

## CARE OF FAMILY MEMBERS OF PEOPLE WITH MALIGNANT NEOPLASTIC WOUNDS AT HOME

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### ABSTRACT

**Objectives:** To understand how caregivers of people with malignant neoplastic wounds perform care at home. **Method:** A qualitative study that involved seven relatives of people with malignant wounds undergoing treatment in a high complexity oncology unit. The data were produced through semistructured interviews and submitted to thematic content analysis, proposed by Bardin. **Results:** Seven family-caregivers, all female, young people who left work to dedicate themselves to the sick person were interviewed. Three categories emerged after content analysis: family members seek guidance to care for patients with malignant neoplastic wounds at home; they adopt strategies in wound care; and report the need for support from health professionals and institutions, because they face difficulties in care, especially in primary care units. **Conclusion:** Family members of people with malignant neoplastic wounds face difficulties, mainly due to the scarcity of technical knowledge and lack of support from health institutions and from professionals.

**DESCRIPTORS:** Palliative care. Home Health Nursing. Family. Wounds and injuries. Neoplasms. Enterostomal therapy.

## CUIDADOS DE FAMILIARES ÀS PESSOAS COM FERIDAS NEOPLÁSICAS MALIGNAS EM DOMICÍLIO

### RESUMO

**Objetivos:** Conhecer como os cuidadores de pessoas com feridas neoplásicas malignas realizam o cuidado em domicílio. **Método:** Estudo qualitativo que envolveu sete familiares de pessoas com feridas malignas em tratamento em uma unidade de alta complexidade em oncologia. Os dados foram produzidos por meio de entrevista semiestruturada e submetidos à análise de conteúdo temático, proposto por Bardin. **Resultados:** Entrevistadas sete familiares-cuidadoras, todas do sexo feminino, jovens que abandonaram o trabalho para se dedicarem à pessoa enferma. Emergiram três categorias após análise do conteúdo: familiares buscam orientações para cuidar do paciente com feridas neoplásicas malignas em domicílio; adotam estratégias no cuidado das feridas; e referem necessidade de apoio dos profissionais e instituições de saúde, porque enfrentam dificuldades no atendimento, principalmente nas unidades de atenção primária. **Conclusão:** Os familiares de pessoas com

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feridas neoplásicas malignas enfrentam dificuldades, principalmente pela escassez de conhecimento técnico e por falta de apoio das instituições e dos profissionais de saúde.

**DESCRITORES:** Cuidados paliativos. Enfermagem domiciliar. Família. Ferimentos e lesões. Neoplasias. Estomaterapia.

## ATENCIÓN DE FAMILIARES DE PERSONAS CON HERIDAS NEOPLÁSICAS MALIGNAS EN RESIDENCIA

### RESUMEN

**Objetivos:** Conocer cómo los cuidadores de personas con heridas neoplásicas malignas realizan cuidados en el domicilio **Método:** Estudio cualitativo que involucró a siete familiares de personas con heridas malignas que estaban siendo tratados en una unidad de alta complejidad en oncología. Los datos fueron producidos por medio de entrevistas semiestructuradas y sometidos a análisis de contenido temático, propuesto por Bardin. **Resultados:** Se entrevistó a siete familiares-cuidadoras, todas mujeres, jóvenes que dejaron los trabajos para dedicarse al enfermo. Tres categorías surgieron después del análisis de contenido: los familiares buscan orientación para cuidar de los pacientes con heridas neoplásicas malignas en domicilio; adoptan estrategias en el cuidado de heridas e informan la necesidad de apoyo de profesionales e instituciones de salud, porque enfrentan dificultades en la asistencia, especialmente en las unidades de atención primaria. **Conclusiones:** Los familiares de las personas con heridas neoplásicas malignas enfrentan dificultades, principalmente debido a la escasez de conocimientos técnicos y la falta de apoyo de las instituciones y de los profesionales de la salud.

**DESCRIPTORES:** Cuidados paliativos. Cuidados de Enfermería en el Hogar. Familia. Heridas y lesiones. Neoplasias. Estomaterapia.

## INTRODUCTION

It is estimated that approximately 5% to 10% of individuals with cancer will present malignant neoplastic wounds as a result of the disease, which are commonly caused by primary skin neoplasms or metastases, with a higher prevalence in elderly people between 60 and 70 years of age<sup>1</sup>.

Neoplastic wounds generate important repercussions in the lives of individuals, mainly due to the evident characteristics observed in this type of injury, such as difficulty in healing and the presence of bleeding, exudation and odor, which sometimes lead to psychological impacts, due to changes in body image, feelings of sadness, shame, depression, stigma and social isolation, and family impacts<sup>2</sup>.

People with cancer, especially in the advanced stage, become more dependent on the family, which requires a reorganization of the family structure to meet the daily needs of the sick person. Families, most of the time, are not prepared to perform the care that will be necessary during the whole process of the illness, so it is up to health professionals to guide and meet the altered needs, whenever possible<sup>3</sup>. Furthermore, family members need to be instructed on how to perform dressings, palliative care to reduce signs and symptoms, with the intention of improving quality of life and promoting comfort and safety.

In this sense, it is understood that the nurse is the professional with practical and specialized competence to identify, evaluate, and treat wounds, providing care focused on minimizing discomfort and pain and thus trying to minimize the psychosocial repercussions that can be caused by these chronic wounds. Nursing care and assistance based on the physical, psychological, social, spiritual and, especially, the family dimensions are possible through actions of support and guidance in health to these family-caregivers, besides helping to improve the quality of life of these people who live with an oncological disease<sup>4</sup>.

This study was guided by the guiding question: How does the family member care for the person with a malignant wound at home? The purpose of this study is to learn how caregivers of people with malignant neoplastic wounds perform caregiving at home.

When researching studies on how family members develop care for the person with a malignant neoplastic wound, it was realized that there is a gap. The studies address wound care, how the health team, especially nursing, should care and guide at home, palliative actions, feelings of professionals, but there are no discussions about how family members care, how they should be trained to perform dressings in home environments and what their perceptions are about this care<sup>4-7</sup>. In view of this, it is understood that qualitative studies allow family members and caregivers to be heard, bringing their real needs and difficulties that can be addressed by professionals, directing assistance and producing research that fills this gap and meets this need.

## METHODS

Qualitative study that is premised on the universe of meanings, beliefs, values and attitudes, seeking to understand and apprehend the phenomenon in depth and complexity, thus allowing the discovery of what is hidden, in the moment experienced by the subjects<sup>8</sup>.

In this sense, the question that guides this study about how the family member cares for the person with a wound can be detected by taking into consideration the emotional, psychological and technical issues about this care. Thus, this type of research allows the researcher to direct the study toward his object, without influencing the researched, leaving him free, thus extracting the spontaneity of the information, reverberating all the content he proposes<sup>8</sup>.

The study was developed in the chemotherapy and radiotherapy sectors of a highly complex oncology unit in a city in Bahia, Brazil. This health care unit was selected because it provides multidisciplinary care to cancer patients associated with the Unified Health System and is a specialized hospital reference institution in the researched region.

The researchers made an active search in these sectors for people with malignant neoplastic wounds and who were with accompanying family members. Both were invited for the nursing consultation and, after that moment, the family caretakers who met the inclusion criteria were chosen: to be adult family members, who were accompanying the patient and who were responsible or co-responsible for the direct care to the person with malignant neoplastic wound, totaling seven interviewees who signed the Informed Consent Form (ICF). The exclusion criteria were: not being cognitively able to answer and being a companion who is not a home caregiver.

The finalization of the search for interviewees occurred when, after interviewing five people, the speeches started to repeat themselves, there was saturation in the answers and, to be sure of this information, two more people who maintained the pattern of answers so far collected were interviewed.

The caregiver and the patient underwent a nursing consultation, performed by a professor and a Nursing student, whose purpose was to carry out anamnesis and lesion evaluation, to elaborate a care plan and provide orientation to meet the identified needs, to deliver the care plan, a folder containing information about the skin care project, called *Projeto Pele Sã* (Healthy Skin Project), and the telephone contacts in case any doubts arose during the home care. The collection took place from April to May 2017, in the morning shift. Other patients and companions who were not part of the research because they did not meet eligibility criteria, but who were under the care of this team, also received the orientations.

After the nursing consultation, the family-caregivers were invited individually to participate in an interview, in a private room, ensuring their privacy. All eligible people who agreed to participate in the research were oriented about the study procedure and signed the ICF.

During the data collection period, the doubts of family-caregivers returning for chemotherapy and radiotherapy sessions were answered by the researchers and the unit's nursing staff. After this period, the nursing staff of the chemotherapy and radiotherapy sectors of the high complexity oncology unit maintained this systematization of care.

The data were collected through a semistructured interview containing sociodemographic and clinical aspects, as well as questions about how the care at home was provided, whether there was an institutional support network or from any other person. The interviews were conducted by a single researcher and the interviewee, in a consulting room, lasting between 15 and 25 minutes; and were recorded in .mp3 format with interference only for clarifications and resumption for the research question to be transcribed in full, by the interviewer herself.

For the analysis, the interviews were transcribed in full and, subsequently, all the material was manually submitted to content analysis, thematic mode, in its three stages: floating reading of the interviews in search of the construction of analysis categories, following the rule of exhaustiveness, covering all the elements of the interviews, defining significant excerpts of the object of study; classification and categorization of the data through the construction of a table with the synthesis of the interviews; interpretation and inference according to the proposed objectives<sup>9</sup>.

From this process, all the transcribed material was analyzed by three professors and two care nurses—one with a Master's degree, two with a PhD, and two nurses with experience in caring for people with cancer. This group validated the construction of three categories of analysis that emerged from the seized speeches.

The project was approved by the Ethics Committee for Research with Human Beings, under CAAE opinion no. 57573016.2.0000.0053 and no. 1,670,332/2016. In order to preserve their anonymity, the family members interviewed were identified by the letter F and numbers 1 to 7.

## RESULTS

Seven family members caring for people with malignant neoplastic wounds, female, aged 24 to 46 years, with low education, participated in this study. The family monthly income ranged from one to three minimum wages and all the family members quit their jobs to become full-time caregivers. In addition, the significant participants who cared for the person with wounds were daughters, granddaughters, sisters, and friends who took turns in the attention required by the sick person.

The analysis categories are described below, and the statements of those surveyed reinforce the findings of this research.

### Family members do not receive guidance in caring for people with malignant neoplastic wounds

With the appearance of wounds, families realized the need to obtain knowledge in order to provide care to the sick person, reduce discomfort, pain, odors, and perform proper dressing. Thus, they sought guidance, consulting health professionals who work in the units where oncology treatment takes place, but often did not receive this information or did not understand what was oriented or, when they did, it was not enough for good home care:

I didn't receive any guidance; I did the dressing on my own (Family member 2).

[...] The nursing technicians here asked us to simply be asepsis every day with soap and water, neutral soap and always put gauze over the wound. (Family member 7).

The family member realizes that the information they receive is not enough to alleviate the suffering of their loved ones, and they seek knowledge by consulting friends, other professionals with whom they have ties, or they resort to the Internet to supply the doubts that arise with the advance of the tumor and, consequently, the wounds:

[...] We learned from a combination of information, research, contacts with other nursing colleagues who work with wounds, and day-to-day experience (F5).

[...] I learned by looking, by asking questions as I could do (F1).

[...] It was on my own (F2).

There is a concern and a will to do the best and provide quality care, even though they understand that they have limitations in knowledge and techniques.

## Family members adopt strategies to care for the person with malignant neoplastic wounds

Regarding the treatment of wounds, these are handled directly by the family members by means of cleaning and application of products. The most frequently used materials were 0.9% saline solution to aid in cleaning, metronidazole gel, cotton swabs, and povidone-iodine antiseptic. Five caregivers used no product to treat the wound:

[...] I wash it all with serum, dry it, put gauze back on, and then close it with adhesive tape. We were afraid to use something other than what was prescribed by the doctor (F5).

[...] I only take care of it once. I put some red stuff there, that I forget the name now, which is about the odor, then I clean it again, put metronidazole inside the wound and the other ointment on the outside (F6).

[...] She has been washing with tap water and soap and she usually does this under the shower when she takes a bath (F7).

The pain, always constant in these people, needs to be better managed to provide relief during dressing changes and comfort during the day, making it easier to handle the wound:

[...] the biggest problem is with respect to pain, because when it came time to clean, she couldn't bear to touch it (F3).

I come with a medicine, after the dressing, when she starts to feel a lot of pain, then, when it lasts 20 to 30 minutes, it gives her some relief, because it burns and she goes to sleep (F1).

When handling the wound, family members use strategies to mitigate odors and avoid direct contact with secretions by wearing a mask, gloves, and using 70% alcohol:

[...] I take a shower, I come with alcohol on my body, then I put a cloth over it so it doesn't get greasy and for every situation I use a glove (F1).

[...] I put two masks on to be able to clean because the odor is very strong (F6).

Family members report facing difficulties in caring for the person with cancer and their wounds, mainly because these wounds cause intense pain, exudate, bleeding, unpleasant odors, necrosis, and limitations in mobilizing the patient. Some find it difficult to manipulate the wound, due to its complexity, mainly because of the pain:

[...] I do have difficulty. There is a part of it that still releases some dead flesh, so I get scared, but the nurse at the health center said that this is good to get the new one as it is happening... (F1).

So, because she was a relative, it was very difficult this process of getting this cleaning done in a proper way, seeing how much pain she was in (F3).

The strategies developed by the caregivers are individualized, range from physical care to approaches for psychological and emotional comfort, and are thought of by these people as another form of care.

The care offered by family members to the person with neoplastic wounds, most of the time, is of an integral nature. Strategies for emotional care, in addition to wound management, were also observed in this study when we identified that some family members reported not expressing their emotions and feelings of grief in front of the ill person to avoid worrying them. Others reported demonstrating joy and tranquility especially during dressing:

[...] Sweetie, I remain tranquil. I can't transmit my nervousness to her, then I play with her. When she goes to check, she asks: have you had the dressing done yet? Then I say: I have already done it, Grandma. That's it. Then she answers: Hail Mary, that was fast today. Every day is like this, a different thing to do to make her smile, to distract her mind, we always do this (F1).

[...] We are not discouraged, because we know that we have to bring joy to her. We cannot leave her isolated and it is a learning process also for us because of the strength she always has every day (F7).

## Family members report the need for support from health professionals and institutions

The difficulties in accessing the public health service for general care of the person with cancer, especially with wounds, and the scarcity of products for dressing are evident. Having a support network, especially with the help of health professionals, contributes to promote more safety to the caregiver-family, especially when performing the dressing. The need for guidance in dealing with the wound is highlighted in the following speeches:

[...] It was soon after the chemotherapy, so we were at a loss as to what course of action to take ... Before that we didn't know. I faithfully looked from one public health center to another, and even went to a clinic to see if they took care of these injuries but they didn't (F7).

[...] At the health center there is never anything (F1).

[...] We missed someone, because I realized how important these instructions should be right away (F7).

Another issue reported is the need for a professional who would go home, mainly due to the clinical conditions of the person with cancer:

[...] I wanted a professional who was there, like if I was bleeding a lot, to tell me "You are bleeding a lot because it is normal" ... But I wanted a professional with me like that, you know? (F1).

[...] Every day there should be a person to perform the dressing (F2).

Besides the need for home care, the lack of materials for dressings was also reported, because there is a discontinuity in the supply by the public health system, generating costs for family members and a decrease in the quality of the procedure:

The health center, when they have material, they give it; when they don't have it, I have to buy it. Because sometimes it lacks (F6).

[...] Yes, there was the issue of expenses, because the whole material of the treatment is he [the sick person] who has to pay for it (F5).

The need for support from the health services and their professionals goes beyond technical assistance in the dressing procedure. There is a lack of welcoming, empathy, and respect for the sick person and their family members. The experiences reported are of embarrassment, pilgrimage in search of care, and discrimination in primary care units, where some health professionals, unaware, refuse to care for the sick:

[...] Right when the cancer process started, she had all the assistance, everybody explained everything. Now when she came back with the relapse, with these wounds, people said: ah there is nothing more we can do for you (F3).

In addition to the negative verbal responses, some family members perceived inappropriate reactions as well as unpreparedness on the part of professionals when seeking help:

[...] One looking at the other, looking at the clock saying that it was no longer on time, saying it was supposed to come such a time (F5).

[...] A professional prohibited him from entering the health center because she said he had a bad smell, so she threw him out (F6).

[...] The doctor was disgusted with my grandmother's wound, at the health center, when she opened the dressing, because pus came out (F1).



## DISCUSSION

The results show how family caregivers of people with neoplastic wounds develop wound care and management and reveal the lack of support from institutions and professionals to help them deal with this issue.

In this sense, a reflection of this reality that can also occur in other oncology health units begins, signaling the need for attention, especially the nursing team for comprehensive care and health education, as well as the guidelines for planning home care actions, supporting and subsidizing the care and self-care of the sick and caregivers.

The advent of a chronic health problem that debilitates the subject for self-care generates the need for care from others, whether health professionals, family members, or caregivers. People with cancer who undergo chemotherapy and/or radiotherapy and, in addition, have wounds, are more vulnerable and in need of physical, psychosocial, spiritual and financial support<sup>10</sup>. All kinds of help are welcome, and it is usually family members who take on the role of caregivers, as observed in this study, where the women in the family are the ones who perform this role, canceling out or reconciling their lives with their new role as caregivers. Culturally, throughout female history, women are the ones who stop working in order to accompany, care for, perform dressings and home procedures<sup>11</sup>.

The bonds of consanguinity can facilitate caregiving, by involving feelings of affection, love, donation, dedication and abdication<sup>12</sup>, but there is a need for technical knowledge, materials, and equipment for safe and quality home care.

The complaints from family-caregivers about the lack of adequate knowledge to care for the person with cancer and the wound are related to the low level of education and the lack of guidance from health care professionals. Furthermore, the lack of access to the educational network and the low financial condition hinder a good understanding and assimilation of the health orientations coming from the professionals, consequently there is difficulty in providing adequate care at home.

Another reason for complaints is the scarcity of professionals in the basic units who provide such guidance or care to explain how to perform home care, especially management of the neoplastic wound, using language appropriate to the level of understanding of these people, performing dressings in their presence, demonstrating the technique and how far the caregiver can go in home care<sup>13</sup>.

The difficulties that go through the lack of professionals and the absence of adequate information lead to a deficit of understanding, interpretation, and execution of medical and nursing prescriptions, to risks of errors and complications, causing insecurity in this home care<sup>14</sup>.

By receiving direct and accurate information, family members feel more secure, which facilitates decision-making when faced with the lesion found, especially when there is worsening of characteristics, due to the evolution of the wound, associated with complications of the disease<sup>14</sup>. The nurse is the health professional who is most prepared to care for people with wounds. It is up to these professionals to provide clear and objective guidance to family members, especially those who deal directly with people who have malignant neoplastic lesions<sup>13</sup>.

When these family members do not receive proper orientation and the people with wounds are not in a reference service, the procedures are performed in an empirical way, based on the influences of the environment and culture in which they are inserted, building their own knowledge in practice, usually in an independent and intuitive way, without necessarily performing techniques and using topical products properly<sup>15</sup>.

Access to the Internet as a source of information has become common among caregivers. However, such information is not always clear and intelligible enough, with the proper scientific basis, besides the fact that technical terms and academic literature are poorly understood by family members, making understanding and practical application difficult<sup>16</sup>, especially when the reader has a low level of education.

Still within the scope of caregivers' knowledge, there is also the guidance provided by friends as an informal source, even knowing that there is not the appropriate knowledge to meet the health need presented, but also having the function of providing encouragement and support as well as exchanges of experiences<sup>12</sup>.

When facing the wound, the caregiver observes characteristics of the injury that need specific treatments on a daily basis and the technical skill of a professional. For not having this help, the caregiver performs the procedure with incorrect techniques, uses products that are often inappropriate to the injury and administers medications without medical prescription

or at inappropriate times, showing how challenging it is, for caregivers, to take care of someone without manual skill and with scarcity of resources and guidance<sup>16,17</sup>.

The international consensus that addresses the management of malignant neoplasia evidences, through reviews, the best techniques for dressing malignant neoplastic wounds, describes the appropriate dressings for each stage and characteristic of the wound, and emphasizes that following these guidelines contributes to improvement, avoids complications, discomfort, and promotes healing or relief of symptoms<sup>18</sup>.

The manipulation of the lesions without any guidance may impair the healing process, favor contamination, infection and the risk of bleeding, very common in this type of wound, besides favoring pain, a sign that must be taken into consideration<sup>19,20</sup>.

The lack of preparation of health care professionals to care for the person with a neoplastic wound and to provide guidance on the management of the lesion may indicate personal limitations, deficiency of knowledge about the characteristics of these wounds, lack of experience and lack of specific training<sup>21</sup>.

When caring for the person with cancer, besides paying attention to the physical aspects, the caregivers deal with subjective issues that need to be faced in an adequate way, to avoid further stress, such as not showing their true feelings to the sick ones, masking or omitting information that may harm the rehabilitation and, thus, avoiding further suffering<sup>22</sup>. In this sense, the psychosocial support offered by caregivers aims to provide comfort and encouragement, which has been shown to be a positive thing<sup>23</sup>. Thus, it is important that professionals focus on psychoemotional factors during their health orientations for both the patient and the caregivers.

Even in the face of the difficulties reported by caregivers in caring for the person with cancer who has a neoplastic wound, what brought the most embarrassment was the perceived disregard and discrimination on the part of some health care professionals. By feeling humiliated and disrespected as users of the public health system, patients may have their general health condition aggravated and caregivers may lose the opportunity to seek help for proper care<sup>24</sup>. The prejudice is a result of the lack of humanization, ethical commitment, and technical unpreparedness of these professionals, which leads to structural stigmatization<sup>24</sup>. The main reason for doing so may be odor, which contributes to social isolation and the lack of interest of health care professionals in caring for the person with a malignant neoplastic wound<sup>2</sup>. To alleviate these issues, it is necessary to have articulation in the assistance spheres.

The network of comprehensive care in its levels of assistance needs to move uniformly. The service in the specialized units relies on the support from the basic units, especially for dressings. Furthermore, home care or even home hospitalization closes this care cycle, contributing to the strengthening of care at all levels. However, it is still difficult to find formal and free support in these spheres<sup>22</sup>.

Ordinance No. 825 of 2016 from the Brazilian Ministry of Health, which deals with home care, emphasizes that health teams should perform care and integrated actions with the family, identifying those who are exercising roles as caregivers to conduct training with them, provide reception and assistance, ask questions, listen to complaints, always considering them as an important part of the care process<sup>22</sup>.

This study has limitations related to the number of family-caregivers who participated in the research; however, it was possible to build the categorical matrix with saturation of the participants' reports. This universe may not represent all the patients and family-caregivers who pass daily through the referral service where this research was developed, which requires further studies.

The results show the relevance of this theme and raise new questions for further investigations, contributing to the construction of discussions, reflections and expansion of knowledge from the perspective of caregivers, as well as subsidizing nursing care for quality care aimed at promoting the training of caregivers, family members and patients for home care of people with neoplastic wounds.

## CONCLUSION

The perception of family-caregivers of people with malignant neoplastic wounds was that there is difficulty in obtaining information about wound care. They seek knowledge empirically due to lack of guidance from health professionals regarding



follow-up treatment at home, feeling of insecurity and fear in the management of wounds, deficiency in the supply of materials for the execution of procedures, by health units, which generates an increase in family expenses. In addition, they present experiences of suffering, discrimination, and embarrassment with the pilgrimage in the search for health care in primary care units.

## AUTHORS' CONTRIBUTION

**Conceptualization:** Lima TR, Lima MSFS and Carvalho ESS; **Methodology:** Lima TR, Lima MSFS and Carvalho ESS; **Data analysis:** Lima TR, Lima MSFS, Carvalho ESS, Paranho RFB, Araújo IFM and Souza AR; **Writing – First draft:** Lima TR, Lima MSFS, Carvalho ESS, Paranho RFB, Araújo IFM and Souza AR; **Writing – Review & Editing:** Lima TR, Lima MSFS, Carvalho ESS, Paranho RFB, Araújo IFM and Souza AR.

## AVAILABILITY OF RESEARCH DATA

All data sets were generated or analyzed in the current study.

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