

# Educational Approach to Cancer Patients: Strategies for Guidance on Chemotherapy Treatment

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## Abordagem Educativa ao Paciente Oncológico: Estratégias para Orientação acerca do Tratamento Quimioterápico Enfoque Educativo al Paciente Oncológico: Estrategias para Orientación acerca del Tratamiento Quimioterápico

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### Abstract

**Introduction:** Cancer is a consequence of failures in the cell cycle control mechanisms. It is a multifactorial genetic disease that can be treated in countless ways. Chemotherapy has been the most common form of treatment, however it acts indiscriminately in all cells, causing adverse effects. In this way, nursing plays a fundamental role in the education and orientation of these patients, as well as making this individual protagonist of their treatment. **Objective:** To propose a model of guidance to the cancer patient about the chemotherapy treatment, through a printed information and the creation of the “patient’s diary”. **Method:** This is an action research exploratory, made from the identification of the needs of the adult chemotherapy clinic of a teaching hospital, a reference in oncology. **Results:** After identifying the needs of the unit, and meetings with the nurses of the service, a new workflow was created, an informational guide on the adverse effects related to the treatment and the “patient diary” in order to involve the individual in your treatment. **Conclusion:** The proposal and elaboration of the instruments was a strategy of great relevance in the education in patient health, since they help and instrumentalize the professional in this process and enable the patient to participate actively in their treatment.

**Key words:** Nursing Care; Health Education; Oncology Nursing.

### Resumo

**Introdução:** O câncer é consequência de falhas nos mecanismos de controle do ciclo celular. É uma doença genética multifatorial que pode ser tratada de inúmeras maneiras. A quimioterapia tem sido a forma mais comum de tratamento, entretanto, age de forma indiscriminada em todas as células, causando efeitos adversos. Dessa forma, a enfermagem tem papel fundamental na educação e orientação desses pacientes, bem como em tornar esse indivíduo protagonista de seu tratamento. **Objetivo:** Propor um modelo de orientação ao paciente oncológico acerca do tratamento quimioterápico, por meio de um informativo impresso e da criação do “diário do paciente”. **Método:** Trata-se de um recorte de uma pesquisa exploratória, do tipo pesquisa-ação, realizado a partir da identificação das necessidades do ambulatório de quimioterapia adulto de um hospital de ensino, referência em oncologia. **Resultados:** Após a identificação das necessidades da unidade, e de reuniões com as enfermeiras do serviço, foram criados um novo fluxo de trabalho, um informativo com orientações sobre os efeitos adversos relacionados ao tratamento e o “diário do paciente”, a fim de envolver o indivíduo no seu tratamento. **Conclusão:** A proposta e a elaboração dos instrumentos foram estratégias de grande relevância na educação em saúde ao paciente, uma vez que auxiliam e instrumentalizam o profissional nesse processo e possibilitam que o paciente participe ativamente de seu tratamento.

**Palavras-chave:** Cuidados de Enfermagem; Educação em Saúde; Enfermagem Oncológica.

### Resumen

**Introducción:** El cáncer es consecuencia de fallas en los mecanismos de control del ciclo celular. Es una enfermedad genética multifactorial, que puede ser tratada de innumerables maneras. La quimioterapia ha sido la forma más común de tratamiento, sin embargo, actúa de forma indiscriminada en todas las células, causando efectos adversos. De esta forma, la enfermería tiene un papel fundamental en la educación y orientación de estos pacientes, así como convertir a este individuo protagonista de su tratamiento. **Objetivo:** Proponer un modelo de orientación al paciente oncológico acerca del tratamiento quimioterápico, a través de un informativo impreso y de la creación del “diario del paciente”. **Método:** Se trata de un recorte de una investigación exploratoria, del tipo investigación-acción, realizado a partir de la identificación de las necesidades del ambulatorio de quimioterapia adulto de un hospital de enseñanza, referencia en oncología. **Resultados:** Después de la identificación de las necesidades de la unidad, y de reuniones con las enfermeras del servicio, se crearon un nuevo flujo de trabajo, un informativo con orientaciones sobre los efectos adversos relacionados con el tratamiento y el “diario del paciente” a fin de involucrar al individuo en su entorno tratamiento. **Conclusión:** La propuesta y la elaboración de los instrumentos fueron una estrategia de gran relevancia en la educación en salud al paciente, ya que auxilian e instrumentalizan al profesional en este proceso y posibilitan que el paciente participe activamente en su tratamiento.

**Palabras clave:** Atención de Enfermería; Educación en Salud; Enfermería Oncológica.

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## INTRODUCTION

Cancer is a disease characterized as a consequence of failures of the control mechanisms of the cell cycle (growing and proliferation). In addition, it is described as the result of a process developed through innumerable stages where genetic alterations occur that are not corrected by the DNA repair, provoking mutations. These cells may invade organs and tissues and still spread to other regions of the body, what is called metastasis<sup>1,2</sup>.

For being a multifactorial genetic disease, cancer can be caused by innumerable factors as heritage, tobacco addiction, alcoholism, habits of life and even virus-provoked modifications. Therefore, the knowledge about the disease and its risk factors similarly to prevention and treatment are essential<sup>1,2</sup>.

In 2018, 559,371 new cases of cancer were registered in Brazil, and more than 240 thousand eventually progressed to death<sup>3</sup>. Cancer is considered a public health problem, it is paramount that education health practices are adopted as strategies to help the individual to understand its disease and grant autonomy for its treatment<sup>4</sup>.

Cancer treatment can be conducted in several manners, as surgery, radiotherapy for local control of the disease and chemotherapy for systemic control, individualized or combined according to the proper indication for each diagnosis<sup>1</sup>. Chemotherapy has been increasingly utilized and is one of the most important forms of fighting cancer, since it can be employed for curative or palliative care<sup>5</sup>.

Antineoplastic chemotherapy treatment is characterized by the use of chemical substances, isolated or combined that interfere in the process of cellular growing and division, destroying the carcinogenic cells<sup>6</sup>. Chemotherapies are non-specific substances, they act in an uniform way in malignant and benign cells causing adverse effects<sup>7</sup>. Adverse effects considered most common are alopecia, intestinal obstipation, nausea, vomits, mucositis, myelotoxicity and renal, lung and cardiac effects<sup>1</sup>. Adverse effects are related to the type of drug, time of infusion and also, to the patient's clinical status<sup>1,7</sup>.

Chemotherapies-related adverse effects occur predominantly in the cells that split themselves rapidly, mainly in the hematopoietic, germinative tissue, hair follicle and gastrointestinal coating epithelium. These effects can reach also other organs in an immediate or late, acute or chronic manner, can be cumulative and, sometimes, irreversible because chemotherapies have strong toxicity power, even when administered in therapeutic doses<sup>6</sup>. Because of this, it is extremely relevant that these effects and, mainly, the alternatives for its control are known in order to ensure the quality of life of the patient.

It is indispensable that the person with cancer, regardless of the phase (diagnosis or treatment), receives full care to identify and follow up the effects that are related to the disease and that affect the individual and its family<sup>8</sup>. For that purpose, the nursing team has a key role in the follow up of the patient and it is necessary to improve its skills of communication to provide a proper management of the oncologic patient and enhance the education in health, either for the patient or its family, giving them the tools to face the treatment and the problems that may appear throughout this span of time to avoid the occurrence of health problems<sup>9</sup>.

It is mandatory that the patient is involved in the process of its disease and treatment, as a co-responsible in pursuing its improvement. It should be a priority to provide guidances about the treatment and its toxicity through information transmitted carefully and patiently within a context of reinforcing the importance of the treatment and benefits chemotherapies can bring<sup>6</sup>.

According to Resolution 210/1998 of the Federal Nursing Council (Conselho Federal de Enfermagem (COFEN))<sup>10</sup>, the chemotherapy nurse is responsible for “promoting and disclosing prevention of risks and issues through education of the clients and family with the objective of improving its quality of life”, therefore, this practice is paramount when the full care to the patient is addressed. Health education is one of the main tools while approaching the promotion of health, however, it must be focused in the development of personal and social skills to endow, consequently, the individual to make conscious and important decisions about its treatment, to further improve its health conditions<sup>11</sup>.

The Resolution of COFEN<sup>10</sup> says still that the function of the nurse is to “elaborate nursing therapeutic protocols to prevent, treat and minimize the adverse effects of the clients submitted to antineoplastic chemotherapy treatment”, as well as “Fully support the clients, its family based in the Nursing Professionals Code of Ethics and the effective legislation”. Based in this, this work had the objective of proposing a model of guidances to the oncologic patient about the chemotherapy treatment through a printed informative and a “diary of the patient” in a philanthropist school-hospital located in the Northern Region of the State of Rio Grande do Sul.

## METHOD

It is an action research exploratory carried out from the identification of the necessities of the adult chemotherapy ward of a school-hospital, a reference in oncology. The Institutional Review Board of the “Universidade de Passo Fundo” approved the study, report number 2.869.824.

The exploratory research has the objective to uncover the problem or build up hypothesis to make it more palatable. This type of study may be developed through different strategies, as bibliographic research, interviews and analysis of examples that stimulate the comprehension<sup>12</sup>. The action-research involves investigators and participants of the study to conduct systematic investigation in association with the resolution of a problem and, as such, help them to improve their practices and, consequently, the working environment of anyone involved. This methodology aims to change specific scenarios<sup>13</sup>.

The adult chemotherapy ward attends nearly 1,300 patients per month through the National Health System (SUS) comprehending the most diverse diagnosis of solid tumors and hematologic diseases. Because of so expressive number of month visits, it is essential that the nursing create strategies to provide proper care to the patients.

The experiences as a resident-nurse in the adult chemotherapy ward granted the identification of the lack of a defined and effective routine to offer nursing-related guidance for chemotherapy treatment. Further to the practice itself, it were also considered the opinions and suggestions of the four female nurses that work in the ward, since they are at the service daily and know its needs, which determined the participants of this study. Therefore, two instruments were elaborated to propose a routine and steer the performance of pertinent orientations in the infusion room based in the most common adverse effects.

The first instrument was a printed hand out given to the patient in the beginning of the treatment, with nursing specific guidance, according to the most common adverse reactions based in each chemotherapeutic utilized by the patient. This informative was linked to the institution computerized system, individualized and can be updated when needed according to the demand, because the adverse effects can change during the treatment.

The second tool created and proposed was the “Diary of the Patient”, with the objective of granting the individual the possibility of reporting, when at home, the doubts about the treatment, the adverse effects that can occur after the chemotherapy sessions and other information the patient deems necessary. Therefore, it will be possible for the nurse, conjointly with the staff of the ward to follow the treatment progress and guide the patient once more and update the hand out, whenever necessary, based in the demands brought in the notes reported in the diary. The diary is individual and must be delivered to the patient in the first day of the treatment together with the informative.

The nurse in the chemotherapy room provides the first orientation about the hand out during the infusion of

the chemotherapeutic and taking advantage of the time the patient remains in the service to optimize the process. The nurse will make the subsequent orientations, whenever the patient expresses its necessity.

When the material suggested is received, the patient will be guided to use it as a diary, and it must bring at every visit and chemotherapy application to allow the team to follow the treatment. This same orientation will be passed over to the family, in case the patient fails to understand the goal of the diary and to reinforce its importance. The patients in ongoing treatment will not receive the material in the first moment, as the concept is to follow up the treatment from its beginning.

At every return visit, a ward nurse will revise the diary to find any sign or symptom or doubt that may have been brought up in the period the patient is at home. The new orientations must be used in this moment at the chair the patient is seated during the chemotherapy infusion with the assistance of a new informative updated according to the demand from the diary.

## RESULTS

Two instruments were elaborated to facilitate the materialization of the nursing orientations objectively and effectively and to define a new flow, which will be conducted by the individual while in the health facility in order to better receive the oncologic patient during its entire treatment. These actions aim to facilitate the performance of the nursing guidances, resolve a problem identified in the health facility as the action-research suggests.

Therefore, after the first visit with the oncologist/hematologist, the patient will be referred to the oncology service through the “Sistema Nacional de Regulação – SISREG” (National System of Regulation). When the patient enters the adult chemotherapy ward, it will be attended by the physician and will be informed about its treatment, medical visits and if in proper clinical conditions, it will be scheduled the first chemotherapy cycle. Prior to actually initiating the infusions, the patient will be seen by the nursing team and will be screened for its safety and if in proper clinical conditions, will be taken to the chemotherapy room where the routine procedures will occur (*checklist* of safe infusion) and then, the first infusion of the chemotherapeutic. The route run by the patient is shown in the Flowchart of the Adult Chemotherapy ward (Figure 1).

The nursing will provide guidances to the patient at the moment of the first infusion of chemotherapy at the infusion room with the objective of using the time the patient remains in the health facility. The first guidance

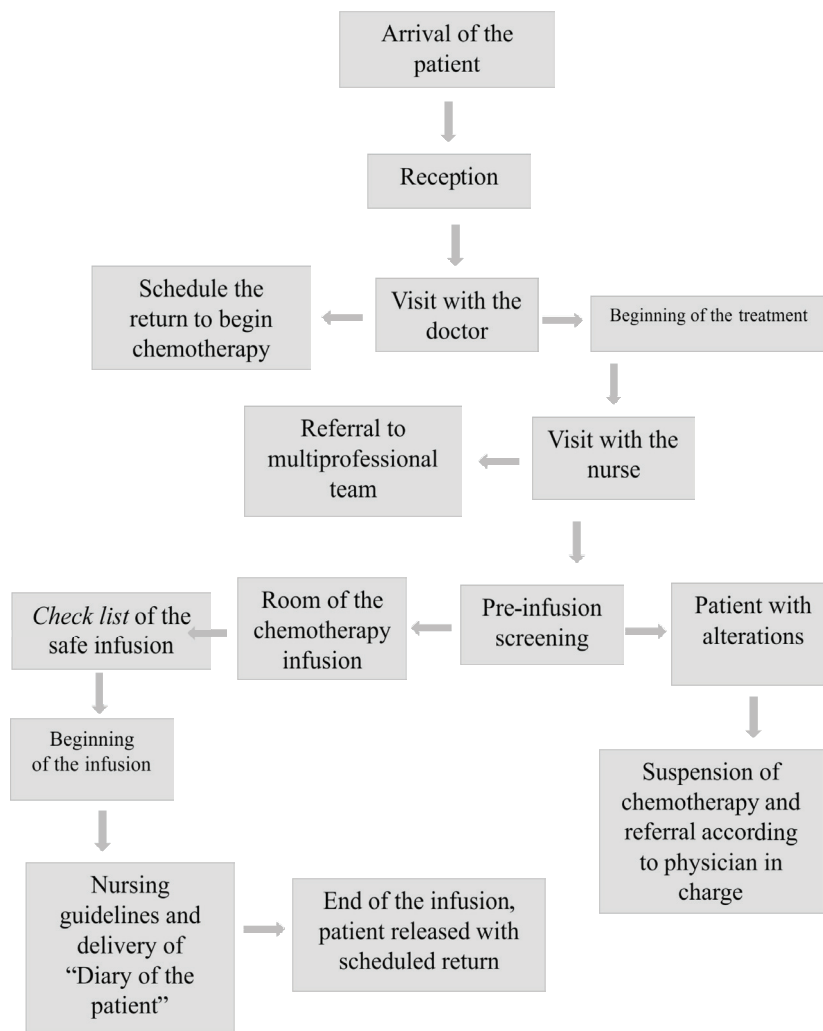


Figure 1. Flowchart of the chemotherapy ward

will be made and the hand out about the chemotherapy treatment (Figure 2) will be delivered, it has the name of the patient, name of the mother, age, diagnosis, protocol utilized for the treatment and respective drugs, for the patient to be aware of the drugs that are being administered. In addition, the hand out brings the pertinent guidances addressing the overall and specific adverse events of each drug utilized as care at home, exposure to risks and proper conducts to improve signs and symptoms.

The “Diary of the Patient” (Figure 3) was elaborated as a booklet and given to the patient in the beginning of its treatment. This diary is individual and has a proper field for identification of the patient and other information in the cover. There are general information inside the booklet about modifications that may occur after the infusion of chemotherapics and has space to report the information as guided by open questions related to the status of the patient, as, for instance: “How am I feeling today?”, “Did

any symptoms appear?” Which ones?”, “What did I do to improve?”, among others. There is also a specific page for the patient to report other important information or doubts to ask the team when returning to the clinic as it prefers. At the end of the diary, there is a field to indicate the date the treatment ended and care with devices, as well as address and telephone number of the health facility.

## DISCUSSION

The hand out elaborated and based in the possible adverse events to occur after a chemotherapy infusion brings the patient information that can diminish its doubts and anguishes. The “Diary of the Patient” grants the individual the possibility of expressing these doubts and to commit with its own care when reporting signs and symptoms. These instruments become important tools for the process of health education, corroborating the literature that brings the rescue of the communication,

**NAME OF THE PATIENT:** Joana de Medeiros      **AGE:** 65 years old  
**NAME OF THE MOTHER:** Maria de Medeiros  
**DIAGNOSIS:** Neoplasm of Colon      **PROTOCOL:** FOLFOX  
**MEDICATIONS PRESCRIBED:** Oxaliplatin, Leucovorin, Fluoracila.

**OXALIPLATIN:** During the treatment, some medication-related adverse effects may occur. These effects are anticipated and can be minimized.

1. In case of leukopenia (drop of immunity), thrombocytopenia (platelet fall) and anemia (decrease of blood cells), it is important to pay attention to:
  - a. Avoid overcrowded places and contact persons who had any infectious-contagious disease (Ex.: flu);
  - b. Avoid situations that may end in falls, as carpets, wet and slippery floors, climb and descend stairs without help, unsafe shoes;
  - c. Watch for signs and symptoms, as flu, difficult to urinate, urinary urgency and frequent urination, urine with strong smell or different from regular, bruises in the body, fever, tremors, chills, fatigue and body ache. If any symptom appears, contact the doctor immediately and/or check in to a hospital;
  - d. Note skin blemish of every size and color;
  - e. Do not take vaccines or medication until authorized by the doctor;
  - f. Care must be taken while using sharp objects as razor blades, nail cutters to avoid bruising;
  - g. Prefer soft tooth brushes to avoid gum bleeding;
  - h. Keep yourself clean (shower, hands washing, mouth hygiene) and skin moistening;
  - i. Keep balanced and healthy nourishment with clean and selected food and drink fluids all through the day;
  - j. Try to rest occasionally to avoid tiredness.
  
2. In case of nausea and vomits:
  - a. Take the medications prescribed by the doctor correctly;
  - b. Try to replace greasy, spicy and very hot food by other food that do not cause too much discomfort as cold food or at room temperature, less greasy and dry;
  - c. Avoid very sweet food or with strong odor;
  - d. Avoid long periods without food intake;
  - e. Some persons feel relief from nausea when suck ice or eat ice cream. Try;
  - f. Avoid places with strong and unpleasant odors;
  - g. Keep always good mouth hygiene.

**Figure 2.** Model of the informative about chemotherapy treatment

information and qualified listening as pillars of the educative process, indispensable for its effectiveness and relevance<sup>11</sup>.

The communication as strategy of caring steers the professionals to provide better and humanized quality services, because it prioritizes the opinion and wishes of the patient and its family, promoting its interaction with the caregivers involved. In addition, when an effective communication is done, it is possible to create a bond between patient and professional, facilitating the identification of adverse effects or other symptoms, and consequently improving the care.

The chemotherapy treatment-related adverse reactions occur recurrently and bring several disturbances to the patient. According to Guimarães et al.<sup>14</sup>, the most common reactions are related to the gastrointestinal system as nausea, vomits and, consequently, the nursing actions are directed to the nutritional support and mainly for the education of the patient and its family, because these adverse reactions contribute to diminish the quality of life. However, these reactions can be minimized with simple actions at home, for instance, as change of eating habits and fluid intake. Another common effect is alopecia that has a great impact in the life of the patients

### **My Diary**

Name _____
Age _____ City _____
Physician _____
Diagnosis _____
Protocol _____
Beginning of the treatment ____/____/____

Hi,

This diary is yours, from today on, you can use it to check information about your treatment and make important notes about the days you were at home and what happened during this time.

Write down whenever you wish, all the symptoms that may appear while at home, so the hospital team can help you when you get back for another chemotherapy cycle.

Ask anything you want to the nursing team of the chemotherapy ward, they will help you.

Have a good treatment.

**What are the adverse effects that can occur after the chemotherapy?**

- Hair loss: Some drugs cause hair loss from 14 to 21 days after the chemotherapy. This effect is temporary and reversible.
- Constipation: Prefer high fiber food, drink many fluids and practice light exercises.
- Diarrhea: Prefer less fatty and spicy food and drink fluids to ensure hydration.
- Mouth bruises: Keep the mouth always clean, after any meal brush your teeth with a soft brush. Avoid acid, spicy and very hot food, prefer liquids, cold and pasty food.
- Nausea and vomits: Avoid fatty and spicy food, prefer cold food. Avoid smelly rooms and physical exertion after meals.
- Skin darkening: Avoid sun exposure, use sun blockers, wear caps or hats when going outdoors, keep your skin hydrated.

**It is important to remind that:**

- Each drug corresponds to a particular treatment for a specific patient, therefore, different adverse effects can happen in each person.
- Not always these adverse effects will happen to you, but it is important to know and how to mitigate them.

- Overall, try to have a healthy nourishment, drink many liquids, and follow the recommendations given by the chemotherapy ward team, they will help you with your treatment.

Do not hesitate to talk to us about any doubts you may have!

**How was your day?**

Date: \_\_\_\_\_

How I am feeling today: \_\_\_\_\_

Any symptoms? Which ones? \_\_\_\_\_

When did the symptoms begin? \_\_\_\_\_

How long did the symptoms take? \_\_\_\_\_

What did I do to get better? \_\_\_\_\_

**Other important notes:**

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**What else do we need to know?**

- Avoid closed, unventilated and crowded rooms;
- Always keep your mouth and body clean;
- Check regularly the skin, mouth, ears and nose for any bruise and/or blemishes;
- Protect the skin against wounds while shaving, nails trimming and avoid squeezing pimples and blackheads;
- Try to sleep well and rest;
- Do not get vaccines without your doctor authorization;
- Go to a hospital in case of fever, skin dark spots and blemishes, bleeding, paleness and fatigue after some effort.

**Is the treatment finished?**

If your chemotherapy treatment is over, your catheter needs to be cleaned every 60 days to ensure it continues working properly. The maintenance needs to be made at a healthcare unit by a skilled professional.

Date of the end of the treatment: \_\_\_\_/\_\_\_\_/\_\_\_\_

Log of catheter cleaning:

Date	Hour	Service	Professional

Figure 3. Model of the diary of the patient

because involves changes in the physical appearance and, consequently, in self-esteem. Therefore, it is mandatory that the professional involved is able to identify itself with this moment and help the patient in the process of coping, creating a bond and a more humanized and less technical and mechanical care.

When the patient is attended in the ward, the treatment is conducted in the oncology service of, but the adverse effects occur eventually in its home and the demands of the individual may rest unattended. This said, the knowledge the patient and its family have about its diagnosis and treatment is essential and defines its adherence. The nursing team is accountable for providing these orientations as best as possible during the entire treatment<sup>15,16</sup>.

The nurses that deal directly with the patient are focused only in the disease, leaving apart other important aspects of the process of education of the individual health<sup>11</sup>. However, it is indispensable that an education process that encompasses factors like culture, beliefs, habits already created by the patient and its family is developed, which could stimulate the patient to acknowledge itself in this process and builds its own knowledge<sup>17</sup>. Common knowledge is also a factor that must be considered, since it is inevitable that the patient is influenced by these perceptions, which directly affect the adherence and the commitment to the treatment and the comprehension of the nursing orientations<sup>18</sup>.

The creation of strategies to instrumentalize the professionals involved in the oncologic patient's care in chemotherapy treatment includes the elaboration of an organized flowchart to grant a full-time long-term follow up of the individual who needs assistance even after the end of the treatment. As a counterpoint, these tools help the patient to understand its disease and its treatment and to be fully involved in the process of improvement through conducts adopted at the hospital and the decisions taken in its home.

The current technologies are allies of the process of health education when it addresses a specific conduct or change to allow the individual to achieve a healthy life<sup>19</sup>. One of the main roles of the nursing is to utilize these technologies to help the patient to cope and acknowledge its process of getting ill, welcome the family to assist them in providing an effective care to the individual, create bonds and bring the family into the treatment<sup>15,20</sup>.

It is relevant that the nurses are capable of seeing beyond the practice and construct new manners of intervening in the reality of the patients attended, showing the importance of their action for the efficacy of the treatment, but also getting close to the patient, making it feel confident to be the protagonist of the process<sup>11,21</sup>.

Therefore, the present study allows, in addition to the follow up of the patient, the creation of its bond with the professionals that will check the diary systematically and facilitate the nurse's role to help the process of education of the patient and its family.

## CONCLUSION

While resuming the objective of this study and analyzing the information obtained through the literature, it is possible to observe the importance of the education and the proper orientation provided to the patient in the healthcare services. It is very important to place the nurse as the principal agent of this practice, mainly when it is addressed the chemotherapy treatment, have the patient understand his responsibility in pursuing the improvement of its quality of life and provide the tools to accomplish this goal.

It is indispensable to mention the obstacles encountered during the creation of the tools and finalization of this study that are related to the difficulty of finding literature that could help the construction of this proposal of improvement of a healthcare service, which is a challenging journey.

The instruments created for this finality are guides of educational approach and are of great relevance for this practice to be qualitative and effective; however, it is important to stress that this process in must be present throughout the full line of care, that receive the individual, regardless of the target-public and it is the obligation of the nurse to ensure that this occurs, since education is one of the pillars of the action of this professional who is present at all times and places.

So, it is possible to conclude that the creation of these tools should facilitate the action of the nurse because it will determine how these guidelines must be performed and, at the same time, will make the patient aware it is the protagonist of the treatment, since it will share its experience. In addition, this study underlines the importance of making the educative approach since the beginning of the treatment, making it clear that the creation of the instruments is important, but does not replace the effective action of the professional, that must act fully to empower the patient and consequently to support its improvement.

## CONTRIBUTIONS

Luana Criciele Aguiar da Silva contributed for the conception and planning of the study, wording, critical review and approval of the final version for publication. Amanda Caroline Signor and Bárbara Rech Dalfollo

contributed for the conception and planning of the study. Andressa Caroline Luft Pilati contributed for the conception and planning of the study, critical review and approval of the final version for publication. Daniela Ramos Oliveira contributed for the conception, planning of the study and critical review.

### DECLARATION OF CONFLICT OF INTERESTS

There are no conflict of interests to declare.

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None

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