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RESEARCH

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The consensual universe of family caregivers and their standing in the care services: a social representation study

O universo consensual do cuidador-familiar e sua ancoragem dentro do cuidado: um estudo de representações sociais

El universo de consenso cuidador de la familia y su atención en el ancla: un estudio de representación social

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ABSTRACT

Objective: The study's aim has been to analyze the relatives' representations of patients under palliative care.

Methods: It is a descriptive research with a qualitative approach, which is based on the Serge Moscovici's Social Representation Theory. **Results:** The research's results showed that death is described as a final physiological stage, in other words, a technically well-ordered process of nature and the only certainty that we have in life. Moreover, death can be understood as an incomprehensive mystery, an unacceptable absurd or can be treated as a taboo or a social representation of a personal universe. **Conclusion:** Although a patient can be cured through standard treatment, he needs either special or palliative care.

Descriptors: Social representations, palliative care, death.

RESUMO

Objetivo: Analisar as representações de familiares de pacientes em cuidados paliativos. **Métodos:** Trata-se de uma pesquisa de abordagem qualitativa de cunho descritivo, a qual visou conhecer as representações de familiares de pacientes em cuidados paliativos, sendo que esta pesquisa baseou-se na Teoria das Representações Sociais criada por Serge Moscovici. **Resultados:** A figura da morte é caracterizada como um estágio final fisiológico, ou seja, um processo tecnicamente ordenado e natural da natureza; de forma geral, é a única certeza que possuímos na vida. A morte pode ser vista como um mistério incompreensível, como um absurdo inaceitável ou como um tabu ou

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uma representação social de um universo próprio e pessoal. **Conclusão:** Aprofundando o resultado, registramos que, apesar de este paciente não possuir mais possibilidade de cura mediante as terapêuticas convencionais, ele necessita de cuidados especiais ou cuidados paliativos.

Descritores: Representações sociais, Cuidados paliativos, Morte.

RESUMEN

Objetivo: Analizar la familia de las representaciones de los pacientes en cuidados paliativos. **Métodos:** Se trata de una investigación de enfoque cualitativo de carácter descriptivo, cuyo objetivo era conocer a la familia de las representaciones de los pacientes en cuidados paliativos, en esta investigación se basa en la teoría de las representaciones sociales creadas por Serge Moscovici. **Resultados:** La figura de la muerte se caracteriza como una etapa final fisiológica, es decir, un proceso técnicamente ordenada y natural de la naturaleza, esto generalmente es la única certeza que tenemos en la vida, donde la muerte puede ser visto como un misterio incomprensible como un absurdo inaceptable o puede ser tratado como un tabú o una representación social de un universo personal propio. **Conclusión:** La profundización del resultado, registramos que aunque este paciente no posee, pero se puede curar con terapias convencionales, que necesita cuidados especiales o cuidados paliativos.

Descriptor: Representaciones sociales, Los cuidados paliativos, La muerte.

INTRODUCTION

It is possible to be noticed that the family is inserted into the caregiver's anchoring amid the new construction of care. Even the family members do not understand the disease reality, they formalize roles using common sense or consensual universe. Thus, family caregivers are needed for the construction of the family care.¹

Once conventional therapy no longer improves the patient's condition, a more humanized care increases his survival time and diminishes the emergence of intercurrent diseases, pain, and suffering. Palliative care must be a basic human right available to hospitalized patients who are in advanced stages of a disease, such as cancer, because it is the only hope for a better life quality.¹

Death is understood as a final physiologic stage, in other words, a technically well-ordered natural process, and the only certainty we have in life. Being irrevocable and certainly one of the biggest questions of our society, death is essential to our existence and covered by mystery, seduction, curiosity, anxiety, fear, and suffering.²

Terminal patients need palliative care: active and total interventions when a disease cannot be improved by conventional treatment. When there is no possibility of cure, the control of pain and other psychosocial and spiritual symptoms become the priority to offer a better quality of life to patients and their relatives, where many of palliative care aspects are also explainable throughout the disease its treatment.³

The objective knowledge of the family caregiver's role through social representations allows the opportunity to analyze the relatives' anchoring in palliative care, which in turn allow a bigger understanding of the difficulties

faced by the family caregiver. This results from the family caregiver-patient binomial anchoring.⁴

By the facing and accepting the situation when providing palliative care, family caregivers exert an important role in the care development, which may be considered a means to support the patient and his family. However, intercurrent diseases may change the family's structure, where one or more relatives take the responsibility of a caregiver to adapt to the patient's needs.⁴

Anchoring, under the family context of the words "death" and "to die", is responsible for the attribution of a greater or lesser personal meaning. As a result, humans are social beings who have well-defined life and death process.⁵

Social representation is described as knowledge anchored in common sense and the individuals' everyday life, where the behavior of the social agents is studied through the sharing of life stories and ideas. This theory focuses on the cognition of the subject, his expression in society, and his role as an interferer of these relationships and collective constructor of this reality.⁴

The contact with terminal patients in hospitals is done mostly by the nursing team, which is the first information source for the family caregiver. Nonetheless, the relationship between the family caregiver and the nursing team causes problems to the relatives that are waiting for a solution, and to the nursing team that cannot provide a solution enough to the relatives' needs.⁶

Since that death is a fact feared and avoided by family, we understand the representations present in the family caregivers' feelings and speech as a palliative care anchored in the feeling of losing someone. In this situation, the nursing team may provide help or unresolved conflicts, in which the reality-scape mechanism or even its possibility is present. Therefore, for the relatives, the meaning of death is inevitable; it is not influenced by the treatment location, which can be a hospital or patient's home, where he creates defense mechanisms to face these situations.²

METHODS

It is a descriptive research with a qualitative approach, which aimed to know the palliative care representations of the patient's relatives. Likewise, by using the Serge Moscovici's Social Representation Theory, we have described and interpreted the relatives' feelings and experienced situations to establish a connection between the literature and what was experienced by the interviewers.⁷

This study meant to understand the social representation phenomenon within the social research area and the relatives' consensual universe about family caregivers, as well as describe the meanings, actions, values, and beliefs in the individual's social context and life story. In this sense, the chosen method does not prevent the researcher from implementing the scientific empiricism logic if it is clearly defined.⁷

This study has had ten relatives of cancer patients participating. The inclusion criteria were as follows: family caregivers monitoring the patient in an oncology

palliative care clinic for at least six months, and having at least 18 years old.⁷

This study was carried out in an oncology palliative care clinic in a referral hospital located in the city of Belém, Pará State, Brazil. Data were collected by semi-structured interviews composed of questions about the interviewees' condition as a family caregiver and their representations according to the patients.⁷ Afterwards, data was submitted to Content Analysis, which favored the synthesis of the cores that compose the communication and construction of the representations, and then contributing to a better understanding of the analyzed data.⁸

The following six essential steps for obtaining the results were chosen through the comprehension of the discursive context: 1) data familiarization, which is the transcription and exhaustive reading of data, and initial annotations; 2) Systematic code generation; 3) Theme search, in which a selected code group are transformed in possible themes; 4) Continuous theme revision; 5) Theme definition, which is the analysis and improvement of each theme; and 6) Final report, suggested by an auto-explained interpretation, thus concluding the data aggregation after choose the empirical categories that influenced the study.

This study was approved by the Research Ethics Committee, under the CAAE No. 48628215.2.3001.5550, and according to the Resolution No. 1.442.346. The ethical aspects were preserved by the relatives' written permission after the explanation of the study's purpose, where the information about them were coded to ensure the anonymity according to the Resolution No. 466/2012 from the National Health Council, which addresses research involving human beings.

RESULTS AND DISCUSSION

The caregivers facing the possibility of death

Death can be understood as an incomprehensive mystery, an unacceptable absurd or can be treated as a taboo or social representation of a personal universe. Therefore, it is an implacable reality that causes a real panic in human beings related to their personal and social references, where fear is the most common response in the face of death. The fear of dying is universal and affects all human beings.⁹ The fear of death is present in the family caregiver's everyday life of a terminal cancer patient since the term "palliative care" is intimately anchored in death, suffering, and pain. Thus, this phase becomes terrible because of his relative's imminent death, as stated by the following speech:⁹

We never know what time is the moment... Sometimes I even feel fear to sleep because, you know, it's very complicated... (E2).

The uncontrollable fear can only be minimized by the consciousness or by accepting the terminality. This is possible through accepting the representation of care in all of its dimensions, which makes the patient capable of dealing with the painful process of dying and the moment of death. However, this process of awareness and acceptance is extremely difficult and complicated for the family caregiver:²

Look... This is complicated because at the same time that I think they accepted it, that they are slowly conformed. At the same time, I see that it's not like this, you know. This is not the reality and they don't accept it... (E2)

So this is the life. I think, you know, this is hard; nobody's going to accept it... (E5)

The construction of the death representation goes through many stages of negation, isolation, and temporary ego mechanisms of defense. Against the physical pain in the face of death, generally, the negation and isolation do not persist for a long period. In one of the interviews, at the moment of knowing the relative's terminal condition, a family caregiver tried to negate it, not believing in the hard reality, as stated in the following testimonial:⁹

It was the worst moment of my life... When she told me I wasn't believing it at all. (E4)

The interviewees reported that they experienced anger, depression and finally acceptance when facing the pre-death situation of their relatives. Also, during this study, all of the interviewees already were in the process of accepting their situation since they no more experience despair nor they deny the reality. They reported that this situation is difficult and they do not feel prepared to face their relatives' death:²

So, this is difficult, but we know it; we know it... I know it; we know it, but we never are prepared. It's logical; we never want that a relative of ours die. (E5)

Health care workers must monitor and guide not only the patient but also their relatives when they are working as a family caregiver during all the process of the patient's death. However, talking to them about this subject is an extensive, difficult, and essential task since talk and communication are present and represented as affection, attention, and support, being possible that the caregiver faces the death of his relative with more tranquility and understand the reality of this hard prognostic.⁹

Suffering and the consensual knowledge creation

Suffering is present in everyday life of a family caregiver since he and his relative share the experiences: pain, anguish, and suffering in the reality of terminal cancer patient:⁸

When somebody dies here at the corridor, I try to smile to her, play with her... When we keep talking, you know, we see that her problem is serious. I always say to myself “my mother doesn’t have anything, my mother doesn’t have anything, my mother doesn’t have anything, my mother doesn’t have anything” so that I can keep like this: smiling, playing... (E9)

To suffer less, family caregivers try to rationalize their suffering, and when this happens, they find a new sense of joy. This change is not determined by pain complacency, but by the revelation of an occult sense of joy and the refusal of easy pleasure. They try to find a new way of living in their everyday life, as highlighted by the following testimonial:⁶

This is very difficult. Sometimes I feel like saying this... So I got desperate, and then I called my brother saying “Come here because I can’t take this anymore”. Sometimes I feel like this; sometimes I feel like breaking down, you know... (E4)

Family caregivers comprehend their role by assimilating the ideas of how to be a caregiver so that they can consider suffering to be an exacerbated symbolism. Nevertheless, suffering means enduring or setting a patience trial. We found that this force is present in both the family caregiver and patient:⁵

We take out strength from nothing, mainly in this sense, because I look back and I see my problem is nothing compared to her problem... (E4)

I think this has helped her to react to the medication a lot. She went very, very bad, you know, and today I look at her and I see she take out an impressive force... She amazed me... You know, sometimes when I want to fall or weaken and I look at her and I see she’s there with that kind of drive and... Gosh! I can’t weaken... (E2)

The representation linked to the comprehension of this reality in the family’s daily life is responsible for the construction of meanings related to pain; it is present in the life and death of the patient, as well as in their relatives. This materialization provides the team resources for planning therapeutic actions and knowing the patient’s existence. Thus, this communication is necessary because it means searching, within the caregiver’s life, ways to minimize pain and show hope.⁹

Spirituality: support for those who suffer and consolation for those who cry

The construction of an individual faith is the first anchor in collective and family representations. Regardless of history age or religion, humanity has been seeking help from spiritual forces and from the power of invisible or visible beings to cure diseases. Seeking cure through faith provides a meaning or decisiveness to the patient’s problems; it may also offer a sense to his life. Thus, spirituality is a strong representation and a search for survival and symbolical protection.⁴

The social representation results from a process of value construction and feelings anchored in the relative’s life, experiences and feelings. This process caused families to assume the breaking of taboos and religious prejudices to seek a comfort through hope and faith in the face of pain and suffering, thus believing in the anchoring of the word “miracle”, as pointed out in the following testimonial:⁴

We keep getting hope because while there’s life, there’s hope. So we can’t give up; we just think in giving quality of life, thinking in the fact that he can suddenly get cured because our life belong to God. Ok, so we believe in the medication, in the physician and in God; we believe that God can suddenly make a miracle; we think that he has to stay here longer, you know. This is a friendly spirituality since he deserves to stay here longer with us. (E7)

But we have faith in God so that she’s going to get cured. (E1)

So, even if you know that this thing still don’t have a cure, there’s always hope that you can see her getting better a little bit; our hope of... Hope in God... We’re here to believe in a miracle. (E5)

Here, we have noticed that the search for a religion to maintain faith and the construction of a social representation of religion are ways for facing and overcoming suffering, as well as for obtaining strength for maintaining life, evidencing the desire of trying to overcome the great injustice: the loss of a loved one. In this sense, the strength of religion helps to face the most dramatic experiences in everyday life:³

Have faith in God. We have faith in God that the pain will be gone because He knows she can be cured. (E9)

You know, to keep going your daily life one has to be in direct harmony with Jesus. Because of this, you also have to be with your mind equilibrated and have to have faith and much equilibrium. (E7)

I’m sure that she’s Christian. So, the guys go to the mom’s house; sometimes one person goes there. My mother is Christian; my uncle is Christian. So, I think that... No, I’m sure that she’s contributing so much that we can face all of this suffering. (E4)

At the moment of death, the family must take the role of a true messenger of the universal love, where it is necessary that the terminal patient feel loved and treated as a special and psychosocial being. For this, it is important that the relatives help during the passage, expressing actions and words of affection and love, providing an environment so that the cancer patient can feel profoundly supported.⁴

Concerning the palliative care, the family caregiver represents a construction of a confrontation strategy that allows the expression of a consensual universe or common sense, bringing comfort and trust for the patient in the face of death. The family caregiver helps to formalize the care and take clinical decisions according to the patient's needs, strengthening the bond between them, the family, and the multiprofessional team.⁴

Considering the representation of care, the patient's relatives have experiences that are anchored in common sense or consensual universe. Therefore, through social representations, the relatives become family caregivers, helping their loved one during the passage from the material phase to the spiritual phase. It is required that the family caregiver prepare his mind and heart and decide to face his ego, prepotency, and fear in order to deal with this challenge.²

Consequently, when the patient cannot deny the disease anymore due to the damage that it caused to him, his indignation ends and a resentment of loss arises, where the family caregiver also experiences the depression stage. In this moment, the loss can have multiple types, such as financial burden resulted from the treatment, aesthetic damage, family maladjustment, among others, which consequently will be able to affect the patient. Thus, we need to find the cause of the depression, eliminate it and encourage the patient to embrace the positive side of life.¹

The traditional argument about the observed suffering according to the social representations resumes to rescue the unhappy side of the human life, showing that the suffering may be useful. For instance, it may have medical-scientific uses (it is a symptom), educational uses (it shows our limitations), moral uses, political uses (it allow us to repair an error), and spiritual uses (it opens the paradise doors).⁹

Therefore, the patient's family must deal with death in a different way so that their members may see it as a painful process that destabilizes relationships. Also, they may have the possibility of thinking about their own life and death. The results of this study will help to broaden the understanding of the daily life of family caregivers who assist terminal cancer patients.⁸

The indignation about the process of death favours a better understanding of the factors that hinder the daily routine of nurses who execute palliative care to cancer patients since even though the family caregiver knows about the imminent death of his close relative, he understands his role as a caregiver and develops a necessity of embracement since, from this knowledge, the nurse will be able to use a strategy that may stimulate the presence of the family caregiver near his hospitalized relative.⁵

CONCLUSION

Given the findings, the majority of the interviewees use a representative faith for strengthening themselves and facing the challenge of facing death since knowing that a close relative may be suddenly lost represents a great suffering. However,

they know that they must provide safety and comfort to the relative in his moments of agony, showing that he is special to the family.

Although the patient has no possibility of cure by conventional treatment, he needs special or palliative care, which can be offered by means of attention, affection, and love from caregivers so that they can provide support, comfort and care either in a hospital or home environment, thus providing a better quality of life and reducing pain and fear.

Hence, helping others is a human act of love that requires responsibility and engagement to provide more tranquility, serenity, and peace for the patient. These are synonyms of anchoring when considering the construction of the family caregiver's role. Moreover, these aspects help the caregiver to confront challenges.

In this study, we observed the suffering as a type of learning since, using the patient's suffering, the family caregiver rationalizes his own suffering to find strength and a new meaning for joy. In this sense, the family caregiver has to renounce inconstant movements because he is in another environment outside of his daily routine and understand the necessity of knowing the representations and the daily life of these relatives.

Furthermore, we have observed here that the interviewees were always concerned about their loved ones and ready to take care of them, providing welfare, support and consequently a better life quality. Moreover, these actions must be performed with caution, patience, and with a good mood since they are also performed by the family members and also the health care team, which provided the family social, emotional, physical and spiritual support to confront the life challenges and the possibility of death with efficiency and tranquility.

From those insights, we were able to recognize that the nursing team must be able to transmit affection, comfort, support and safety to all individuals involved in the process of death, not feeling lost in this fear of the unknown events full of anxiety and restlessness, since this require that the whole team develop and exercise the ability to talk and interact with families so that they can understand that dying is an integral part of life, a natural and predictable as being born, and one of the life events that is certain to happen.

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