THE CANCER CHEMOTHERAPY EXPERIENCE IN A PATIENT’S VIEW

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The objective of this work was to understand the meaning of the chemotherapy from the patient’s point of view on the basis of interpretative anthropology and an ethnographic case study. A breast cancer patient was selected by predetermined criteria, the most important of which was that the patient should be initiating the chemotherapy treatment in order to be followed-up. Data were collected by semi-structured interviews, observations and a field diary. Data analysis was performed in two phases: first we identified the significant meaning unities; then we summarized the meaning that the patient attached to her experience as "the loss of control of her life". This meaning stressed the changes of her social role, especially the difficulties to provide financial support to the family and the relationship with her children. The study emphasizes the need for the nurse care, who should follow up the patient throughout the whole process, trying to offer resources for the patient to resume control of his/her life during this critical period.

DESCRIPTORS: patients; neoplasms-therapy; drug therapy; anthropology, cultural; nursing

LA EXPERIENCIA DE LA TERAPÉUTICA QUIMIOTERÁPICA EN LA VISIÓN DEL PACIENTE

El objetivo de este estudio fue comprender el significado de la quimioterapia en la visión del paciente. Este trabajo siguió los supuestos de la antropología interpretativa y del estudio de caso etnográfico. El caso consistió en una paciente portadora de cáncer de mama, ya operada, que se encuadraba en los criterios de selección, cuyo principal fue la realización de la terapéutica quimioterapia, con el objetivo de observársela durante toda la trayectoria. Colectamos los datos por medio de la entrevista semi-estructurada, observaciones y anotaciones en uno diario de campo. El análisis de los datos fue realizado en dos etapas: en la primera identificamos las unidades de significado; en la segunda sintetizamos el significado atribuido a la experiencia de la quimioterapia oncológica, que fue de que este tratamiento lleva al individuo "a la pérdida del control de su vida". Este significado resalta los cambios de los papeles sociales, principalmente las dificultades financieras para mantener la familia y las relaciones con los hijos. El presente estudio enfatiza la importancia del acompañamiento de la enfermera al paciente durante todo el proceso de tratamiento quimioterápico, buscando reconocer las influencias socioculturales y ayudar al paciente a reanudar el control de su vida en ese período crítico.

DESCRIPTORS: pacientes; neoplasmas-terapia; quimioterapia; antropología cultural; enfermería

A EXPERIÊNCIA DA TERAPÊUTICA QUIMIOTERÁPICA ONCOLÓGICA NA VISÃO DO PACIENTE

O objetivo deste trabalho foi compreender o significado da terapêutica quimioterápica oncológica na visão do paciente. Seguiram-se os pressupostos da antropologia interpretativa e do estudo de caso etnográfico. Participou do estudo uma mastectomizada que iniciava o tratamento quimioterápico. Os dados foram coletados por entrevistas semi-estruturadas, observações e anotações em um diário de campo. A análise dos dados foi realizada em duas etapas: na primeira, identificaram-se as unidades de significados e na segunda sintetizou-se o significado atribuído à experiência como “a perda do controle da vida”. Esse significado destacou as alterações nos seus papéis sociais, principalmente as dificuldades de manter os recursos financeiros para o sustento da sua família e o relacionamento com seus filhos. Este estudo enfatiza a importância do acompanhamento do enfermeiro ao paciente em tratamento quimioterápico, que deve reconhecer as influências socioculturais e ajudar ao paciente a reassumir o controle de sua vida durante esse período crítico.

DESCRITORES: paciente; neoplasias-terapia; quimioterapia; antropologia cultural; enfermagem

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INTRODUCTION

There are basically four approaches to the treatment of cancer: surgery and radiotherapy as local treatments; chemotherapy and the use of biological agents (such as hormones, antibodies and growth factors) as systemic treatments. Chemotherapy plays a central role in cancer treatment, using drugs alone or in combination. These drugs interfere with cell growth, division and survival, killing not only the tumor cells but also normal cells that have similar biological characteristics (1).

As a consequence, chemotherapy is associated with undesirable physical effects such as nausea, vomiting, anorexia, constipation, diarrhea, fatigue, mucositis, neuritis and bone marrow depression. The diagnosis of cancer has a considerable social impact on the patient’s and his or her family’s life, and the addition of the collateral effects of chemotherapy may contribute to the patient’s feeling of impotence to react to the disease and fight for survival.

Health professionals recognize the importance of the various approaches for the cancer treatment, however their attention should not be limited to the care of the disease itself, but should extend to the environment that surrounds it. This means that the attention must extend beyond the biological world of the disease, to include the whole body of the patient in its sociological connotation. Under this perspective, the body is a culturally determined entity: the sense that the body is highly complex and its functions exceed the sum of its biological features, especially in cancer (2).

The present study is based on this perspective: it proposes to describe how the persons build the experience of submitting to the cancer chemotherapy. To achieve this end our objective was to use a case study to understand the meaning that the patient attaches to the experience of undergoing chemotherapy.

THEORETICAL AND METODOLOGICAL FRAMEWORK

For the analysis we followed the thinking of the interpretative anthropology, which is oriented to understanding the experience from the perspective of the active participants. To attain this objective it is necessary to interpret the living world of the actors, to assimilate the process of constructing the cultural meanings of illness and treatment, and how they are incorporated into the language and the actions of the social actors (3-4).

Within this approach, culture is envisaged as a network of meanings assembled by the subject and shared by the social group, which serve as an orientation for the behavior of members of the group. Cultural analysis is not primarily concerned with the behavior itself, but rather with the interpretation and understanding of what it transmits, since culture is related to the framework of meanings established socially (3-4). Thus, the cultural elements of the life in group – knowledge, beliefs and values – are normalized to constitute a symbolic system of common sense. Medical anthropology, derived from the interpretative anthropology, considers health and illness to be the result of the interaction of the biological, the cultural and the subjective experience (5). The person who has cancer and looks for its cure may utilize the cultural elements to interpret the experience of undergoing chemotherapy, which is the object of the present study.

The anthropological study consists to unravel this meaning, either implicit or explicit in the individual’s language, and to understand and interpret its intentions, history, background and subjectivity. The subject’s experience becomes public by means of the language, that is intentional, and the discourse can be understood by its meaning. Although the experience may be common to many individuals, knowledge is private because it requires both personal and inter-subjective elaboration, mediated by common sense, which serves as a reference for each individual (5).

Ethnography is the best methodological approach to study this subject, i. e. the meaning of the personal experience of cancer and chemotherapy, which requires the follow up of the disease, the therapeutic measures and the speeches involved (6). In this way, the methodology was adapted to an ethnographic case study. A “case” can be a person, a specific group of persons, an organization or a particular event; the only requirement is that it must have a physical or a social limit that confer identity to the case. Thus, a case may be chosen because it is an example of a class or because it is of interest by itself (6-7).
In the present study, the case is a patient with breast cancer who had been mastectomized and was submitted to chemotherapy.

**METHODOLOGY**

After approval of the project by the Institutional Research Ethics Review Board of the Faculty of Medicine of the Triangulo Mineiro, a representative patient was selected to carry on the case study. The woman invited to participate was receiving medical care in a specialized oncological hospital integrated into the Brazilian Health System (SUS = Sistema Único de Saúde) and fulfilled the inclusion criteria: being informed of the diagnosis and the treatment, being more than 18-year old, starting the chemotherapy treatment and agreeing to participate by signing a term of informed consent. She may be classified as belonging to the popular social class, on the basis of her social conditions, which included a amount of education, low income, and she was an urban dweller with restricted access to material and cultural goods. Although members of this social unit must have a particular way of expressing their individuality, it is important to characterize the experience of a cancer patient undergoing chemotherapy who belongs to this class because they receive medical attention preferentially in government hospitals. These hospitals are the main providers of cancer diagnosis and treatment, and employ the majority of nurses in our country.

Data collection was carried out between March and September 2004, the period of chemotherapy. Three basic approaches were used: semi-structured interviews, non-structured observations and examination of the field diary. We carried out eight interviews with the patient, either in chemotherapy outpatient clinics or in her home. The guiding questions were: "Tell me how you discovered that you had cancer", "Tell me about this disease", "What have you done to treat and take care of this disease?", "What do you think about chemotherapy?", "How is your life after you started chemotherapy?", "What do you expect after chemotherapy?". Initially the meetings were weekly and afterwards every fortnight.

The non-structured observation focused on the attitude during the data collection, such as gesture, body signals, changes of voice intonation, which may be relevant for the posterior interpretation of the registered interviews. Notes about the interviews, the observations and the data from the medical file related to the evolution and medical follow-up were recorded in the field diary.

The interviews were transcribed and the data were integrated with those from the field diary. We carried out several readings of this material in order to identify the units of meaning. These units are segments of the report that have a specific meaning, containing the description of a situation or an experience, that reflect the importance that the participant attached to it. The units that we found were: the discovery of cancer and search for assistance, the knowledge about cancer, the trajectory of chemotherapy, the networks of support, the lack of control of one’s life, the uncertainty about the future and the expectation in the future.

On the basis of these units of meaning, we summarize the patient’s view on her experience with cancer chemotherapy as “the loss of the control over one’s life”.

**RESULTS AND DISCUSSION**

Case presentation

The patient, referred to here as Francisca, is 39-year old, completed high school, is divorced and lives with her two children in a separate area of her father’s house. She is a seamstress and supports herself and the two children. After the marriage break-up she had one love relationship, but at the moment of the data collection she was single. Her sister had breast cancer at the age of 28 and soon died of the disease. Although she did not accompany her sister’s disease, the family members have recounted the more significant episodes to her. Francisca discovered a nodule in the left breast during self-examination. Her first reaction was to ignore the finding. She only went to a doctor after one year, because of the insistence of a friend and of her daughter. In a period of one month she was submitted to several types of medical examinations, received the diagnosis of breast cancer, was submitted to radical mastectomy and soon afterwards was advised to start chemotherapy.
The unities of meaning

-The discovery of cancer and the search for assistance

The left breast nodule was observed during self-examination. Although she knew that it could be a sign of cancer, due to the past experience of her sister, Francisca put off the solution of the problem for she did not wish to believe the fact: ...there is a small lump here, it is hard, I do not know what I must do! ... I have known of this lump for a year! ... It did not hurt. I felt it with my hand and it moved from one side to the other, as if it were a small egg. People say that women who breast-feed do not have breast cancer! The affected breast was the left breast, the one that I used most for breast-feeding. I thought that maybe it was the milk that caused it, some type of inflammation... I went to the gynecologist who examined me and asked for an ultrasound. I did the exam; I gave no importance to the whole thing because the doctor said that it could be related to hormones, a nodule, and I did not return to the doctor. After a year I thought: I will go directly to my doctor (mastologist), he will solve this! I went, he ordered the examinations and confirmed, you see! But, I had my suspicions because I had the disease in the family, isn't it! But I never thought that it would happen with me! I became very worried; I thought that I was going to die, same as my sister (1st meeting).

Studies have shown that recognizing a body signal or symptom depends on the perception of a symbolic reference that orients the individual within a system of knowledges and beliefs. Only after that the symptom can be recognized as the expression of a disease and an initiative can be taken before it. Due to fear of the disease and the absence of pain Francisca did not take the finding seriously and put off the search for medical advice, a behavior that is frequently observed among people of all social classes (10).

-The knowledge of cancer

Francisca had information about cancer and its treatment that she had acquired from her social group, from her family and the media. Whenever Francisca referred to cancer she used a soft voice and used terms such as this, the disease, that, a subterfuge of language in the Latin-American culture that reveals the social stigma of cancer, since the disease is seen as a consequence of moral behavior (11). During her life the patient had known other persons who had had cancer, besides her sister, and reported a situation that impressed her very much:

There was this friend of ours that also had the disease in the intestines. My mother and I went to visit her, after my sister had passed away. Then I said to my mother: poor thing, she won't survive until tomorrow, such was the bad condition she was in! And you know what, the woman is still alive today, can you believe! That's how I got strength. I saw that I could too, I wouldn't be like my sister, who was only one case... the vaccines (chemotherapy courses) were bad, but I know that they help me (1st meeting).

She commented on the mastectomy surgery in casual and calm way: Then, on the 19th of February I went to the surgery. I soon was discharged and went back to work; it didn't affect me in any way! (3rd meeting)

For Francisca, having had cancer, a bad disease, having been submitted to a major surgery that evolved without problems is part of her past. Chemotherapy is the treatment of the present that can lead to a future without disease, to survival.

-The trajectory of chemotherapy

Very soon in the first meeting Francisca made a point of exposing her beliefs about cancer treatments: I said to the doctor: if this disease has no cure you can tell me, because in this case I do not wish any treatment. I know how it is ... When you treat you have one year of life, if you don't treat you may have two years. It prolongs your life a bit... I said this because, if there is no hope, why to treat? If you stay still you live longer! He told me that that depends on the case: if the disease is already too advanced, it is not worth to treat! But he treated me and I had hope (1st meeting). In this speech the patient reveals conceptions of cancer and its treatment similar to those revealed by other studies with Brazilian subjects from the popular classes. This view may result from the frequent examples of treatment failure divulged within the social group (11-12).

About the purpose of chemotherapy, the participant said: I think that chemotherapy is one way to fight... it is the same thing as the medicines that I take for flu. It is a treatment (8th meeting). She also related her reactions to the procedure, which were part of her repertoire of symbols and influenced her perceptions: ... it came to my head that I might be cured! I didn't give a damn for the nausea and vomiting... I didn't accompany my sister, only her hair-loss. I expected that it'd be different, normal vomiting, not that horrible feeling... (1st meeting). This thing about being sick
People living through a severe disease seek religion as a way to overcome difficulties. Religion has several cultural roles: it helps to create an identity that links people together, helps to cope with threats, and strengthens the fight for survival before a fatal disease. Under the influence of religious faith, the patients assume the speech of a better and stronger person, who preach solidarity and participate actively in the social group. By stating that religion helps raise the expectation of cure and to overcome the fear of death, of losses and of pain, people are stressing its role to restore the meaning of life (13-14).

Francisca told that during the period of chemotherapy she had support from different sources, besides religion. She emphasized the good relationship with her doctor, from the moment that the disease was diagnosed, which had a strong positive influence in her adhesion to treatment.

But the most important support for surviving the experience came from the network formed by family and close friends. According to Francisca, her father is her principal support: … when I received the fifth course of chemotherapy, I arrived at home and threw up. Never before I had vomited! I went to my daddy’s and talked with him, he was feeling down, even crying ….! He helps me a lot! (7th meeting).

Her long-time friend is included in this framework: Friends are those who stay with you in the hardest times. I’ve got a friend who helped a lot in my fight, she gave me strength. She comes here, brings medicines, teaches me things… She is the one who took care of me, very close. I went to the doctor because of her. She supports me a lot. She’s really my friend! (7th meeting).

The other patients with whom Francisca related at the chemotherapy outpatient clinic also functioned as part of the network of support: There are days when you meet good people in there! I was crying. Then, he calmed me down, talked to me, you know. With me! Then, one feels better, starts to talk and feels better! (7th meeting).

Although the process of illness and suffering relates to personal and singular experiences, in the social context it is by means of relationship that people bring out their interior reactions to express emotions and feelings, since the lack of social relationship leads people to lose their reference or their identity15).

-Lack of control of one’s life

The third chemotherapy cycle represented a turning point in Francisca’s life: it separates before
from after. Until the second session of treatment her malaise lasted for two or three days, but starting with the third session the reaction became stronger and lasted for a week. The frequency and intensity of the reactions had a negative impact on her life, especially on her income.

She supported herself and the family by her work as a seamstress. The adverse effects of treatment made her stop working for some periods, with a consequence reduction of her financial resources: Chemotherapy brings a lot of anxiety, because I don’t know if I can accept an order for or not. You know, there is no lack of work, but if you don’t deliver as promised the costumers forget about you. It’s bad time for work now…. But it’ll become better. Sometimes I feel the bad taste of chemo. You see, there are so many problems… (3rd meeting).

The patient made an effort to overcome the financial difficulties and ventured into an informal society; she bought new sewing machines and contracted a paid seamstress, which brought her additional problems: ... I became downcast because my new work didn’t succeed. But, I said, I can’t do the chemotherapy with all those problems. I need to solve one thing a time…. I can’t handle it all, it is too much… (4th meeting). I support my home, what will I do? I have no money! I can’t stand it any more (5th meeting).

Her strength to overcome difficulties and to endure what she was living through was impressive: I am winning, God be blessed! I am paying the installments; I am ill and am paying the installments! My father’s helping me with the houses’ expenses (6th meeting). At the same time that she fights for survival, Francisca confesses her fragility: ...when I feel well I do my sewing work. But there are days when it’s impossible to work, ... I’m not able to work .... and you have to accept it. It is a very hard treatment (6th meeting). At the end, I couldn’t stand it any more ... (8th meeting).

In addition to the financial problems, the patient stressed the difficulty to maintain a good affective relationship with her children, owing to her frequent malaises. She said that the daughter, who was older, understood what was happening, but she was worried with the younger son, who was still growing up and required more attention: My son is so cute! After I have received chemotherapy he stays around me. He doesn’t want me to sleep, he stays with me, calls me often (5th meeting). If I stay later in bed he calls me: mammy, get up, get up! He doesn’t like to see me lying down in bed. If I’m in bed it is because I am sick... then he keeps on saying: mammy, are you all right? Today I didn’t say much about the chemo so that he’ll not be too worried (7th meeting).

The course of this woman’s treatment reveals that chemotherapy excludes the patients from their social roles, making them feel impotent, increasing their uncertainties and threatening their integrity. The feeling of impotency is a consequence of how society establishes the appropriate behavior, appearance, contribution and productivity expected from each of its members, without giving them alternatives. Thus Francisca fights, submits herself to the situation, missing the control over her own life, but at the same time expecting a better future (13,15).

In our Latin-American culture, suffering in relation to cancer and its treatment is commonly expected. Francisca behaved as she felt was expected by her group, facing the suffering caused by the drug reactions as an act of acceptance. Thus, even though her family and friends suggested that she communicated to her doctor that she was having severe reactions to the drugs, she did not behave this way, because this would not conform to the standard role of having cancer and suffering with the treatment.

-The uncertainty of the treatment and the expectation for the future

As the treatment progressed, there was a continuous process of reinterpretation of the situations. Francisca was anxious to resume the sense of control, especially in view of what had happened with her sister, and with her own at the diagnosis, the surgery and the suffering of undergoing treatment by chemotherapy.

However, the observation of other patients at the chemotherapy outpatient clinic made her consider the possibility of relapse of the disease, and this made her unsure about the success of the treatment: There was a patient who commented … she had it in the intestine. Now it came back in other part of the body. Why? We receive chemotherapy to kill everything! What a mess... you feel anything, no matter how insignificant, and you already think that it may be the end of the world! I go there, and the girl tells me that her disease has come back! Then I said: my god, to have to go through all this again? (5th meeting).

After the end of the chemotherapy treatment, Francisca evaluated her experience and brought back her doubts about the success of the treatment: Do you wish to know? Sometimes I don’t believe, because there are so
many cases that come back! At the hospital I talked to a lot of people ... I've got the impression that chemotherapy is perhaps a means that the doctors think that may fight the disease, do you understand? But it is not yet sure; if it was sure, how come that the disease would come back? (8th meeting).

In an ambivalent way, Francisca needed something to give her hope in future, and she sees the possibility of financial recovery as something that would bring her back to a normal life: I think that I'm going to work, because when I'm working I don't see the time passing. Finishing the chemotherapy, everything will go better ... I can work and live a normal life (5th meeting). Now I know that there is no more disease, I am tranquil! Then, I'll go back to my normal life. I was able to win and now I'm cured, God be blessed! When I finish paying for the sewing machines I will have a better income, and I'll live a more relaxed life. Now I'm working on Saturdays, Sundays, holidays, days and nights, to handle this situation (8th meeting).

This case study demonstrates a cultural pattern that members of the popular classes use to re-structure their lives during the experience of a severe disease, aiming at overcoming the limitation of the diseased body that leads to the loss of the control of their own lives. This model view emphasizes the fact that both the body and the experience of suffering are linked to our identity.

When the symptoms caused by the anticancer drugs were less prominent, a fact that surprised her, the patient relied on the common sense and questioned the effectiveness of the medicines that she was receiving. When the collateral effects became intense she starts to question her own life, because it is her body, and not the nauseas and vomiting, that made the development of her work, her income and the relationship with the children difficult. These are the conditions that lead her to finally summarize the meaning of this experience as “the loss of the control over her own life” and make her feel impotent.

In the final period of chemotherapy, when the side effects of the treatment diminished again, Francisca concluded that she was bringing the cancer under control. She built a new relationship with her body and with herself, a resource to give direction, knowledge and values to her life. Thus, the search of normality or of re-establishment of the conditions previous to the disease, notwithstanding the uncertainties, remains a permanent goal.

**FINAL COMMENTS**

The approaches of interpretative anthropology and ethnography contributed to our interpretation that when people speak about their experiences with cancer and its treatment, they take as a basis their own biographic memory, re-constructing and reproducing the past events, in a way that is congruent with their present understanding. Thus, the present is explained in reference to the reconstructed past, and the private feelings about both the present and the past are used to generate expectations for the future. As with other cognitive processes, these memories are mediated by cultural frameworks that function as orientations to perceive, organize and interpret the experience related to an event, in this case, chemotherapy. These orientations characterize the interpretative model for the experience, on the basis of the common sense of the cultural group, which differs from the bio-medical model.

We can conclude that the patient organized the experience of chemotherapy that she lived through under the interpretation of loss of the control over her own life. This experience was marked by the conflicting feelings of suffering and fight for survival, owing to her body’s responses to the medicines, that prevented her from fulfilling her roles of mother and provider of financial support to the family. Even in this situation the patient made an effort to organize her attitudes in relation to life.

The meaning that she constructed corroborates the idea that the experience of chemotherapy treatment involves a dimension that goes beyond nauseas and vomiting, an aspect that is not always taken into account by health professionals, including nurses.

A practical consequence of these observations is the need to implant the nurse consultation as part of the follow-up of cancer patients under chemotherapy treatment in the Brazilian public hospitals, directing the attention to demystifying cancer and its treatments. Community resources to help cancer patients undergoing chemotherapy must be identified as well as the means to transfer them to the patients. Finally, to act efficiently in this context, the nurse needs to understand how the disease and its treatment affect the patient, and how the patient interprets them.
REFERENCES