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ORIGINAL ARTICLE

THE NURSE IN EDUCATIONAL PRACTICE TOGETHER WITH THE FAMILY OF CLIENTS WITH BREAST CANCER SUBMITTED TO CHEMOTHERAPY

O ENFERMEIRO NA PRÁTICA EDUCATIVA JUNTO AOS FAMILIARES DE CLIENTES COM CÂNCER DE MAMA SUBMETIDAS À QUIMIOTERAPIA

EL ENFERMERO EN LA PRÁCTICA EDUCATIVA JUNTO A LOS FAMILIARES DE CLIENTES CON CÁNCER DE MAMA SOMETIDOS A QUIMIOTERAPIA

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ABSTRACT

Objective: to identify how is the work of nurses in caring for women with breast cancer in cancer chemotherapy. **Method:** An exploratory study, a qualitative approach, performed at the Center for Chemotherapy, Antonio Pedro University Hospital - Fluminense Federal University / UFF. Five nurses and one resident participated. It was held with recorded script with semi-structured interview and non-participant observation interview. The analysis was performed from the Technical Content Analysis in the thematic analysis method. The project was approved by the Ethics Committee in Research, Opinion 243/09. **Results:** there are factors affecting the effective work of nurses due to lack of records, and no specific protocol, and routine nursing visits does not exist in the sector. **Conclusion:** there is need for specialist knowledge and continuing education for nurses, and the need to develop strategies to clarify doubts and increase patients' knowledge; essential to the effectiveness of the Systematization of Nursing Assistant. **Descriptors:** Health Education; Health Care; Oncology Nursing; Family; Chemotherapy.

RESUMO

Objetivo: identificar como se dá o trabalho dos enfermeiros no atendimento às mulheres com câncer de mama em quimioterapia antineoplásica. **Método:** estudo exploratório, de abordagem qualitativa, realizado no Centro de Quimioterapia do Hospital Universitário Antonio Pedro - Universidade Federal Fluminense/UFF. Participaram cinco enfermeiros e uma residente. Realizou-se entrevista gravada, com roteiro de entrevista semiestruturado e observação não participante. A análise se deu a partir da Técnica de Análise de Conteúdo, na modalidade Análise temática. O projeto foi aprovado pelo Comitê de Ética em Pesquisa, Parecer nº 243/09. **Resultados:** existem fatores que interferem na atuação efetiva do enfermeiro devido às carências de registros, ausência de protocolo específico e não existir no setor a rotina de consulta de enfermagem. **Conclusão:** há necessidade do conhecimento de especialista, da formação contínua pelos enfermeiros e de que sejam criadas estratégias que esclareçam dúvidas e aumentem o conhecimento dos pacientes, essenciais para a efetivação da Sistematização da Assistência de Enfermagem. **Descritores:** Educação em Saúde; Assistência à Saúde; Enfermagem Oncológica; Família; Quimioterapia.

RESUMEN

Objetivo: identificar como se da el trabajo de los enfermeros en el atendimento a las mujeres con cáncer de mama en quimioterapia antineoplásica. **Método:** estudio exploratorio, de enfoque cualitativo, realizado en el Centro de Quimioterapia del Hospital Universitario Antonio Pedro - Universidad Federal Fluminense/UFF. Participaron cinco enfermeros y una residente. Se realizó entrevista grabada con guía de entrevista semiestructurada y observación no participante. El análisis se dio a partir de la Técnica de Análisis de Contenido en la modalidad Análisis temático. El proyecto fue aprobado por el Comité de Ética en Investigación, Parecer nº 243/09. **Resultados:** existen factores que interfieren en la actuación efectiva del enfermero, debido a las carencias de registros, y ausencia de protocolo específico, y no existir en el sector la rutina de consulta de enfermería. **Conclusión:** hay necesidad del conocimiento de especialista y de la formación continua por los enfermeros, y la necesidad de criarse estrategias que aclaren dudas y aumenten el conocimiento de los pacientes; esenciales para la efectución de la Sistematización de la Asistencia de Enfermería. **Descriptor:** Educación en Salud; Asistencia a la Salud; Enfermería Oncológica; Familia; Quimioterapia.

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INTRODUCTION

According to the Pan-American Health Organization PAHO, "Non-communicable Chronic Diseases are characterized by having an uncertain etiology, multiple risk factors, long periods of latency, prolonged course, non-infectious origin and for being associated with disability and functional disability." The NCD started to lead causes of death in the country in recent decades, surpassing the rates of mortality from infectious and parasitic diseases (IPD) in the 80s.¹

For the National Cancer Institute (NCI)², cancer is the name given to a set of more than 100 diseases that have in common the disordered growth of cells that invade the tissues and organs and may spread to other regions of the body. According to the World Health Organization WHO,³ the disease arises mainly as a consequence of individual exposure to carcinogens in individuals who inhale, eat, drink or are exposed in their work environment. Personal habits, such as smoking, diet and physical activity patterns, as well as professionals and environmental conditions, and not genetic factors, tend to play the main role in the development of cancer.

Estimates of 2008, for female breast cancer, were 234,870 new cases, being the breast cancers and of the cervix the more incidents, following the same profile of the magnitude observed worldwide. In Rio de Janeiro, it is estimated 7,680 new cases of female breast cancer, in the Southeast, it is estimated new cases 28,430.² This neoplasm is also the most incident and more frequent among women of the South, with 67 cases per 100 thousand inhabitants, Midwest, with 38 cases per 100 thousand inhabitants, and the Northeast region, with 28 cases per 100 thousand inhabitants. In the North, breast cancer is the second most neoplasia with 16 incident cases per 100 thousand inhabitants. In Brazil, it is estimated 49,400 new cases.²

Due to the long duration, costs are a problem attributed to this disease. It is among the most demanding actions, procedures, and health services, as direct costs and indirect costs arising from absenteeism, early retirement and loss of productivity.

Studies⁴ conducted with women indicated that, upon receiving the diagnosis of breast cancer, the woman begins to face a difficult time in her life, going on to experience three different stages and complex: the diagnosis with cancer, word loaded of negative feeling in our society; The realization of a long and

aggressive treatment, often in need of partial or total removal of the breast to restoration of health; The acceptance of a body marked and coexistence with this image.

The illness of a family member with cancer, especially the woman with breast cancer, can interfere in the other, because the treatment modalities, such as execution of a mutilating surgery, given the mastectomy surgery, compromise the patient's body image and family relationships. Often, the family is not prepared to face this disease and support the suffering of the family member, in this way, the presence of the family in the patient's therapeutic process is required for support and guidance.

The family throughout the treatment lives several experiences, like assisting their loved one suffering this illness, generating feelings of confusion, insecurity, powerlessness, fear and doubt. Family affection allows the woman to maintain a certain stability to fight against the disease. Therefore, she can meet their emotional needs, achieving a better acceptance and behavioral guidance.⁴

Another problem in relation to women with breast cancer on chemotherapy refers to the guidelines given by health professionals in order to minimize the impacts of the treatment. The nurse is an important professional in the host process, medication administration and in the guidelines to the risks and benefits of treatment, among others.

Nurses recognize the importance of the various cancer treatments, but the priorities should not fall only on the management of the disease, but also to the built environment around them.⁵ In other words, the care should not just have the biological world of patient's disease but also include the world of their body, in the sociological sense.

OBJECTIVES

- To describe the work of nurses in orientation of relatives of women with breast cancer on chemotherapy anticancer.
- To identify strategies/health education procedures that nurses use with the families of these women.

METHOD

Exploratory study of a qualitative approach. The location of the research was the chemotherapy Center, located on the ground floor of the University Hospital Antônio Pedro, from Fluminense Federal University,

large hospital in the municipality of Niterói/RJ.

The subjects of the study were five nurses who acted on chemotherapy and a nurse Resident of chemotherapy of HUAP, because they did the nursing care to patients with breast cancer in chemotherapy treatment, except of anticancer IV, of the institution chosen, after the acceptance of the informed consent term, complying with the ethical issues of research.

For the production of data, the recorded interview was used, with semi-structured interview script, followed by non-participant observation. For data analysis, the Technique of content Analysis was employed, in Thematic Categories mode. Thus, two categories were determined: ♦ **Limits and possibilities in the role of the nurse to women with breast cancer on anticancer chemotherapy** and ♦ **Strategies/nursing procedures in education and health care for the families of women with breast cancer on anticancer chemotherapy.**

To preserve the anonymity of the subjects, they were identified by names of flowers. It is highlighted that the research does not involve in any harm to the subject, since the objectives and data collection instrument do not constitute any harm to the integrity of the customers, because they will have their identity respected, as well as the confidentiality of the data obtained. On the other hand, the benefits achievable enabled to know theoretical-methodological resources the nurse uses in preparing the woman with breast cancer, in anticancer chemotherapy treatment, and their families.

The research was sent to the Committee of Ethics in Research of HUAP in order to fulfill what advocates the Resolution 196/96, adopted by the National Health Council in October 10, 1996. Registered under number 243/09. According to this Resolution, the research should always treat human beings with dignity, respect them in their autonomy and defend them in their vulnerability, relying on the informed consent of research subjects and/or their legal representatives.

RESULTS AND DISCUSSION

♦ **Limits and possibilities in the role of the nurse to women with breast cancer on anticancer chemotherapy**

All respondents answered to have been guiding the family and women in the first meeting, when it is marked the first cycle of chemotherapy in this sector or when questions

arise. However, patients and family members showed their knowledge deficits accented on the chemotherapeutic drugs, being related to lack of information provided by health professionals or in the way of their transmission.¹⁰

It was evidenced the importance of scientific knowledge for nurses who work with families of women in course of CT, because these professionals guide on prevention of problems related to CT, the process of treatment, the illness and recovery of health. The guidelines shall address the purpose, characteristics, actions and reactions of the medicines, with the purpose of increasing the quality of the treatment of these patients, being elaborated and implemented assistance plans relating to the treatment and cure of the patient since their admission in the sector.¹¹ Thus, the task of education, in addition to convey what is important, should provide means for the subject to realize the importance of what he wants to teach.¹²

Family members of clients submitted to chemotherapy treatment need to know about health conditions and disorders caused by therapy, to help them understand, accept their conditions and prevent possible complications. The nurse helps minimize the disorders with his guidelines. Similarly, according to the International Accreditation Standards Hospital Manual¹³ "Education of the patient and families helps them to have the knowledge and the necessary information so that they can participate and make decisions about their care."

In addition to the nurse to have his technical paper related to the handling of drugs, must also act as a multiplier of correct information about the treatment, considering the cultural aspects and also the stigma that exists, thus, dispelling doubts and undoing taboos, fears and prejudices in patients and in the general population.¹⁴ These factors can cause abandonment of treatment or difficulties in assimilating the information needed.

Considering the instructions provided by the nurses to family members, it was observed that they focused on chemotherapy and its effects on the disease, warning signs, anxiety, mastectomy arm exercises, curative care and fluid intake. The guidelines are a support so that the family can help women at home, minimizing the risks of treatment and their quality of life. It must be taken into account the way of guidance, elaborated and structured manner, the needs and the

conditions of individuals, to be retrieved from a good learning and a quality nursing care.

Effective education begins with the assessment of the learning needs of the client and their families. This evaluation indicates not only what should be developed through learning, but what is the way to guarantee learning for this individual, subject of this process. Nurses can encourage families to learn how to maintain health, such as restore it or how to adapt with more independence to possible situations of imbalance in health, which represents a criterion of efficaciousness.¹⁵

The client usually requires a detailed understanding about his condition in order to maximize the opportunities for recovery and maintenance of their health¹², but under the guidelines, it was observed that there is a proper instrument to record the behavior and guidelines held to the families and women during nursing consultation or in other situations of doubt after the consultation. The nursing consultation is held only on the first attendance of the patient, when is marked his first cycle of CT, there is no new appointments to this assessment by the nurse.

The lack of this instrument can impede the Systematization of Nursing Care Assistance (SAE), which is the private nurse, according to COFEN Resolution Number 272/2001, which provides for on the Systematization of Nursing Care Assistance-SAE- in Brazilian health institutions.

SAE uses method and strategy of scientific work for the identification of the health/disease situations, subsidizing nursing assistance actions that can contribute to the promotion, prevention, recovery and rehabilitation of the health of the individual, family and community; the institutionalization of SAE as a practice of a worker process appropriate to the needs of the community and how the assistance model be applied in all areas of health care by nurses; SAE implementation constitutes effectively improving the quality of Nursing Care.¹⁵

SAE implementation, according to article 3 of the COFEN Resolution Number 272/2001, shall be formally recorded in the patient's chart (COFEN, 2006). The process of nursing assistance is planned to meet the specific needs of the patient, and being directed so that all the people involved in the treatment may have access to the assistance plan (16). Without this instrument, other health professionals who are involved in assisting this patient does not know what information has already been transmitted, if they are being

successful or not and what is the condition of the patient.

The systematization of nursing activities must be based on an instrument: "Nursing process", because it allows to carrying out the activity of nurse's assistance to Nursing Consultation, using the time necessary to meet the individual needs of each client.¹⁷

The Nursing Consultation is "(...) application of the nursing process. Therefore, assistance to the individual apparently sound or in outpatient treatment." The consultation has nursing teaching strategies directed to customer learning, in this way, an activity in constant search of knowledge, in addition to the didactic teaching practices.¹⁸

It should be noted that the nurse during the Nursing Consultation, exerts his autonomy necessary to performance an autonomous practice, either teaching or assisting, guided continually in legal patterns with the whole responsibility and commitment invested in the mister of the profession, which are current and in force as standards of behavior, for a more human and effective care in the service of another.¹⁴

The nursing consultation is important for gradual construction of knowledge of the nurse, of the patient and to the improvement of his practice. However, some factors may hinder the achievement of nursing consultation for all patients prior to CT, in order that the sector has researched only five nurses and a resident of nursing, to an attendance of more than 300 patients monthly of CT. In 2009, 3,951 CT were carried out, according to the report of chemotherapies consultations and chemotherapies of Oncology of HUAP.

There are some relevant aspects that prevent or hinder significantly the Nursing Consultation¹⁹ that are distinguished: theoretical and practical training of nurses; lack of technical knowledge and professional devaluation; continuing education programs; accumulation of functions (administrative and assistance); lack of personnel in the team; precarious conditions of work environment; infrastructure and other features disabled; social and technical relations of area health services; ignorance of the legal aspects which result in omission; and negligence on the priority of the Nursing Consultation as exclusive activity of nurses, these factors hamper the progress and scope of the nursing consultation.²⁰

The perspective of any and all organizations/institutions should be focused on: customer expectations that build on three

basic points aiming at improving the quality of assistance; strategy - planning actions, execution, control and a gradual process evaluation; people - everyone involved in a spirit of individual and/or collective service; systems - places where assistance is designed competing to provide the best working conditions.

It was sought to know if the nurse is concerned with collecting information from patients. Most of them seek to collect the patient's number and a contact, seeking information about where he did the surgery, how long, pre-existing diseases, if he knows about the disease and if he had any problems. In this way, it was observed that the nurse is concerned with collecting information, but does not follow a script or is not systematically, with the risk of some important information not being asked or lost due to the absence of an instrument for registration, as mentioned.

The Nursing Consultation includes the interview, for data collection, physical examination, and establishment of nursing diagnoses, prescriptions, nursing care and guidance implementation of actions relating to detected problems.¹⁷

All participants of the research come in contact with the relatives and women when there is no medication; when the chapel of laminated is broken; when they reach medicines and on change of date medication. In this sense, the nurses had to provide the patients and family complications for sector not moving from their residence to the Hospital, minimizing possible conflicts, making transparent the realities of the institution and strengthening confidence with these.

Consistent and accurate information is essential for the families to feel safe to deal with adverse effects of chemotherapy at their home, in a suitable coping to the disease and effective participation in care. This information also contributes to the patients in the process of treatment and behavioral changes, thus ensuring the success of the nursing interventions expressing improvements of health level.

♦ Strategies/nursing procedures in education and health care for the families of women with breast cancer on anticancer chemotherapy

In testimonials found, 66.6% of nurses responded that they guided with folder/brochures, created by nurses in the sector, and one of them, in addition to the

brochures, cited the phone to take questions from the patient; 16.6% through the waiting room and lecture, especially in palliative care and 16.6% just took questions that appear during treatment and for the new cases. It is confirm this through the lines:

Folders are provided with guidelines for patients and their families. (COPO DE LEITE)

Through conversations with patients and families and also pamphlets created for us nurses and by phone. (TULIPA)

Through the waiting room and lectures. (MARGARIDA)

The relatives are guided according to the need coming into service accompanied by the patient.(HORTENSIA).

With respect to the distribution of pamphlets, IT was cited the difficulty of supply them to patients, as they are printed, mostly through the help of a patient who is in terminal phase and the institution is not always performs photocopy due to lack of paper sheets, according to the following statement.

There are flyers created for us and printed with the help of a patient (pause) that is terminal. We don't know how we're going to do next if this patient goes away. Sometimes the hospital copied, sometimes in the hospital does not have paper for copies. (TULIPA)

The nurse just performs the consultation in the first care nursing of the first cycle of chemotherapy. They deliver folder and say its contents. Thus, it was observed that the patient only receives this information and the folder on the first day, and later held other guidelines continuously. It should be noted that the lack of knowledge by users can generate undesirable effects and ensure the effectiveness and safety, culminating with ministrations and inappropriate actions.¹⁵

Over the years, it has been observed that the lack of specific information during treatment with anticancer chemotherapy may be related to lack of proper control of the side effects produced and, consequently, to the aggravation of symptoms.²³ The educational activities with family members, patients or caregivers need to be carried out continuously, for better understanding of diseases and treatment, minimizing gradually the doubts that may arise during treatment with chemotherapy and greater patient compliance.

The nursing team follows up the patient during his treatment, then the continuous information flow becomes necessary, as well as the co-responsibility of the nursing staff,

and strengthen the necessary precautions to avoid new harms to health.¹⁰ In addition to the need to develop skills in communication, since the good relationship between patients and nurses is a differential in quality of care.¹⁸

In relation to the guidelines of nurses regarding symptoms and possible solutions, five (83%) nurses boarded the symptoms and offered suggestions for solution with the medication prescribed by the doctor and 1 (16.6%) offered solutions with 100% of the nurses diet. 100% of nurses cited nausea, fever above 37.8°C, vomiting and alopecia, moreover, two (33.2%) added care of the arm on the side of the surgery and one (16.6%) cited vaccine, fall of immunity, pain and seek emergency if symptoms persist.

There is a disparity in the guidelines carried out by nurses and, in some cases, lacked important information to be addressed with the relatives, which can generate insecurity, fragility and hinder their treatment adherence. In addition, it should think of strategies to facilitate the knowledge of patients.

Studies indicate that patients have concerns about the side effects, especially those that affect their everyday life. The side effects are the biggest causes of abandonment of the treatment being required to provide information primarily targeted to its control, promoting the participation of patients in his care.¹⁰ It should be noted that the patient is entitled to information and this should be provided with respect to their ability of understanding and the extent of their need. The nurses are committed to promoting education to oncological patient to improve their conditions.

Faced with the investigation, there is a manual or Protocol provided by the institution to direct nurses in practice, three (50.0%) respondents replied that this material does not exist in the sector, two (33.2%) responded that there are the pamphlets and the Protocol made by them and used as manuals and one (16.6%) cited that the manual did not exist, but they used the flyers, according to the following lines:

The learning is in the acting area (...).
 (GIRASSOL)

We have the flyers created for us. (TULIPA)

The Protocol was done by the nurses in the sector. (BEGÔNIA)

It is observed that there is no manual/Protocol institutionalized and that nurses are based on protocols created by them. Faced with the absence of this manual, three (50.0%) of nurses reported that sought

materials available in other sources, such as the following statements:

Professionals seek in literature and updates over the internet. This makes the work because the knowledge of the evolution of diseases and their complications end up being experienced and receiving the interventions at the time that happens, as the demand for assistance from other professionals. (HORTENSIA)

Protocols are available from the Ministry of Health and the NCI, to support the guidelines. (MARGARIDA)

(...) the Protocol is the book of nursing actions of the NCI, but should have a manual directed to the HUAP. (GIRASSOL)

It is noticed that the absence of this manual/protocol causes to disorders nursing care and time loss occurs with the demand for this material in other sources or with learning in the life of the rarer cases of symptoms (in anticancer). The institution having a manual, or benchmarks, to be made available to employees in the sector, would be complying with the commitment to ensure the uniqueness of actions, the quality and improvement of teaching-service and health care of all the professionals involved, bringing them closer in interventions, procedures, guidelines and special care to family members and cancer patients, as well as provide them with greater safety of operation.

As regards how the nurse evaluates if his guidelines reach his goals on the family and the client, three (50.0%) stated that the assessment is made with the return of the patient administration of chemotherapeutic drugs; two (33.2%) reported that there is a difficulty in the evaluation due to the lack of records and one (16.6%) cited that the evaluation is conducted in the return of the patient, but with great difficulty due to the lack of records, according to the following reports:

In the return of the patient, the next drug administrations. (BEGÔNIA and MARGARIDA)

With the return of CT applications client. There is an interaction with the team so that we understand whether or not there was uptake of the guidelines made. Ideally, nursing, nutrition consultations, medicine with registration of the guidelines made by all professionals involved in the treatment. (GIRASSOL)

As there is an instrument for evaluation, it occurs a scouting difficulty facing the achievement of goals. There is need for establishment of outpatient nursing Oncology for a better approach to the patient/family. (COPO DE LEITE)

The assessment is difficult due to absence of registration on the guidelines. We are few (related to quantity) professionals, there is still the possibility to consult individual nursing (with each patient and their family). Even so, most patients and their families seeking us to take many doubts, informally. (TULIPA)

With the return of the patient for treatment, but is disabled due to lack of an instrument of continuity to the records, nursing interventions and guidance, because we don't deal with the chart with only the unique records. (HORTENSIA)

It was evident the difficulty of assessing whether nurses have reached their goals in front of relatives and patients, mainly by the lack of an instrument for registration. To be efficaciousness of activities, it is necessary to evaluate the whole process of constant development of the patient.

The multidisciplinary team of the Oncology sector of HUAP has nutritionist, social worker, doctor, nursing staff and when needed, psychologists. Nurses perform referrals within the sector and, in rarer cases, they lead them to other services of the hospital, as quoted to physiotherapy, and surgical Center officials, in case of catheter is clogged. Only one (16.6%) cited that provides the contact of Life Enhancement Center (free emotional support voluntary service that works 24 hours a day, every day).

Interdisciplinary actions on care to breast cancer should be initiated early and must be part of an action together between health professionals and women, considering the involvement of family members in discussions about diagnosis, treatment options, side effects and possible outcomes. This experience tends to help woman/family in building roles relevant to the confrontation of different depictions of the disease. Furthermore, it aim to intercede effectively in the restoration of function and quality of life after treatment, favoring as a priority the return to physical activities, the performance of activities in daily life and their social and professional roles.¹⁹

The multidisciplinary actions are essential in the prevention of complications arising from the treatment and should be performed in every disease process, treatment, recurrence of the disease and palliative care, so it is important to know and identify the needs of women and the impact of these phases on their daily lives, to ambulatory and hospital treatments, specific home guidance, educational groups, which have contributed to

the functional return, the rehabilitation and reintegration of women into society.

CONCLUSION

The nurse can help the patient by inserting the family member in the confrontation of disease process, mainly by being directly connected to him, offering him emotional support in the act of caring. The nursing staff is most of the time with these customers and has technical and scientific skills to extend the knowledge and involve the family in this care, provided security, dissolving doubts and taboos.

Nursing actions and guidelines to the relatives are held only on the first day of the cycle of chemotherapy, not being performed nursing consultation throughout the treatment, even being a teaching strategy addressed to the client's learning. The absence of an instrument of the nursing record makes it impossible to access the plan of assistance to other professionals involved in the treatment.

In the whole process of treatment it is necessary that created strategies that clarify doubts, increase the knowledge of patients and to develop communication skills, to be established a relationship of trust and transparency with clients, assuring them efficaciousness. There are some difficulties in nursing care such as: printing the brochures/pamphlets; the absence of a manual/Protocol institutionalized and an instrument of the nursing record; and insufficient number of nurses. In this sense, they diminish the quality of health care and educational actions, and make it impossible to evaluate the effectiveness of the guidelines given to the family and women in chemotherapy treatment.

It is also observed the importance of a multidisciplinary team for the prevention of complications arising from the disease process, treatment, recurrence of the disease and palliative care. Therefore, it is necessary to meet the needs of women and the impact of these phases on their daily lives, in order to contribute with the return, the functional rehabilitation and reintegration of women into society.

The teaching strategies are based on practice assistance and in the scientific knowledge, by nurses, with a view to the implementation of their guidelines to the relatives of women with breast cancer undergoing anticancer chemotherapy, composing a factor of extreme importance for

the guidance of those who live with this form of treatment.

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