

## Social Representations of Pediatric Patients' Relatives without Current Therapeutic Treatment

Representações Sociais de Familiares de Pacientes Pediátricos Fora de Possibilidades Terapêuticas Atuais

Representaciones Sociales de Familiares de Pacientes Pediátricos Fuera De Posibilidades Terapéuticas Actuales

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### ABSTRACT

**Objective:** The study's goal has been to describe the understanding of caregivers with regards to pediatric clients without current therapeutic treatment to cancer and its repercussion for home care. **Methods:** It is a descriptive research with a qualitative approach that used the Social Representation Theory. **Results:** The data of this research were obtained through data collection: the free association of ideas, where the following units appeared: Palliative care – the caregiver facing the care; The essence of caring when dealing with limit situations; The oncological child - the need for careful attention; and, Caring for the child at home: a caring family. **Conclusion:** It was observed that the relatives of a child need a follow-up from the healthcare professionals. At the household care, the nurse can offer the necessary information about the main health care at this stage of life; furthermore, they can offer emotional support and also help minimizing doubts about the treatment established.

**Descriptors:** Cancer, Palliative Care, Caregivers, Nursing.

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## RESUMO

**Objetivo:** Descrever a compreensão de cuidadores de clientes pediátricos FPTA sobre o câncer e sua repercussão para o cuidado em domicílio. **Método:** pesquisa foi descritiva, com o emprego de uma abordagem qualitativa empregando a teoria das representações sociais. **Resultados:** Os dados desta pesquisa foram obtidos por meio da utilização de uma técnica de coleta: a livre associação de ideias, emergindo as unidades: cuidado paliativos: cuidador diante do cuidar. a essência do cuidar nas situações limites, A criança oncológica - a necessidade de um cuidar atencioso e o cuidar em casa – um cuidar familiar. **Conclusão:** Observou-se que os familiares de uma criança necessitam de um acompanhamento da equipe de saúde. a nível domiciliar, mais precisamente do enfermeiro para oferecer as informações necessárias sobre os principais cuidados de saúde nessa fase da vida, para oferecer o suporte emocional e minimizar as dúvidas sobre o tratamento instituído.

**Descritores:** Câncer, Cuidados Paliativos, Cuidadores, Enfermagem.

## RESUMEN

**Objetivo:** Describir la comprensión de los cuidadores de los clientes pediátricos de FPTA sobre el cáncer y su repercusión para el cuidado a domicilio. **Método:** investigación fue descriptiva, con el empleo de un abordaje cualitativo empleando la teoría de las representaciones sociales. **Resultados:** Los datos de esta investigación fueron obtenidos por medio de la utilización de una técnica de recolección: la libre asociación de ideas, emergiendo las unidades: cuidado paliativo: cuidador ante el cuidar. La esencia del cuidar en las situaciones límites, El niño oncológico - la necesidad de un cuidado atento y el cuidar en casa - un cuidado familiar. **Conclusión:** Se observó que los familiares de un niño necesitan un seguimiento del equipo de salud. A nivel domiciliar, más precisamente del enfermero para ofrecer las informaciones necesarias sobre los principales cuidados de salud en esta fase de la vida, para ofrecer el soporte emocional y minimizar las dudas sobre el tratamiento instituído.

**Descritores:** Cáncer, Cuidados Paliativos, Cuidadores, Enfermería.

## INTRODUCTION

According to the *Instituto Nacional de Câncer (INCA)* [National Cancer Institute],<sup>1</sup> the cancer is a disease whose incidence has been increasing considerably and standing out as a public health problem, both in relation to the control of registered cases and in prevention activities, socioeconomic situation, and regional inequalities.<sup>2</sup> In Brazil, it was estimated that in 2014, with repercussions for 2015, there would be more than 576 thousand new cases of oncological diseases, which shows the scale of this issue.<sup>1</sup>

When analyzed in children's public, cancer becomes the main cause of death due to illness. Between 2009 and 2013, the disease accounted for about 12% of deaths in the age group from 1 to 14 years, and 8% from 1 to 19 years according to data from the *INCA*.

Differences between childhood and adult cancers consist primarily of morphological aspects, clinical behavior, and primary locations. In children and adolescents, the neoplasia usually affects the cells of the blood system, the nervous system, and the supporting tissues. In adults, epithelial cells, which cover the organs, are the most affected.<sup>1</sup>

The child with chronic illness has his daily life modified many times with limitations, being frequently hospitalized for exams and treatment, according to the evolution of the disease. Chronic illness brings changes in the life of the child and his family, and this requires readaptation and strategies for coping. The child also changes his habits, becomes aware of the disease, and must learn to deal with his physical discomforts.<sup>3</sup>

The caregiver should be the family member or friend who has affinities with the client, and feelings such as appreciation, gratitude, affection, respect, and responsibility associated with understanding about cancer. These should be clarified of the limitations that your patient may experience, such as: nausea, vomiting, anorexia, dyspnea, bladder and intestinal elimination, pain, aphasia, paresthesia, drainage of secretions with foul odors, paralysis and others. When we work actively with a family member or even the unborn child who proposes to learn to help a terminal patient in palliative care at home, we should be careful to review the importance of their understanding of the disease, attention should also be given to their health and well-being of both the patient and the caregiver.<sup>4</sup>

This study uses as the theoretical contribution the Social Representation Theory, which provides the theoretical knowledge to obtain indications about the way of thinking and acting against cancer, in this way we sought to understand the relationship established by the population studied with this consensual act.<sup>5</sup>

The referential of the theory of social representations allows us to clarify how the process of assimilation of the facts occurring in the environment occurs, how they are understood by individuals and groups and how the knowledge built on these facts are expressed through their communication and in their behaviors.<sup>6</sup>

It is important to know the social representations of family members about pediatric cancer, since it will enable the reformulation of preconceptions and the elaboration of new concepts about cancer and each pathology. Hence, cancer being a public health problem in Brazil deserves great attention from the health professionals, especially the Nursing professionals, who can contribute to disease control through health promotion, prevention and detection precocious. The study aims to describe the understanding of caregivers with regards to pediatric clients without current therapeutic treatment to cancer and its repercussion for home care.

## METHODS

It is a descriptive research with a qualitative approach that used the Social Representation Theory. The concepts about care were used as a theoretical-conceptual support for this research.

We chose a descriptive approach for the need to describe the phenomenon of caring for a terminal cancer patient. The reality that we experience in our workplace and the care provided to the hospitalized child and family. Still referring to the descriptive study, defined as: “studies characterized by the need to explore an unknown situation, which requires more information.<sup>7</sup> Exploring a reality means identifying its characteristics, its change or its reality.”

The qualitative approach was chosen because it is a research that aims to know the qualities of an object of investigation. The qualitative research is that when the interest is not focused on counting the number of times a variable appears, but rather the quality in which it appears. With this type of research, we try to understand the problem from the perspective of the subjects who experience it, that is, part of their daily life, their satisfaction, disappointments, surprises and other emotions, feelings, and desires. It is therefore concerned with the social context in which the event occurs,<sup>8</sup> in other words, “it is a question of formulating a knowledge about the properties that are inherent to it, intending to present them in its essence, and thus knowing how things are, we become capable of distinguishing them from others.”

The study was carried out in a State Public Hospital in Belém city, Pará State. Reference in cancer treatment in the northern region of Brazil. The data of this research were obtained through the use of a collection technique: the free association of ideas. A script of the socio-cultural evaluation was used.

The data found through the research described through the technique of content analysis of social psychology, being able to analyze, interpret and generate data, to be understood through the expression of data representation of a qualitative research through the thematic analysis of the obtained data, being (1) Familiarization with the data, which occurs through transcription of the data (if necessary), active reading of the data and annotations of initial ideas; 2) Code generation, which occurs through the systematic coding of relevant data; 3) Search for themes, in which there is a grouping of codes in order to turn them into potential themes; 4) Continuous revision of the themes, as new ones are elaborated, generating a thematic “map of analysis”; 5) Definition of the themes, through the analysis of the data, aiming at the improvement and specificities of each theme; 6) Conclusively, the production of the concluding report through an explanatory and inductive interpretation.<sup>9</sup>

The data were collected through a semi-structured interview script containing 3 open questions of individual application, according to the availability and convenience of the interviewees. This technique is characterized by a verbal communication that reinforces the importance of the language and the meaning of the speech, already, on

another level, serves as a means of collecting information about a particular scientific theme.<sup>10</sup>

This research was submitted to the Research Ethics Committee in Human Beings respecting the Resolution No. 466/12 from the National Health Council, which regulates and standardizes the research involving human beings and approved by the Research Ethics Committee of the Center for Biological Sciences and Health from the *Universidade Federal do Pará*, initially registered in the Brazil platform under the Legal Opinion No. 1.442.346 and the *Certificado de Apresentação para Apreciação Ética (CAAE)* [Certificate of Presentation for Ethical Appreciation] No. 48628215.2.3001.5550. The theme of the research was as follows: “Social Representation of the Family Caregiver about the Communication Used in the Oncologic Patients Care”.

## RESULTS AND DISCUSSION

The first part of the instrument of data collection of socioeconomic cultural profile sought to characterize the subjects participating in the study. When we evaluated the age factor we observed the variation in this field between 25 and 62 years old and 50% of the interviewees were between 25 and 29 years old and were exclusively mothers, 41.6% of the interviewees were between 30 and 39 years old and were mixed among unmarried mothers, uncles or other family caregivers, and 8.4% of the respondent population defined as grandparents and were aged up to 62 years old. There was not an age that prevailed, but among the interviewees, the average of 35 years old was the one that stood out the most.

The marital situation was another variable analyzed by an important factor, because we know that it can contribute or confuse the care of terminal clients at home, since, the love in the family also collaborates in the union of the partners in attending their home at home in all their needs, because in this situation the participation of all who involve him leaves the caregiver freer to better assist his patient.

It was found that 50% of respondents said they were married, 33.3% of respondents said they did not have a civil union with their intimate partner, but they played in a stable union and used the term “convivial relationship” to define the relationship. 16.7% of those interviewed were singles and did not mention whether a married partner was present.

When analyzing the schooling factor, it was possible to observe that the majority of the study population, 50% of interviewees had only the first full degree, another 44% said they had finished high school and only 6% of the respondents said they had completed higher education.

Concerning the religion, most of the family caregivers surveyed, 83.3% of respondents answered to be Catholic and 15% were evangelicals and 2% of the total answered to be part of other religions or simply to believe in God, none of the interviewees declared not to believe in a superior force. We consider this factor of paramount importance to

be the intermediary of the development of noble feelings of love for our neighbor, affection, dedication, which can favor the acceptance of the relatives and caregiver of the patient's prognosis, so as to collaborate in this life journey near death, as well as their willingness to believe in a possible cure of disease through faith.

### **Palliative care - the caregiver facing the care**

During the research we found that ten interviewees highlighted the word suffering as a synonym for cancer, often they leave in an agonizing way, as follows in the reports:

*"I answered suffering because of the pain the patient suffers..." (E1).*

*"... because they feel many pains and sometimes unbearable..." (E4).*

*"... pain is constant and in various places of the body..." (E7).*

Suffering is the act of suffering, physical pain, anguish, affliction, disaster. "Suffering refers to a global, psychic, and bodily disturbance caused by a generally violent excitement." This can be recognized as a broadly ill-defined emotion.<sup>11</sup>

The perception of pain is multidimensional and varies in quality, intensity, duration, location and a symbolic image according to individual characteristics of each being. Pain is not merely an immediate and inevitable consequence of tissue injury; is modified by factors related to the development and situational, emotional, ethnic, age and family factors.<sup>12</sup>

The caregiver's importance in the health care of the cancer patient is unquestionable, offering direct care (hygiene, food), or indirect support.<sup>13</sup>

The family caregiver, although lay, assumes responsibility for the physical and emotional needs of the other who is incapable of caring, accepting that it is the responsibility of the family to care for its members.<sup>13,14,15</sup> This factor becomes more noticeable when it is related to the care of pediatric patients.

Caring is more than an act; it's an attitude. Therefore, it covers more than a moment of attention, of zeal and care. It represents an attitude of occupation, concern, responsibility and affective involvement with the other.<sup>16</sup>

Regarding the financial issue, the item monthly income we highlight that six of the caregivers surveyed have a monthly family income of up to two minimum wages. We know that the financial factor is important data in all stages of human life because work brings dignity to man. We also observed that the twelve caregivers interviewed were away from their work in order to be able to perform their role of caregiver either in the hospital unit or at home.

In relation to the family's economic situation, it can be totally altered, since the treatment of the patient can be very expensive, the caregiver can lose the job, being necessary to resort to the financial reserves of the family, when the

patient is the source of income the situation may become even more complicated.<sup>17</sup>

We observed among the interviewed caregivers that the female gender stood out because all are women. This is because of the behavior of women compared to the man being differentiated, the man in the way of rules are less gentle. The woman from the beginning cares for her offspring and her relatives in order to protect them by surrounding them with affection and care.

The women's activities, traditionally, is to take care of, care for and treat, in fact, it corresponds to guaranteeing or compensating for vital functions and which essentially organizes itself around two poles, birth to death

Caring for a person in the final stage of life is a very big burden and requires a lot from the caregiver, it is not uncommon that in this situation he also begins to present health problems. Often, there is a rupture and imbalance in the family structure, appearing conflicts and difficult situations. This family needs support to reflect and seek alternatives and solutions.

### **The essence of caring when dealing with limit situations**

The patients Without Current Therapeutic Treatment (WCTT) "are those patients for whom the current resources known for their cure have been exhausted." In other words, to this clientele the predominant care is no longer the curative, but rather the palliative.

We understand that palliative care prioritizes pain control, quality of life improvements, and dying in the place of choice of the client or legal guardian, in harmony with their relatives, reassuring the competence of the patient's care at home. We consider this period as the farewell time, which acts as a facilitating agent in the process of preparation and acceptance of mourning.

In nine of the testimonies present in the research, the relationship between terminal pediatric oncologic patient and death is evident, in the sense that there is nothing else to do, as we observed in the following speeches:

*"... I answered death because terminal already says end..." (E3).*

*"... I answered death because it has no cure, what remains and expect death, even when they have not yet lived long" (E12).*

*"I answered death, because from now on only God can help... He could still live longer." (E9).*

There are several meanings of death, such as: "the act of dying, the end of animal or plant life; end term; undoing; refusal; great pain; deep regret". We understand that death can be understood as peace of mind, the arrival at the end of a journey with the awareness that you have done your best in every moment of life. Death will always exist, for dying is

part of our life and the existence of the human being, being as predictable as being born.

It is observed in the interviews a certain difficulty in the acceptance of dying in a child, mothers and caregivers refer that dying at this stage is to reverse the natural order of life, thus evidencing the need for an emotional accompaniment in order to have adequate care for the sick child.

Nowadays, it is common for WCTT patients to live with silence, helplessness, and misinformation. Fear and suffering are due to the existence of taboos impregnated with stigmas such as: omission of information about the prognosis. For some caregivers to tell the patient that he has cancer can cause him to die faster. They also reported that the fact that the patient is informed that he is at the terminal stage of the disease makes it difficult for the home treatment to contribute to social isolation, loss of autonomy of the body and independence, thus shortening the perspective of his life.

There is a certain relationship, even today in talking about cancer, when the disease presupposes the underlying idea of death. The author,<sup>18</sup> further clarifies that people sometimes avoid talking about the subject of death, fearing the emotional reaction of the patient more than the relatives. We agree with this statement, for death, even as part of life, has a difficult acceptance on the part of the collective; for signifying the loss of loved ones to which we are attached throughout our existence.

### **The oncological child - the need for careful attention**

It evidences care as an act of caring, assisting, encompassing the idea of providing care, help, and help, being understood as a result of the actions of assisting. Palliative care, on the other hand, emphasizes physical, social, emotional and spiritual needs in collaboration with the multi-professional equiee.<sup>19</sup>

Palliative care emerged in ancient times and received the name of hospice, which had two divisions: one for patients with a cure, and the other for those without a cure. Currently, this name of care is used as a way of highlighting the palliative care developed at the home of the terminal oncological client that enables the child to be in a family environment and less stressful than in a hospital environment being submitted to possible invasive procedures that are seen by the companions and children themselves as the cause of suffering.

We observed that in the case of advanced cancer, the increasing recognition of the inefficacy of expensive and invasive medical treatment, as recommended by the carteziano model and whose main goal is the cure, did not prolong the suffering of patients with WCTT.<sup>20</sup>

At the present time, the central focus of palliative care at home is based on the experience of health professionals working with this reality in their daily lives; as well as patients and family members living with an advanced disease - now incurable. Such abilities favor the familiarization of the process of dying, softening the suffering mutually.

In this study it was evidenced that 58.3% of the interviewed caregivers point out as the main goal of care the attention to the patient, as evidenced by the following reports:

*"We have to pay special attention to him, especially to be a suffering child who feels frequent pain." (E6).*

*"Now, I'm going to let him do whatever he wants to do, he's been through a lot of pain, he did not deserve it." (E7).*

We understand that attention serves as the main characteristic of the act of caring because from it we have how to prevent problems and not only re-establish them. This arises because care requires attention, it must be active aiming at the quality of watching at home, not the amount of life at home.

Contemplating a person is designating he/she as a caretaker of a terminal client is such a responsibility, as it means that this is what most are dedicated to the client. It is clear that care involves noble and interpersonal relationships composed of human manifestations, and affinity is a necessary attribute for caring. We emphasize that the adequate assistance advocated by the home palliative care program requires the interaction of the health team, the caregiver, and the client. This statement solidified in the reports of six caregivers who related care with adequate care to the terminal cancer client:

*"Patients with cancer need adequate care" (E2).*

*"Because when they speak to you care the person speaking is alerting you to something that can be dangerous." (E1).*

The most important in palliative care in the home and quality of life of this client, in addition to the care and affection provided by their relatives. The relief of the pain of these clients in general, devoid of comfort that in most of their desires is that there is someone known who treats him with exclusivity and dedication.

### **Caring for the child at home: a caring family**

Home care is the component of a continuous care where resources are offered for maintaining the client's health in their own home. In the study in question, seven caregivers associated caring with the terminal oncological patient with the responsibility of caring at home, and the passivity and understanding of the goals proposed by the oncologic homeopathy palliative care program became evident. As noted in the speeches below:

*"We should be careful with her at home, especially with medication at times because of the pain." (E11).*

*"Doing at home what the professionals most advise... taking care of her at home with the family recovery can be even faster having the support and care of everyone." (E9).*

Home care is an option for the caregivers of patients considered to be WCTT, and who do not need hospitalization, but rather from the comfort of the home. This being the client's natural environment, which preserves the power of self-sufficiency of the client and his/her family members, reporting the maintenance and performance of activities of their daily lives.

The stress of the caregiver in the face of complex care at home, associated with family conflicts and anxiety arising from the difficulties attributed by differential care to the terminal cancer client, favors the preference for hospital care rather than home care.

We understand that it is not an easy task to train caregivers to develop care at home, and its maintenance requires: continuous education, constant evaluation, meetings with the group in such a way that there is an exchange of experience between the caregivers and the health team.

It shows that for the Brazilian Society of Cancerology, cancer can be defined as a degenerative disease resulting from the accumulation of lesions in the genetic material of the cells that induce the process of growth, reproduction and abnormal dispersion of cells (metastasis).<sup>21</sup>

Given the aforementioned, literature always reveals that cancer is not a contagious disease, but it is passive of development in any human being and those who are predisposed to this pathology are favored. In other words, those who already have a dominant autosomal dominant gene inheritance cancer or individuals who develop cancer by exposure to risk factors such as: smoking, alcoholism, inadequate eating habits, socioeconomic factors, sexual lifestyle, exposure to sunlight between others.

The lack of health education in regard to prejudice is due to the disinformation on cancer and risk factors, creating in the patient and caregivers a barrier that favors the development of the fear of the unknown. This clarification when performed at the beginning of treatment contributes showing the real reality, not causing insecurity and fear in caring for this client at home.

We believe that for the decision-making process related to the care sites, and the planning of care for terminal oncology clients at home, they need to be developed in triplicate; professional team - client - caregiver. Therefore, we believe that the involvement of all would help to remove the doubts of the caregiver and client, in order to alleviate the suffering of this family in having to take care of the domicile of their loved one.

Another relevant point in the study is what concerns a consensual manifestation of cancer, which is the pain caused by the disease. Pain consists of a disharmony between the internal and external environment of the individual that provides a state of tension that represents a state of alertness, showing that something is wrong, requiring its normalization.<sup>22</sup> As a way of demonstrating what was said, then see the following dialogues:

*"When she says she feels pain, I feel a desperation not knowing what to do" (E 2).*

*"I would rather the pain be in me... She cries and has cried a lot because of the pain" (E 3).*

The pain of being always subjective and personal causes feelings of the impotence of the caregivers in front of the pain makes to think that cancer means a progressive disease always more painful ending in an agonizing death. This feeling may lead to the abandonment of treatment at home. We understand that the client refers us to pain is because it exists in its dimension in the same way it is reported. Pain is what the patient claims to be existing when he claims to exist.

Health professionals should clarify that even when they cannot be cured or softened, it is possible to be supportive, using care with their definitions as: love, affection, and affection thus contributing to a better quality of life of the patient, because with the application of these forms of the suffering of the same.

## CONCLUSIONS

This study evidenced the understanding of caregivers of clients considered WCTT on cancer and its repercussion in the care given to this clientele. In doing so, we perceive how caregivers understand the pathology that affects their patient. As well as the assimilation of the guidelines used by the multiprofessional team of palliative care to terminal cancer patients; being the association of these fundamental factors in home care.

The descriptive study using a qualitative approach allowed us to know the phenomenon of caring for terminal cancer patients at home. As well as knowing the cognitive of people who are not from the health area, but are responsible for developing care for this clientele.

The method of free association of ideas was the facilitating agent of this research, by providing the construction of the reality of this group, besides the understanding of the psychosocial context in which the interviewees were included.

The statements presented in the study generated spontaneously and without risk of contamination of the researcher, on the occasion of the use of the free association of ideas; allowed us to capture the doubts and anxieties of the caregiver about the hospitalization at home.

We know that cancer is neither contagious nor transmissible, but it causes functional and anatomical changes in the individual that contribute to the fear that society has of this secular pathology. When detected early, it is curable in most cases. This becomes an aggressive, invasive, cruel and incurable disease when it is not given importance to the beginning of its clinical manifestations.

Caring for a terminally ill patient is not an easy task for those who hold little-reified knowledge of this disease; this care is more difficult when the patient is a child and a child

or a close relative. Feelings such as compassion, dedication, and others, should sensitize the multiprofessional team to the familiar contemplated as caregiver of this client. Reinforcing whenever it is considered WCTT, does not mean that there is little left for the patient, but rather that there is a new collection of care to be implemented.

We have identified a totally female caregivers, this is because care is a practice most evidently experienced in women's daily life, due to the feminine attributions such as: caring for their home, being a mother and wife, they all identify the woman as a caregiver by excellence.

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