of social research, this approach aims to understand the universe of meanings, aspirations, beliefs, values and attitudes belonging to the individual's social context.⁵

In this sense, the descriptive study aims to observe, record, analyze and correlate facts or phenomena without adulterating them. In other words, it seeks to find out, as precisely as possible, the frequency with which a phenomenon occurs, its relationship and connection with others, its nature and its characteristics.⁶

Research setting and participants

The research was carried out at the Ophir Loyola Hospital (HOL), located in the Metropolitan Region of Belém do Pará. The institution is a reference in cancer treatment in the public health network in the state of Pará, at all stages of the disease.

Research participants

The research was carried out with 30 family caregivers of patients with end-stage cancer, whose choice of subjects will be based on convenience sampling. Inclusion criteria: family caregivers over the age of 18, of both sexes, who will express their willingness and interest in taking part in the study after learning about the objectives and signing the free and informed consent form. Caregivers who had been involved in caring for terminal cancer patients for less than a month were excluded.

Data collection technique

Data was collected using a semi-structured interview technique guided by a script. This method allows the researcher to discuss the proposed topic and have the freedom to add new questions to the script in order to deepen and clarify points that they consider relevant to the objectives of the study, while allowing the interviewee the free will to express themselves on the subject addressed without failing to follow a script.^{5,7}

The form is subdivided into two parts: the first will look at the profile of the participants, and the second at the subjects' social representations of palliative care and its implications for terminal cancer patients. Regarding this semi-structured interview, it should be noted that this option arises from the need to direct the research, thus facilitating the gathering of data taking into account the proposed objectives.⁸

Therefore, the place of choice for the interviews is at the discretion of the participant, and can be in the hospital itself in a private room or in their home. The only requirement is that the person being cared for is not present during the interview, as the participant may conceal certain information, thus compromising the development of the study.⁸

The Data Analysis Technique

The results obtained were analyzed using the thematic Content Analysis technique. This analysis technique was chosen

because it highlights the core meanings of the participants' statements and classifies them into categories.⁹

The authors formulated a guide consisting of six phases in the use of thematic analysis, and these phases can either follow consecutively or go backwards during the process. They are as follows: (1) Becoming familiar with the data itself - transcribing the data, reading and re-reading the data, writing down initial ideas; (2) Generating initial codes - coding interesting features of all the data in a systematic way, comparing the relevant data with each code; (3) Searching for themes - grouping the codes into potential themes, bringing together all the relevant data for each potential theme; (4) Reviewing the themes - checking the working themes against the coded extracts (phase 1) and the data as a whole (phase 2), generating a thematic analysis map; (5) Defining and naming the themes - ongoing analysis to refine the specifics of each theme and the overall story of what the analysis has learned, thus generating clear definitions and names for each theme; (6) Writing the report - the final integration of the analysis by selecting clear descriptions, convincing extracts, to use as examples, relating to the final analysis, returning to the study question(s) and the literature, producing a research report.⁹⁻¹⁰

Risks and benefits

All resources were used to provide reliability, privacy, data confidentiality, image protection, non-stigmatization and guaranteed non-binding of information obtained during the research. In no way will any data from this research be a direct or indirect source of harm to the participants, as they will not be identified or exposed at any stage of the process.

Ethical aspects

The project will comply with Resolution 466/12 of the National Health Council, which regulates research involving human beings. Participants will be guaranteed anonymity before data is collected.

Participants in the research were offered and duly informed, by reading and explaining the Free and Informed Consent Form (FICF), which will contain all the information about the nature, reason, objectives and procedures of the research, data and contacts of the researchers, rights of the participants and other relevant information contained therein. It should be noted that this project has been approved by the Research Ethics Committee of the Ophir Loyola Hospital, under opinion number: 1.442.346 and CAAE: 48628215.2.3001.5550.

RESULTS

Common sense and cancer

Since the theory of social representations develops from social thought, it is important to know about the knowledge of caregivers when it comes to cancer and how this knowledge was passed on. In this way, we can identify how common sense is present in the interviewees' responses, and also how the media are essential for transmitting information.

"It's a bit of a harsh word. It's knowing that the person is unlikely to live. In all the cases I've seen, people die. When you say it, you immediately think of death." (E1)

"Through the media such as newspapers and television." (E2)

"At first, it's the end. It's something fatal, serious, with no cure.;"
"On television and in the hospital itself by the professionals. And also because I've had breast cancer in my family." (E3)

Common sense has always been and always will be part of society, and it is from this that studies begin. And it was from this free association of ideas that the studies for this project began. In the beginning, it is always difficult to see a loved one in a debilitated state, but caregivers always try to do their best with a lot of love so that their loved one has a good quality of life. At this early stage, it was easy to see the similarities between the caregivers' ideas about cancer and about caring.

"I think it's a very treacherous disease, very cruel. You have to have a lot of love, affection. It's an act of love." (E8)

"I think first of all... When I thought about caring, it was difficult. I try to see how all the care is done. You have to dedicate yourself a lot, pay attention. Actually, there have been cases in the family, but I was always afraid." (E 22)

Although most people have little knowledge of the disease, this is essential if we are to learn more as the treatment progresses. And thus provide better assistance to the sick family member, also serving as a warning in the event of future problems. In this way, the professional team is always important to help pass on information.

"It's a hereditary disease, especially since I'm a granddaughter. My mother had breast cancer and I have to take care of myself. Cancer is very silent, if you don't have tests it's already advanced and then there's no way to treat it, it's difficult. Because the treatments are more aggressive than the disease." (E22)

Palliative care, the patient and caregivers

It is important that palliative care begins as soon as the cancer is diagnosed. The multi-professional team will be ready to receive the patient and provide all the necessary support. However, this team will not always be made up only of trained professionals; the family caregiver also provides this care, as they also aim for the quality of life and well-being of their loved one, as seen below:

"Today she needs me a lot. She's become very dependent. She needs not only the care of the doctors, but also her family... I left my husband and my children to look after her." (E1)

"It's having all the affection, patience to be by her side. I left my children to look after her..." (E3)

"Bathing her, cleaning her, feeding her, carrying her on my lap as if she were a baby." (E6)

The whole treatment process is very uncomfortable for the patient, sometimes they even think about giving up, which is why specific attention needs to be paid to their particularities. And that's when family caregivers do their best to ensure that the patient doesn't go through this situation alone, and that's when caregivers do their best to ensure that their loved one has a better quality of life.

"It's very difficult for her today. Because she didn't accept the treatment, she didn't do hygiene. Today we do everything for her because she can't do it on her own, she needs us to take care of her hygiene. For example, she won't take a bath on her own." (E3)

"Look, we try to offer the best care. The limitations, at the moment he's still not aware of them. He doesn't even walk or sit." (E7)

Palliative care provided by family caregivers makes all the difference during treatment. That's why the knowledge they carry is so important; they are always looking for more so that they can care for the patient and provide a better quality of life.

Caregivers and their social representation

When a person is diagnosed with an illness, not only do they need care, but also their family. In most cases, the caregiver of a cancer patient is their family member, who always goes through difficulties together with the patient. That's why it's so important that the caregiver is well supported throughout the treatment. This is how we see caregivers working with their sick relatives:

"My care I take to make sure he's not defecated, feverish, cold... I help him with his bath, cut his nails, shave and cut his hair. I worry about his diet and hygiene. If he's peed." (E10)

"I help with bathing, when it comes to medication, I try to be attentive, the IV, when it comes to feeding, hygiene, all of this I help with." (E22)

Caregivers are sometimes considered just companions, but they are the ones who know and take care of the patient's particularities. And only they know how difficult it is to look after the patient and themselves at the same time. Giving up their duties in order to devote themselves completely to someone else becomes a difficult moment for caregivers, but they still struggle to meet all of someone else's preferences.

"...I left my children to look after her..." (E3)

"I feel very sad. But I try to make sure she doesn't notice. I try to show her strength, to let her know that she's not alone." (E12)

"I feel bad in this situation. I ask God for a lot of help. Help me to be patient, give me strength. May God work a miracle." (E14)

It is therefore clear that the caregiver is not just a family member, but someone who suffers along with the patient, especially those with terminal cancer, and therefore also needs guidance for their physical and emotional care.

DISCUSSION

To have a notion of Social Representation is to know that it was conceived in order to explain what unites each person to a particular group or society and what makes them act together. The Theory of Social Representations (TSR) focuses on how subjects construct their representations based on their experiences, their participation in different groups, their position in the social structure and their knowledge, both formal and informal.¹¹⁻¹²

TSR is about knowing how representations are constructed and how what is unfamiliar is incorporated into consensual universes. The construction of these representations involves two formative processes: anchoring and objectification. Anchoring has the function of giving concreteness to a given concept, in other words, giving materiality to an abstract object, transforming what is represented into an object, in other words, an individual will materialize an abstract idea as a function of their own personal experience and creativity, as well as the norms and values that govern society. Objectification, on the other hand, makes the represented concept or object familiar, it is taking the concrete and giving it meaning, in other words, it refers to any new element that will be interpreted by the individual according to a previous frame of reference, in other words, everything is interpreted according to old paradigms, so it supports the permanence of pre-existing beliefs and systems of interpretation.^{11,13}

From the moment it was created, TSR has fought against the idea that common sense is a mistake, and thus seeks to understand its functions and the needs to which it responds. What to someone else is considered wrong, to the subject of knowledge is meaningful and totally relevant. This being the case, common sense does not disappear and is never replaced by science; it defends its space and becomes, in late modernity, an "enlightened common sense", which is open to both beliefs and science.¹⁴

The TSR reinforces that social communication is a vehicle for the individual's active role in the social construction of everyday reality, since it is through social communication that a social object is elaborated by the community, with the aim of behaving and communicating socially. In this way, social representations, as well as being constructed, are disseminated through interaction between people by means of communication. And it is through this communication that agreements are negotiated in order to know how to deal with the events that occur in reality.^{11,13}

Communication is essential in the daily lives of patients, their caregivers and the multi-professional team. And, according to Moscovici, through the art of conversation, a community of meanings is created among those who take part in it, and these meanings are carried by social representations in such a way as to consist of a set of concepts, propositions and explanations that originate in everyday life through interpersonal communications. Social representations are sustained by the social influences of communication, and thus constitute the realities of caregivers' daily lives, which is why they serve as the main means of establishing associations with which individuals connect to one another.^{12,15}

Palliative care uses a multi-professional approach to meet the needs of both patients and their families. It encompasses various mechanisms to ensure the patient's well-being, ranging from the relief of pain and distressing symptoms to a support system to help the patient and their family cope with death and bereavement. The focus is on care, integrating medical, nursing, psychological, nutritional, social and spiritual actions, as these also influence the type of death the patient will experience.¹⁵

In this sense, the family caregiver is seen as having to live with the illness and its consequences in order to provide better care. However, care is more than an act or service, it is an attitude that is a proof of love, of contribution, of giving, of meaning so that life is the greatest good. This is why the caregiver must seek out and learn about the normative and conceptual aspects surrounding their practice. They carry with them theoretical questions about care and, in order to understand their social representations, it is necessary to delve into the consensual world of which they are a part, to understand the group to which they belong, its symbols, beliefs, languages and values.^{12,15}

The family caregiver plays a very important role in caregiving because, as a member of the family, they know the particularities of their loved one and their support makes all the difference during this time. The caregiver is seen as having special qualities due to the traits of love, humanity, solidarity and giving towards others. This is clearly shown in some of the reports, when the caregivers said that they had left everything, their family, their home, their work, just to support their hospitalized loved one. In this case, TSR allows us to understand how these caregivers understand their world, from the environment in which they maintain social relationships to aspects of their own identity with care.¹⁴

The social representations of caregivers in relation to care make it possible to know what feelings they acquire when they perform the act of caring, also favoring that this popular knowledge becomes known and has a great social impact, thus crossing generations and being part of several moments, which refer to the preservation of health and life.¹⁵

FINAL CONSIDERATIONS

It is clear that the caregivers already possessed the consensual knowledge that was passed on to them through the media or through communication with other people who also carried this knowledge. This shows that the Theory of Social Representations is correct in presenting common sense knowledge as a universe with a major impact on society. In the field of health, family caregivers are of paramount importance in caring for their loved ones, especially when this care is palliative, as it involves various issues that greatly affect the patient's quality of life.

These caregivers are often worn down by various situations, as they give up almost all of their priorities to care for someone else who needs greater care, and yet they always care with love, affection and seek to learn more to give their loved one the greatest comfort at this difficult time.

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