

## Os impactos da terapia quimioterápica e as implicações para a manutenção do cuidado. Um estudo de representações sociais

Impacts of therapy chemotherapy and implications for maintenance care. A social representations study

Efectos de la terapia y quimioterapia implicaciones para la atención de mantenimiento. Un estudio de representación social

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### ABSTRACT

**Objective:** The study's goal has been to understand the impacts of chemotherapy and its implications for care maintenance in order to analyze the patients' social representations. **Methods:** It is a descriptive study with a qualitative approach. The study uses as theoretical contribution the phenomenon of the Theory of Social Representations, which was developed based on the findings related to the speeches of 26 patients undergoing chemotherapy treatment. Data analysis has been done by applying the psychology thematic analysis technique. The study was approved by the Research Committee and complies with the Resolution No. 466/12. **Results:** The study's results have shown how relevant it is to understand the representations of the subjects undergoing chemotherapy treatment, thus, recognizing its complexity. **Conclusion:** Therefore, it is worth highlighting that is very important to experience beyond the quotidian and the daily life of the patients under chemotherapy. Additionally, evaluating the patient sadness, anguish, victory, as well as having direct contact with them, thus, arising the need to know better the patient reality.

**Descriptors:** Chemotherapy, quotidian, social representations.

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## RESUMO

**Objetivo:** O estudo tem por objetivo compreender os impactos da terapia quimioterápica, as implicações para a manutenção do cuidado e analisar as representações sociais desses pacientes. **Métodos:** Trata-se de um estudo descritivo com abordagem qualitativa. **Resultados:** Utiliza como aporte teórico o fenômeno da Teoria das Representações Sociais desenvolvida com embasamento nos achados relativos às falas dos 26 pacientes em tratamento quimioterápico a análise aplicou-se a técnica de análise temática em psicologia. **Conclusão:** O estudo possui aprovação do Comitê e atende a Resolução nº 466/12. Nos resultados do estudo evidenciamos o quanto é necessário compreender as representações dos sujeitos em tratamento quimioterápico, reconhecendo, dessa forma, sua complexidade. Vivenciar além do cotidiano e a vida diária dos pacientes em quimioterapia, avaliar as suas tristezas, angústias, vitórias, assim como ter contato direto com o mesmo assim surgindo a necessidade de conhecer melhor a realidade dos pacientes.

**Descritores:** Quimioterapia, cotidiano, representações sociais.

## RESUMEN

**Objetivo:** El objetivo de comprender el impacto de la quimioterapia, las implicaciones para el mantenimiento de la atención y analizar las representaciones sociales de estos pacientes. **Métodos:** Se trata de un estudio descriptivo con enfoque cualitativo. **Resultados:** Uso como el teórico el fenómeno de la teoría de la Representación Social desarrollado con base en los hallazgos relativos a las declaraciones de 26 pacientes sometidos a análisis de la quimioterapia aplicada al análisis temático en psicología. **Conclusión:** el estudio tiene la aprobación del comité y sirve Resolución N° 466/12. Los resultados del estudio se observaron la forma en que es necesario entender las representaciones de los sujetos sometidos a quimioterapia, reconociendo de este modo su complejidad. Experiencia más allá de lo cotidiano y la vida diaria de los pacientes en quimioterapia, evaluar sus dolores, miedos, victorias, además de tener contacto directo con la necesidad todavía emergente para comprender mejor la realidad de los pacientes.

**Descritores:** Quimioterapia, diario, representaciones sociales

## INTRODUCTION

Once the cancer is installed we can resort to various therapies, such as chemotherapy, radiotherapy, surgery, hormone therapy and immunotherapy, which depending on its pharmacological activity and its pharmacodynamics can be done by combinations.<sup>1</sup>

Primarily, chemotherapy is used before the main treatment aiming to reduce the tumor size in order to facilitate its control. The curative treatment, in order to be truly achieved in adults, lasts on average five years, while the adjuvant treatment is when the chemotherapeutics are administered after the main therapy to eliminate possible residues of the disease and to avoid the synthesis of more oncogene cells, which is known as metastasis.<sup>2</sup>

The advent of modern medicine and the mass investment in new techniques and drugs, have led us to reach a number of different types of cancer treatment, which is an immense advance and achievement for those who prescribe the treatment and the patient who undergoes all the procedures

presented to them aiming to give a better life quality, although the cancer treatment has several ramifications, however, chemotherapy is the one with the highest incidence of cure and the one that increases cancer patients survival.<sup>2</sup>

In the chemotherapy treatment the intention and main goal is often to reduce the chance of the disordered cells growth, tumors and genetic mutations, and this way significantly decreasing the chance of the disease progress. There is a concern with antineoplastic, also called adjuvant treatment, which can provide prolonged time without any evidence of the disease, also called either cure or control.<sup>3</sup>

All the effects of antineoplastic chemotherapy come from a non-selective action of the drugs, or even from the lack of knowledge of the administration protocols and even from the poor relation between the team and the patient, thus allowing the patient to be unaware of the full care after the prolonged use of these original chemotherapy drugs, in other words, acting on healthy cells and at the same time the target of cancer cells, then causing nausea, vomiting, diarrhea, myelosuppression, alopecia, appetite loss and mucositis.<sup>3</sup>

One of the most accepted and indicated for the treatment continues being the chemotherapy, therefore, the procedure is relativized to a type of therapy that uses drugs isolated or combined, with the result of the target in acting in the process of cell division, directly in the division of the genetic material, in other words, interfering with the growth of new cancer cells and even combating the synthesis of new mutant cells. Therefore, these chemotherapeutic drugs classify alkylating agents, antimetabolites, antitumor antibiotics, alkaloid plants, multiple agents, hormones and hormonal antagonists.<sup>4</sup>

When there is no more possibility of cure we have palliative therapy, chemotherapy does not influence the survival of the person, because when we use this treatment principle the patient does not have the prognosis of survival. Thus, we use the therapy to improve their standard of living, decreasing pains etc., which is used to reduce the tumor, relieve symptoms, improve the quality of life of the sick person, as well as related to treatment and psychological counseling.<sup>5</sup>

Many of the goals within a chemotherapy treatment are intended to palliative approach. Thus, the team tries to annihilate cancer growth without getting rid of it completely, in order to prolong life or even improve the standard of living and patient survival. It is known that many of the patients end up, for reasons of lack of knowledge or even lack of cognition and having an affective bond with the team that takes care them.<sup>6</sup>

## METHODS

In order to work the social representations aspects, in this research the qualitative descriptive study was performed, adopting as theoretical support the Theory of Social Representations, because when we studied about it we observed that it was applied in the thesis of the Psychoanalysis of Moscovici, where it presented the phenomenon of the absorption of science by common sense, that through communication, and language.<sup>7</sup>

The study was carried out at the chemotherapy outpatient clinic of the *João de Barros Barreto* University Hospital, where the subjects of the study were 26 patients under chemotherapy treatment, under care at the *Unidade de Alta Complexidade em Oncologia (UNACON)* [High Complexity in Oncology Unit] located in the city of *Belém do Pará*, both women and men, several types of cancer, without exclusion of age, who are currently undergoing chemotherapy for at least six months of therapy, since we intend to value and respect the feelings, values and beliefs of these patients. We also believe that the percentage mentioned becomes relevant.

The thematic analysis technique was used to analyze the statements collected through the acceptance of informed consent term, which method aims to identify, analyze and report on patterns or themes, organizing and describing the data set and aspects of the search object.<sup>8</sup>

Thematic analysis follows a recursive process. Its structure consists of 6 fundamental steps: 1) Familiarization with the data, which occurs through transcription of the data (if necessary), active reading of the data and notes of initial ideas; 2) Code generation, which occurs through the systematic coding of relevant data; 3) Themes searching, in which there is a grouping of codes in order to turn them into potential themes; 4) Continuous review of the themes, as new ones are elaborated, generating a thematic “map of analysis”; 5) Themes definition, through the analysis in progress with a view to improving the specificities of each theme; 6) Production of the report through an interpretation.<sup>8</sup>

The research was supported by the Resolution No. 466/2012 of the National Health Council on research involving human beings, which deals with “Guidelines and Norms” of research involving human beings, especially with regard to free and informed consent and ensures compliance ethical aspects in its realization. The research obeyed all the criteria of a research project developed in a Hospital of Education and Research, undergoing an internal analysis inside the Hospital, and afterwards it was approved by the Research Committee of the *João de Barros Barreto* University Hospital on 23/06/2015, with the Legal Opinion No. 1.119.886.

## RESULTS

### Chemotherapy and the deconstruction of autonomy in the face of the healing process

To the author, the sickness added to the barriers of chemotherapy makes it difficult to perform daily life activities, representing a treatment that interferes with the daily life and its autonomy, so that the patient becomes a limited and stressful place, where hospital routines and the environment itself diminishes the repertory of activities that he or she was accustomed to perform, a fact found in many of the speeches:<sup>5</sup>

*“She has changed a lot, she has not totally implicated, but she is so to those who were accustomed to working to do things in their day to day, I encounter a certain difficulty, because it prevents me from doing certain things that I had been doing in the past. I now depend on people to help me, there I find a barrier with it, even more that I was used to doing my little things and not depend on anyone for me was a difficulty, so I felt a very big difference.” - QT1*

*“For me it means a well being, despite all the symptoms that this must be a normal symptom of chemotherapy, despite that it is being a well being for me, like this gives hope that you live more knows.” - QT21*

The results that the cancer and its treatments, mainly the chemotherapeutic, directly affect the life of the patient and their daily life, since once discovered to the disease, changes occur in their habits and ways of life, being able to compromise its quality its autonomy quality of life and its treatment, as follows:<sup>6</sup>

*“It has changed a lot like this, in the part of the work in my house that I can not do everything, because this way I do not like to be stopped, but what I have to do I do, which I do not give I limit myself here, so many things are different now, because I can not stay at home, changed the routine every time I have come here to the hospital, at my niece’s house sometimes it bothers but it’s the way, right? So much changes in the routine of people’s lives right.” - QT6*

The physical symptoms and the aggravations produced by the chemotherapeutic treatment in the patient’s autonomy can lead to significant changes in life itself, among them, the remoteness of paid work and its daily activities, generating as a consequence a feeling of incapacity, loss of autonomy, difficulty in decision making and guilt, where we observe that many of these patients are the main financial contributors of their relatives, leading to feelings of guilt, expressed in the speeches:<sup>9</sup>

*"I get very weak, I get very weak, I do so very little because I have to do too, because I live alone with my husband, the things I have to do, I have to do food, sometimes I have to wash clothes, sometimes I do it without being aware of it, I do it because it has to do even, look how now I came walking a little from the front here I came here dead tired." - QT12*

*"I'm seeing myself as a patient, but easy to give it to me, because I'm passing, I know what I feel, I know what I think." - QT26*

When we talk about cancer as a disease in itself, we realize that treatment therapy can lead to physical, emotional, psychosocial problems and alter their daily life activities, thus interfering with their autonomy and freedom.<sup>5</sup>

### **The bio-psychosocial well-being as an influencing factor in the life quality of the patients undergoing chemotherapy**

When analyzing the well-being state, at emotional and functional levels, where the relations between optimism and morbidity (depression and anxiety) in cancer patients, it was verified that more optimists mentioned fewer symptoms of anxiety and depression, reported as the following:<sup>10</sup>

*"Is that right? It all depends on the state of the patient too, if you have diabetes, a high blood pressure will all cause you harm." - QT20*

*"You live longer, so you just have to endure, right? The person came here and put it in the head that will improve, will live a better life after that, you have to have strength in the psychological, because if you do not have it weakens everything at once." - QT6*

*"First do not get upset about it, I'm very practical, if I need to do such a thing to get well I'll do such a thing ... is there going to solve my problem? I understand, do you understand? So there's no such thing, if that brings me to a cure and a survival I cannot think badly." - QT26*

Chemotherapy is the most used therapeutic method in the fight against the advance of the cancer, and therefore the sooner to start the treatment, the better the control of the disease, thus avoiding possible complications referring to the incapacities of cancer, since it is a therapy in which using drugs that destroy cancer cells, interfering with cellular functions, being one of the ways to fight cancer progress:<sup>6</sup>

*"Changed because I pretend to be a young man, a new man, because now, June 29<sup>th</sup>, I turned 80 years old, until this social worker charged me the cake (laughs), changed I feel strong, sometimes even gives me, I want to run, but only I will not do it, and life is like this, and this life we have to watch over." - QT13*

Regarding the treatments, chemotherapy is seen as a way of coping with the disease, since the meaning is directly related as a way of being alive within a possibility of survival through the insertion of more effective drugs in the control of disordered growth of cancer cells, but even with side effects of chemotherapy they can explain how a perception of the stress of patients under treatment, according to the statements:<sup>10</sup>

*"It gets affected and can come back in a while, so the chemotherapy for me is very important because it will leave me with such confident support that I will not have any more in a while." - QT4*

*"... I also do not suffer in anticipation, the day I have it... then the chemo for me has no difference [...] treatment, closeness of healing over life" - QT26*

*"[...] reactions in the first and second applications I had itchy hands, which is one of the characteristics of the chemo, of the chemicals I take, and right on the second day I dawned with that itch in my hand, if I caught in the detergent it increased more [...] than I can not get strong sun I can not catch the sun [...]. " - QT26*

*"That I would have to adapt to everything, what would be new now, start a new life, then I had to come to chemo, the first cycle I did I was stressed, until the staff had a lot of patience with me. I was very stressed, it was passing, it was passing and I was adapting, and I began to adapt with the new life, I was adapting myself, adapting myself I was calming, we have to live with each day with each thing, and chemotherapy that I think." - QT19*

### **Before and after, the chemotherapy, the changes in daily life and the malicious effects**

We understand that within its pharmacodynamics the therapy is responsible for the gains and damages that the patient happens to have, therefore, we understand that these drugs also by the effect of their chemical can destroy healthy cells of the organism, causing adverse effects like vomiting, diarrhea, nausea, anemia, constipation, myelosuppression, mucositis, neutropenia, thrombocytopenia, among others, associated with difficulty adhering to the following treatment:<sup>2</sup>

*"It's changed, because I do not do anything else, I do not work (laughs) I cannot wash a house, sweep a house (laughs), do some dishes, I have to come every day from the countryside to here, For me I did not even come any more, the children are pushing me here (laughs) "* - QT14

*"It changed a lot, because when I was operated on, I was like I was good there when I started chemotherapy and it got worse a little bit, right back to the consequences as I can tell the vomiting the nausea, can not get sun."* - QT4

*"He gave me sick, it made me sick to the food like that, and the feces are dry, I think it has changed, and when I go to take water I feel like thorns in my throat."* - QT18

By the patient's own health condition, they are instructed to avoid certain actions, which reduces interaction with people and deprives them of their daily living activities, sometimes causing fear in the face of disease, stigma related to their progression and difficulty to treatment adherence, which can be reflected in negative feelings such as anger, sadness, depression and abandonment, related in speech and results:<sup>12</sup>

*"I think it's to try to kill the bacteria, to try to kill the bacteria of the cancer that stays in the blood, right now, the cancer comes from the blood, because it comes from the blood, then chemotherapy comes to kill the bacteria, that's a bacterium that exists, right."*-QT19

Understanding the patients' meanings and feelings within the treatment process is necessary for building trust in handling and healing, reaching the deconstruction of imagery and representations of negative feelings and fear of death, allowing for more courage in dealing with the disease as a possibility of survival, helping to handle the situations of depression, fear, anguish, possibility of death, strengthening hope in this way and being positive to continue in the chemotherapeutic treatment.<sup>12</sup>

### **The role of the family caregiver, the construction representations of the consensual figure of caring**

The family as a therapeutic support is the first representative link in which the human being inserts and interacts responsible for the construction of his social characteristic, being thus the main network of relations, responsible for the concretization of the identity. It is at this moment when his feelings will influence in their own representations about life and becoming ill, thus being the important family in the promotion and maintenance of health in the face of cancer, seen in the statements:<sup>4</sup>

*"During our treatment the neighbor (chemotherapy colleague) died, he is fine but he died, the social worker called and said that he went away for lack of family, he did not have the family near him, there is no use having only chemotherapy sessions, having you here (multiprofessional team), have everything back. "* - QT21

*"You may be under care 24h, but if there in your house the you do not have family is done, he was making a plan to build his house, and could not, died for lack of family, family is part of the treatment, during that time of chemotherapy that we did with the Zé, all this time here he did not bring any relative..."* - QT23

By itself, the family within the context of the treatment of cancer, is the most reliable structure of all the experiences of the patient, a condition that is responsible for the knowledge of all the habits of the patient, thus, the disruption of the same will lead to the disruption of this care, resulting in either little or inefficient adherence to treatment, based on the thematic of the interviewees:<sup>1</sup>

*"I think you got it, then I have to give you with the over-caution, because you cannot, I do not know what! I say people, if you bury me before the time I stop talking to you, it's horrible for us as a patient is the worst thing, is you already have to give it with its impossibilities, arising from natural process of treatment of disease, and you have to manage the bonds that people want to put for you, for care, there you have to have patience, you have to understand that it is care, it is a way to take lovely care, to do you good. "* - (QT26)

In defining the role of the family, we are faced with the process of denial of the disease, representing a painful experience in relation to the survival and improvement of the health of the family, where this set of feelings permeate between the rupture of the expectations regarding the problems related to the patient's picture and frustration to the fear of death, thus bringing feelings of fear and anguish.<sup>1</sup>

### **Scientific nursing as a representation of integral and holistic care**

By observing the world through the representations of the patient, we perceive the need to build a professional relationship with the nurse that transcends empathy, through the establishment of the affective bond, as part of the treatment, minimizing the obstacles and discomforts related to the chemotherapeutic treatment, helping and assisting in the disease, facilitating compliance with treatment, confirmed in the statements:<sup>5</sup>

*“Through nursing we give the first support of information and after the nursing, sometimes we even talk to the nurses who do not speak there to the doctor, and any little thing that you feel, the people who are closest are the people of nursing “ - QT7*

Caring for cancer patients requires, in addition to technical-scientific skills required by professionals and multiprofessional staff, empathy for the needs of the patient, as well as to increase the relationship between gentle care and their psychosocial status, individually and collectively respect to their needs and fears, and then together to be able to construct a plan of humanized care appropriate to each pertinent point of the patient:<sup>7</sup>

*“Oh man, you’re trained for this, I know that, if you want to give her a grade, it is 10 for the chemotherapy team? Sure, note 10, over there is very nice, very cool” - QT20*

By observing the constructions built through the representation of nursing for the patient, we understand that good communication with the team is an integral part of the confrontation of cancer, perceived in this difficult phase of life as a process of struggle and survival, where patients demand a more humanized view of the nursing professional, adding simple, clear and objective communication, so that the patient and the family know the disease and then understand the steps for the success of the treatment itself.<sup>4</sup>

## DISCUSSION

During this study we have noticed the need to discuss the best therapy with the family, in addition to the risks and complexity of the treatment, so many believe that dealing with patients can be a difficult task and there are several reasons that professionals cannot discuss the prognosis. Many professionals are afraid that they will increase the patient’s suffering, by the inexperience within the academy in the relationship of communicating with their patients.<sup>1</sup>

Nonetheless, experiencing the disease becomes an expressive social event that triggers modifications within the scope of the person’s relations and in the daily life of the family and society, thus the results of the neoplasm within the patient’s body difficult to deal with and understand with their repercussions for both the patient, family and staff, especially when there is no success in therapy.<sup>3</sup>

*“They are social productions of an essentially heterogeneous nature, once they are ‘specific’, so, belonging to a historical moment in which science or reified universe emerges as the outstanding source of explanations of reality, from which the common sense, or consensual universe, actively nurture; and ‘general’, since the flow of scientific and ordinary (re)significations*

*are anchored in historically elaborated and accumulated productions, and that offer to the present of societies constructs that are recruited according to the premises of social time or episteme.”<sup>13</sup>*

Regarding the pain, there are several subfactors that directly interfere with the final treatment result. It can affect the nutritional status, the electrolyte balance and the quality of life of the patient, if we observe that all these stimuli combined with the intravenous techniques and the cancer physiological results may end up increasing anxiety and stress leading to psychological depression, resulting in the delay or even abandonment of the treatment.<sup>3</sup>

The social representations have the following functions: communication orientation and conduct, this as a social function; protection of social identity, identified as an affective function; and familiarization with the new, the latter as cognitive function. The latter function has an intimate relationship with two fundamental processes, which are: anchoring and objectification, in other words, the naturalness in the formation that a figure reproduces a particular concept bringing it to reality.<sup>13</sup>

*“The social representation as a form of knowledge elaborated socially and shared in order to build a reality common to a social set. It recognizes social representations as a system of interpretation of the relation of man to the world and of man to man, so that they guide and organize social behaviors and communications.”<sup>13</sup>*

Findings within the chemotherapy treatment results as being formed for more detailed discussions on the survival benefits, and whether the same are needed prior to therapy, as well as explaining the gains and losses within the chemotherapy therapy, so there is a need for the professional to attempt toward the body signals.<sup>14</sup>

The action of chemotherapeutic drugs has traumatic influences on patients and their relatives, who when encounter the disease and its harsh reality are affected by different types of feelings, such as fear, loneliness, self-punishment and insecurity. Cancer generates imbalances that go beyond the body aspect of the patient, requiring reorganization in different dimensions of family life.<sup>3</sup>

*“Social representation can be understood as a form of knowledge, elaborated in the social environment and shared in it, aiming to contribute to the construction of the reality common to a particular social group. It is called as common-sense knowledge or naive, natural knowing, differentiating itself from reified or learned knowledge, but is regarded as an equally legitimate object of study because of its importance in social life and the elucidation that enables cognitive processes and social interactions.”<sup>13</sup>*

It is believed that the subject of study and debate about social representations within the reified universe of chemotherapy still needs to be further studied and debated, where knowledge needs to be improved, since we have observed that the representations of the interviewees uncovered a universe that has not yet been explored. Yet, it is rich in meanings and knowledge, which in turn help us in understanding this still unbroken paradigm that surrounds it.<sup>9</sup>

*“Elements such as information, opinions, beliefs and attitudes that individuals have in relation to an object form a set that, arranged in an organized way, is structured in a socio-cognitive system. Thus, in order to define a social representation, it is necessary to know not only its content, but also to identify the central and peripheral elements that can explain its organization and structure.”<sup>13</sup>*

## CONCLUSION

The study has shown how relevant it is to understand the representations of the subjects undergoing chemotherapy treatment, thus, recognizing its complexity. Therefore, it is worth highlighting that is very important to experience beyond the quotidian and the daily life of the patients under chemotherapy. Additionally, evaluating the patient sadness, anguish, victory, as well as having direct contact with them, thus, arising the need to know better the patient reality. Given the above, we can verify the phenomenon of the absorption of science by common sense.

During the study we observed that chemotherapy is the most effective among other treatment, but we noticed that the interviewees put that optimism has total influence in the course of their journey towards a better quality of life. Although the use of these drugs lead to symptoms that affect directly or indirectly in the patients' daily life, there are reports of some interviewees who say that the treatment is already important and must be carried until the end in order to guarantee a life for this individual.

The family was described as being a greater contribution in the confrontation, as described in the patients' speeches, it was observed that the figure of the relative is of immense importance, considering that they are characters responsible for the patient's adherence to the treatment. Since they have affective relationships allowing a greater expression of the patient, which is presented in the development of activities, where the family member can acquire greater confidence of the patient, allowing the nursing professional to enter into this relationship of trust.

We then realize that although the familiar has the knowledge of the common medium expressed through the representativeness of the reified universe, we must understand that through his social representation he or she becomes a caregiver, so we must understand the importance of the familiar in the construction of our care plans, thus

being the link between the success of the treatment and the communication between them.

As nurses, we must observe the communication and understanding between family and patient, also linking to the figure of the relatives, a forgotten character within the process of caring. So, as nurses we must practice the human feeling, understanding that our care should also reach the relatives, and as health educators implement and help in building their self-care.

In the last analysis within the fourth unit, it was possible to observe the parameters related to the implications for care maintenance, where the patient, the family, and the team are all responsible for the treatment success, thus, it was analyzed proposals of interventions within the representational sight of each interviewee based on their bio-psychic-social needs.

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