



ARTICLE CLINICAL CASE REPORT

NURSING AND PALLIATIVE CARE OF A YOUNG MAN WITH RHABDOMYOSARCOMA CUIDADOS DE ENFERMAGEM E PALIATIVO DE UM JOVEM COM RABDOMIOSSARCOMA CUIDADOS DE ENFERMERÍA Y PALIATIVO DE UN JOVEN CON RABDOMIOSARCOMA

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ABSTRACT

Objectives: to report the case of a young patient diagnosed with advanced alveolar rhabdomyosarcoma; describe the planning of nursing care provided to the patient and his family.

Method: this is a qualitative, descriptive, clinical case study of a patient admitted to a large general hospital. For the care planning, the stages of the Nursing process, techniques and conceptual models were used: communication of bad news; construction of skills for self-management and the principles of humanized care (welcoming and extended clinic). **Results:** it is reported that the patient evolved to death, and he and his family were the focus of interventions from the detection of twelve Nursing diagnoses: ineffective protection; risk of falls; risk of acute confusion; integrity of the damaged oral mucous membrane; chronic pain; anxiety related to death; willingness to religiosity improved; spiritual suffering; defensive confrontation; stress overload; risk of feeling powerless and tension in the role of caregiver. **Conclusion:** it is concluded that complex cases require the appropriate and systematic use of theories and conceptual models that subsidize care, in addition to the use of techniques for the communication of bad news.

Descriptors: Oncology; Rhabdomyosarcoma; Nursing Diagnosis; Palliative Care; Self Management; Nursing Care.

RESUMO

Objetivos: relatar o caso de um paciente jovem diagnosticado com rabdomiossarcoma alveolar avançado; descrever o planejamento da assistência de Enfermagem prestada ao paciente e sua família. **Método:** trata-se de um estudo qualitativo, descritivo, tipo estudo de caso clínico de um paciente internado em um hospital geral de grande porte. Utilizaram-se, para o planejamento do cuidado, as etapas do processo de Enfermagem, técnicas e modelos conceituais: comunicação de más notícias; construção de habilidades para o autogerenciamento e os princípios do cuidado humanizado (acolhimento e clínica ampliada). **Resultados:** relata-se no caso que o paciente evoluiu para óbito, e ele e sua família foram os focos das intervenções a partir da detecção de doze diagnósticos de Enfermagem: proteção ineficaz; risco de quedas; risco de confusão aguda; integridade da membrana mucosa oral prejudicada; dor crônica; ansiedade relacionada à morte;

disposição para religiosidade melhorada; sofrimento espiritual; enfrentamento defensivo; sobrecarga de estresse; risco de sentimento de impotência e tensão do papel de cuidador.

Conclusão: conclui-se que casos complexos exigem o uso adequado e sistemático de teorias e modelos conceituais que subsidiem o cuidado, além do uso de técnica para a comunicação de más notícias.

Descritores: Oncologia; Rabdomiossarcoma; Diagnóstico de Enfermagem; Cuidados Paliativos; Autogestão; Assistência de Enfermagem.

RESUMEN

Objetivos: reportar el caso de un paciente joven diagnosticado de rabdomiosarcoma alveolar avanzado; describir la planificación de la atención de Enfermería proporcionada al paciente y su familia. **Método:** se trata de un estudio cualitativo, descriptivo, a modo de estudio de caso clínico de un paciente ingresado en un gran hospital general. Para la planificación de los cuidados se utilizaron las etapas del proceso de Enfermería, técnicas y modelos conceptuales: comunicación de malas noticias; construcción de habilidades para la autogestión y los principios de la atención humanizada (recepción y clínica ampliada). **Resultados:** se reporta en el caso que el paciente falleció y él y su familia fueron el foco de intervenciones basadas en la detección de doce diagnósticos de Enfermería: protección ineficaz; riesgo de caídas; riesgo de confusión aguda; integridad de la membrana mucosa oral deteriorada; dolor crónico; ansiedad relacionada con la muerte; disposición para mejorar la religiosidad; sufrimiento espiritual; afrontamiento defensivo; sobrecarga de estrés; riesgo de sentirse impotente y tensión del rol de cuidador. **Conclusión:** se concluye que los casos complejos requieren el uso adecuado y sistemático de teorías y modelos conceptuales que apoyen el cuidado, además del uso de técnicas para comunicar malas noticias.

Descriptores: Oncología Médica; Rabdomiosarcoma; Diagnóstico de Enfermería; Cuidados Paliativos; Automanejo; Atención de Enfermería.

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INTRODUCTION

Rhabdomyosarcoma (RMS) is known to be the most common soft tissue sarcoma in childhood and represents a high-grade malignant neoplasm of myoblast type cells.¹ RMS is categorized into embryonic, alveolar and pleomorphic, the pleomorphic subtype being the one with the highest incidence in adults.²

It is demonstrated as a neoplasm of rare incidence of soft tissue, which can appear in any age group. It is added that alveolar and embryonic subtypes are extremely rare in adults, making research on incidences scarce. A reference center in the treatment of patients with sarcoma in the city of London, England, registered 66 cases over a period of 27 years, and the overall survival rate over five years among all adult patients with alveolar and embryonic MSR was 27%. The results showed a great difference in pediatric patients with the same subtypes, whose five-year global survival rate was reported to be 70 to 80%.³⁻⁴

Approximately 600 new cases of MSR are diagnosed per year in the United States, 41% of cases involve adults and 59% involve children,⁵ However, in Brazil, the National Cancer Institute (INCA) does not have data on this type of cancer.

The curative intention will depend on the treatment of the control of the primary tumor, which may arise in different anatomical locations, as well as the control of the disseminated disease, which is known or presumed to be present in all cases. Currently, several clinical, pathological and molecular characteristics that are fundamental for the decision of the therapeutic plan are incorporated by the RMS staging. The plan can include cytotoxic chemotherapy, surgery, ionizing radiation or the combination of these modalities.¹

It is necessary, given the complexity and seriousness of the diagnosis, to carry out a thorough evaluation of the patient and his family from the diagnostic phase, seeking to characterize biopsychosocial and spiritual needs for care. The assistance plan should focus on the patient and the family, considering the biological demands related to the diagnosis and therapeutic plan, the effective management of signs and symptoms, as well as other psychological, social and spiritual care needs throughout the treatment until the end of life or disease-free survival.⁶

The concept of self-management has been incorporated to the assistance planning of people with chronic diseases with the intention of building skills for decision making. The partnership between health professionals and patients, as well as their families, for the best management of care, from therapeutic, emotional and functional perspectives, is implied by the assistance based on self-management. It is pointed out that educating the patient and the family for self-

management means providing the development of skills for problem solving, decision making, action, adequate use of available resources and effective relationship with health professionals.⁷⁻⁸

The care plan of patients and families who experience chronic and complex clinical contexts from the perspective of severity should be based on multiple tools, such as education based on problem solving methodology; application of the principles of practice based on scientific evidence (better scientific evidence, professional experience and patient's desire); hospitality; integrality of care; effective communication techniques, among other resources that generate quality care, well-being and safety for the patient and his or her family.⁹⁻¹⁰

It is observed that certain clinical situations are very challenging for health professionals, especially when the evolution of the disease culminates at the end of life and, therefore, it is justified to report them to become support for decision making on similar clinical cases.

OBJECTIVES

To report the case of a young patient diagnosed with advanced alveolar rhabdomyosarcoma; describe the planning of nursing care provided to the patient and his family.

METHOD

It is a qualitative, descriptive, clinical case report type study,¹¹ as it provides complement, or refinement, of certain knowledge and to generate learning to work with similar cases. It was approved by the Research Ethics Committee of the Federal University of São Paulo (UNIFESP) under Protocol nº 344/2019.

The study was carried out in a large general hospital in the city of São Paulo (SP), Brazil, destined to the care of the Unified Health System (UHS) and university teaching, linked to UNIFESP. It is informed that, in the institution, there are programs of medical and multiprofessional residency in Oncology, being the nurse one of the professionals of the multiprofessional residency program. The patient with cancer and his family are mainly cared for in an outpatient and, when necessary, hospital environment.

Oncologic assistance has been offered in the hospital institution the collaboration of a university extension program registered in the Pro-Rectorry of Extension of UNIFESP entitled Acolhe-Onco: interdisciplinarity in the integral care of the patient with cancer; residents, postgraduates and undergraduates participate, adding to the structure of the hospital complex and the residence programs. The Acolhe-Onco maintains educational-assistance activities in person and a Telephone Counseling Service, maintained uninterruptedly, from 7 a.m. to 10 p.m., so that patients and family members can clarify doubts during inter-consultation periods.

The steps of the Nursing Process (NP) were used for the planning of nursing care: data collection; nursing diagnosis; care plan; implementation and evaluation of care.¹³ Empregaram-se os modelos conceituais comunicação de más notícias,¹⁰ construção de habilidades para o autogerenciamento¹⁴⁻⁵ e os princípios do cuidado humanizado: acolhimento e clínica ampliada.¹⁶⁻⁷

The NANDA-I18 classification was used for the determination of the Nursing Diagnostics (ND). For the determination of interventions and results, the Nursing Interventions Classification (NIC) and the Nursing Outcomes Classification (NOC) were used.¹⁹⁻²⁰

Care was mainly provided by resident nurses of the Multiprofessional Oncology Residency Program of HSP-UNIFESP, supervised by tutors and preceptors, and by nurses of the hospitalization and emergency room units of the host institution.

RESULTS

The case of a 19 year old male, white, single, with higher education, complete high school, non practicing Catholic, natural and from São Paulo (SP), Brazil is reported; resident with his mother and two uncles, in his own masonry house, with five rooms, provided with electricity and basic sanitation.

It is described that the first signs and symptoms occurred at 18 years of age, characterized by a progressive growth of lymph nodes in the left cervical region, fever and headache, with implications in daily life activities. In May 2018, a left periorbital edema associated with fever and nasal secretion, persistence of headache, cervical bulging and loss of five kilograms in one month was presented. It is added that the first consultation in the Oncology Department took place on October 31, 2018. Tomography (CT) and magnetic resonance imaging were performed at admission, which showed a solid, heterogeneous lesion, with ill-defined limits and infiltrative aspect, with heterogeneous contrast enhancement, whose geometric center was located in the region of the ethmoid sinus, with extension before the nasal bone to the left and later filling the sphenoid sinuses with obliteration and enlargement of the sphenoid recesses and dehiscence of the optic nerve canal to the left. It is detailed that, on the right, it determined bulging of the papyraceous blade and, on the left, it extended into the optical cavity, causing lateral displacement of the eyeball and proptosis on this side. Erosion of the cribriform lamina was determined, presenting intracranial extension, with occupation of the olfactory drips and compression of the adjacent frontobasal parenchyma. It extended inferiorly to the nasal cavity with erosion and important displacement of the septum and nasal shells, occupying practically all its light; it filled the left maxillary sinus and presented foci of erosion in all its walls. Lymph nodes with necrotic centers were found, sometimes forming conglomerates, the largest in the Ib, IIa and IIb chains on the left,

the largest measuring 7.2 x 3.8 x 3.6 cm. It was permitted, by examination of aspirated material and immunohistochemical lymph node, to diagnose metastasis of alveolar RMS. It was defined by the other tests, including chest, abdomen and pelvis CTs and bone scintigraphy with no evidence of other sites of disease, T4 (tumor), N1 (lymph node), M0 (metastasis).

The patient was presented as a family history: father deceased by malignant hyperthermia during thyroidectomy surgery and cousin with unspecified ovarian cancer at age 14 (father's side). In his trajectory for the diagnosis, the patient sought several medical services in private and public networks, however, with the severity of signs and symptoms, he was referred to the HSP, site of the study, for being a center of diagnostic excellence. It is pointed out that the estimated time between the initial symptoms and the diagnosis of locally advanced alveolar RMS was five months (May to October 2018).

Three cycles of Antineoplastic Chemotherapy (CTX) with the VAC protocol²¹ were applied in the patient from November to December 2018, as a pharmacological therapeutic plan every 21 days (Vincristine 1.5mg/m² D1 + Dactinomycin 0.045mg/m² D1+ Cyclophosphamide 1,200mg/m² D1 + Mesna 1200mg/m² D1 every three weeks), with the use of the Granulocyte colony-stimulating factor (G-CSF), however, there was a progression of the disease, with an increase in the number and size of lymph nodes.

In February 2019, a new protocol²² with the drugs Carboplatin 150mg/m² D1-4 and Etoposid 150mg/m² D1-4 was initiated, referring the patient to Radiotherapy (RT) in the cervical region for control of local signs and symptoms, especially pain, having received five sessions. Despite the treatment, he presented a new disease progression, locoregional and, in the sequence, he performed a cycle with monopharmaceutical²³ Vinorelbine 30 mg/m² D1 and D8 every 21 days.

In March 2019, the patient with loss of performance - score 4 on the Eastern Cooperative Oncology Group (PS-ECOG) performance status scale: completely unable to perform basic self-care, totally confined to the bed or chair²⁴ and important algic picture (scores between 8-10, using a numerical scale of 0-10), requiring continuous infusion of morphine. It was evidenced, at this moment, by a control image examination, on 03/04/2019, increase of intracranial lesions, with left lateral ventricle compression, besides bone disease progression. It is pointed out that he remained in a hospital institution for 28 days until evolving to death, making seven months after the diagnosis of cancer.

Initially, they were assisted by a patient mother and a maternal aunt and, near the end of their lives, a paternal aunt. During the last 28 days in hospital oncologic treatment, 12 ND were identified, denoting the psycho-spiritual needs of the family and the patient, plus the physiological

changes generated by the advancement of the neoplastic tumor, forming a succession of events during the evolution of the disease.

It is explained that, in the oncology service in which the patient was diagnosed and treated, medical and nursing consultations take place in an integrated manner, that is, the patient, his/her companion and the medical and nursing professionals are in the same physical space so that the information and conducts can be discussed and agreed upon. After each consultation, if self-management education is required, the nurse with the patient goes to a doctor's office or Nursing procedures room.

It was observed, from this patient's perspective, since the first consultation, in which the cancer staging, the clinical and emotional conditions of the patient were evaluated, that the palliative care actions should be instituted immediately. The objective was, according to the principles of palliative care, to offer comfort and quality of life to the patient and support their families through approaches that make it possible to face the life-threatening disease, prevention and relief of suffering, early and impeccable identification and treatment of pain and other physical, psychosocial and spiritual problems.²⁵

The communication approach was based on bad news communication protocol, with the SPIKES¹⁴ technique, acronym for: S-Setting up (plan the interview); P-Perception (evaluate the perception); I-Invitation (invite to the conversation); K-Knowledge (offer knowledge/information); E-Emotions (approach the emotions); S-Strategy (scheme strategy and summarize the conversation). It is believed that this approach was fundamental because, from the beginning, the patient's prognosis was gloomy due to the histological type of malignant tumor, later confirmed by the rapid evolution of the disease in the presence of antineoplastic chemotherapy and radiotherapy, both without therapeutic success.

The main NDs, the expected results and the nursing interventions undertaken by the nursing team, initially to the patient and later to the mother, are shown in figures 1 and 2.

In figure 1, the ND, results and nursing interventions are listed. Ten NDs were identified, from the initial treatment phase to the end of the patient's life: ineffective protection; risk of falls; risk of acute confusion; impaired oral mucous membrane integrity; chronic pain; death related anxiety; improved religious disposition; spiritual suffering; defensive confrontation and stress overload. It is observed that, in the last column, the Nursing interventions undertaken were detailed.

NURSING DIAGNOSES ¹⁸	EXPECTED OUTCOMES (NOC) ²⁰	NURSING INTERVENTIONS (NIC) ¹⁹	OPERATIONALIZATION
Ineffective cancer-related protection characterized by immune deficiency, anorexia, disorientation, dyspnea, fatigue, weakness	Severity of generalized and prolonged fatigue.	Nutritional control;	1. The Fatigue Pictogram ²⁶ was applied and patient and family members were advised to use it at home *.

and neurosensory impairment.			
		Assistance in self-care;	2. Patient was referred to a nutritionist belonging to the Multiprofessional Residency Program in Oncology.
		Protection against infection;	3. Orientation and hygiene procedures were carried out in the edematous and ocular regions with saline solution, exclusively, until the beginning of the RT, then it was advised to follow the orientation of the radiotherapy specialist nurse.
		Radiotherapy Control (RT);	4. CTX and RT procedures were explained from the patient's and family's knowledge.
		Control in antineoplastic chemotherapy (CTX).	5. Clarified the reasons for neutropenia, anemia and thrombocytopenia risks.*
			6. Effective, affective and dialogic communication was stimulated. ²⁶
Risk of falls related to environment with excess furniture and objects, history of falls, proprioceptive deficits, hearing difficulties, visual difficulties, neoplasia (fatigue), decreased strength in the lower extremities and impaired physical mobility.	Correct use of auxiliary devices;	Monitor the way you walk, the balance and the level of fatigue with walking;	1. It was explained about the risk of falling and how to prevent it through detailed guidance on why the patient was at risk: rapid and significant weight loss; loss of acuity of eyesight compromised; side effects of drugs causing dizziness; fatigue by the drugs and the very illness by cancer.
	Elimination of agglomerated objects, spilled liquid, floor brightness;	Placing personal objects within reach of the patient;	2. During hospitalization, adaptations were made, placing personal objects within the patient's reach and disposing of the room in a safer manner.
	Use of safe procedure when transferring;	Suggest adaptations at home to increase security;	3. Patient was referred to a physiotherapist belonging to the Multiprofessional Residency Program in Oncology for appropriate guidance regarding the way to move.
		Educating family members about risk factors that contribute to falls and how to reduce these risks.	4. During the treatment, he oriented himself on fall prevention measures in the home environment, where the family made adaptations so that the patient would not need to use stairs.
Risk of acute confusion related to pain,	Ability to accurately identify place, time and person.	Reduction of anxiety;	1. Together with the multidisciplinary team

pharmaceutical agent, change in cognitive function and impaired metabolic function.			and the family, the treatment of medications was carried out with the objective of preserving the cognitive functions, avoiding drug interactions.
		Environment control;	2. The schedules were agreed upon so that family members and the patient himself could respect them, favoring the family routine and drug adherence.
		Control of medication.	3. A calendar sheet was used to record the taking of medication, in which it was written what side effects to observe and how to proceed preventively and in their validity.
Integrity of damaged oral mucous membrane, related to chemotherapy, radiotherapy and immunosuppression, manifested by mucositis grade 3. ²⁷	Oral hygiene;	Restoration of oral health;	1. Guidelines on prevention and care for maintaining the integrity of the oral mucosa during treatment have been carried out. ²⁸
	Normal structural integrity and physiological function of the skin and mucosa.	Precautions against bleeding;	2. Orientation was given and hygiene procedures were performed in the oral cavity, until the beginning of the RT; then, it was advised to follow the orientation of the specialized nurse.
		Chemotherapy control; Infection control; Pain control; Nutritional control; Radiotherapy control; Drug control; Water control.	3. Referred to dental service and nutritionist belonging to the Multiprofessional Residency Program in Oncology.
Chronic pain related to chronic physical disability, characterized by altered ability to continue previous activities, facial expression, fatigue, reduced interaction with people, irritability, changes in sleep pattern, pain scale coded reporting, pain reporting and sympathetic nervous system mediated responses.	Pain control.	Pain control;	1. The use of pain scales was taught: numerical, descriptors and colors.* ²⁹
		Analgesic Administration; Improvement of pain management; Positioning; Therapeutic touch;	2. An instrument was provided to record pain and analgesic drugs. Together, a schedule of medications and time frames was made.*
		Monitoring of vital signs.	3. Oriented regarding non-pharmacological interventions for pain relief.*
Anxiety related to death, related to the anticipation of suffering, characterized by a feeling of powerlessness.	Psychological and physiological comfort regarding your end-of-life situation.	Understand the level of anxiety the patient presents;	1. The SPIKES ¹⁰ protocol was used as a bad news communication strategy so that, in a dialogical and affective way, it would be possible to alleviate the suffering.

	Understand the patient's understanding of the process of finitude;	2. Active listening was carried out, assistance was given in building skills for self-management and, through the knowledge of the principles of humanized care, the appropriate welcome was given. ¹⁶⁻⁷ The condition of gravity has never been denied, but it has been emphasized to clarify the clinical condition presented in daily life, verbalizing the improvements, encouraging it for the next steps in a hopeful and realistic manner.
	Remove excessive stimulation;	3. From the perspective of the unpleasant symptoms, the options for interventions were also clarified and short-term improvement goals were combined, essentially.
	Speak slowly and calmly, use short and simple sentences;	4. A conversation was held with the patient, together with the medical team, who also proceeded to the steps of communicating bad news.
	Teach strategies to decrease anxiety to be used when stressful situations cannot be avoided;	5. Afterwards, the patient was talked to in isolation so that he could express his worries and anxieties separately from his mother and aunt, initially the most present. The Telephone Counseling Service was made available for clarifying doubts. This resource is maintained by the Acolhe-Onco Extension Program; resident nurses, on a rotational basis, perform it under the supervision of the tutor of the residency program. The medical residency participates actively, answering questions not contemplated in the agreed protocols.
	Perform activities that reduce anxiety and fear, such as music, aromatherapy, relaxation exercises, image mentalization, massage.	6. During the period of chemotherapy and radiotherapy, an attempt was made to encourage hope, but pondering the seriousness of the case and the need to maintain a vigilant situation for oncologic emergencies, such as bleeding and feverish neutropenia.

			7. Care was taken to control the environment in order to avoid excessive stimulation during hospitalization, a situation in which the patient received opioid in continuous infusion. The priority was bed comfort: maintenance of clean and dry bed and support of bone protuberances in pads.
Improved religious disposition characterized by expression of the desire to increase the use of religious material.	Connection with oneself, with others, with a higher power, with life, with the Universe that transcends and strengthens yours.	Spiritual support;	1. Through the hospital chaplaincy, spiritual support was offered. When the evangelical pastor called by his family came, doubts were identified and clarified so that he could conduct his intervention in a manner appropriate to the real condition of the patient.
		Support to decision making.	2. Clear and affective communication was carried out to strengthen decision making throughout the illness process, clarification of doubts, demonstration of availability, repetition of information provided by the medical team, clarification of medical terms, demonstration of compassion for the situation they were experiencing, both the patient and family members.
Spiritual suffering related to increased dependency on another, characterized by increased dependency on another.	Personal actions to maintain control during the approaching of the end of life.	Improvement of confrontation;	1. Offered emotional support through active listening and empowerment for decision making.
		Decision-making support; Active listening; Assistance in anger management; Emotional support; Facilitation in the process of grief; Facilitation in the guilt process.	2. It was oriented in advance about the adverse effects resulting from the diagnosis and the proposed therapeutic plan for the control of signs and symptoms. Stimulated self-care, the ability to self-evaluate the clinical and emotional condition and the expression of feelings during medical and nursing consultations.
Defensive confrontation related to unrealistic self-expectations, uncertainty, insufficient resilience, characterized by distortion of reality, denial of weaknesses, projection of guilt and projection of responsibility.	Acceptance of significant change in health status.	Active listening;	1. The patient's perception of death and the context in which it was found were actively heard throughout the whole process of illness.²⁴

		Early guidance;	2. The patient was asked about the people in the family identified as providers of social support so that the patient would realize that her mother would be supported.
		Counseling, emotional support; Facilitation in the grieving process.	3. Orientation and active listening were carried out about the regret of being a young person with a bad prognosis.
Overload of stress related to repeated stressors (pathology and death process), characterized by increased impatience, increased anger, excessive stress, feeling pressured and impaired decision making.	Personal actions to control stressors that end individual resources.	Reduction of anxiety;	1. The patient's greatest stress was the concern about how his mother would look after his departure; family counseling was carried out and it was shown that his mother would have the necessary support, in the family and in the religious community in which he was inserted.
		Assistance in anger self-control; Improvement of confrontation; Spiritual support; Increased security.	2. Together with the staff of the internment unit, they have articulated the increase of security and strengthening of the support network, authorization for the visit of all the close relatives, girlfriend and pet, providing the patient with improvement in the reduction of anxiety.

*Specific Educational Pamphlets about Signs, Symptoms and Care, produced by *Acolhe-Onco* and delivered to the patient and family in the educational action for self-management. The booklets contain: definition; relevance; identification; conduct; main doubts; how to proceed and phrases of encouragement for decision making.

The NDs established for the patient's mother, in different situations of the caring process, pertinent to the aunts who accompanied the patient, were demonstrated. However, the presentation of the actions performed with the mother was prioritized, mostly, according to the figure 2.

NURSING DIAGNOSES ¹⁸	EXPECTED OUTCOMES (NOC) ²⁰	NURSING INTERVENTIONS (NIC) ¹⁹	OPERATIONALIZATION
Risk of feeling powerless related to anxiety, caregiver role, ineffective coping strategies and progressive disease.	Personal actions to minimize melancholy and maintain the interest for life.	Emotional support;	1. Offering humanized care, taking into consideration the perceptions, feelings and needs of the mother and aunt to carry out the education process in order to promote safety in patient care and awareness of self-care.

		Improvement of confrontation;	2. There was a separate conversation with the mother and the aunts, seeking to observe weaknesses and strengths in interpersonal relationships, as well as the need of each in relation to feelings of pain and anguish caused by the condition of advanced disease and, later, the end of life of the patient. It was verified that the mother would have the support of her aunt, her sister, and it was tried to reinforce this affective bond.
		Support to decision making.	3. An attempt was made to undo maternal guilt beliefs regarding the diagnosis of the child's cancer. Clarification of the multicausality of cancer and, in this specific case, the possible genetic component in the development of the disease, since the mother was attributed negligence. These explanations were repeated, on several occasions, as the feeling of guilt was perceived in the maternal discourse, and she was allowed to freely express her thoughts. ³⁰
Tension of the caregiver's role related to the unpredictability of the caregiving situation and the severity of the patient's illness, manifested by ineffective confrontation and increased nervousness.	Improvement of coping.	Support to the caregiver and improvement of the coping;	1. The community and family support network was articulated to help face the grief.
	Energy control.	Facilitating the weighing process; Spiritual support;	2. The hospital chaplaincy service was offered.
			3. In all the emergency room and hospitalizations, three in the last 60 days, the patient was visited and a therapeutic relationship was maintained with the mother and aunts to clarify doubts and comfort in the situation of risk and imminent death.
		Reduction of anxiety; Rest of the caregiver.	4. There were moments of rest for the caregivers during hospitalization.

* Educational Pamphlet for Care that contains explanations about the process of getting sick from cancer, how to proceed in the different phases and encouraging phrases for decision making.

Figure 2. Nursing diagnoses related to the mother of a young man with alveolar rhabdomyosarcoma. São Paulo (SP), Brazil, 2019.

DISCUSSION

It is noted that the knowledge about soft tissue tumors, such as sarcomas, among them, the histological type called alveolar RMS, has few published studies, because it is relatively rare in head and neck.³¹

It was possible, however, to compare the natural history of disease in this case with another US retrospective review study, conducted with 186 patients aged ≥ 18 years, who were diagnosed with sinonasal RMS between 2004 and 2013, registered in the National Cancer Database (USA), in which the alveolar subtype was the most common (66.7%). Global survival in five years was recorded at

28.4%, with no statistical difference between alveolar and embryonic subtypes, and most of these were under 35 years of age (31.9% vs 24.4%, $P = 0.014$). Metastatic disease, present in 27.7% of the patients, was associated with the worst global survival in five years (14.7% vs 33.9%, $P < 0.0001$) and as for the treatments instituted, most patients were treated with adjuvant radiation chemotherapy (49.5%) and only 25% of the patients underwent surgery followed by chemotherapy (25.8%).³²

It is recalled that for the patient in this case study, surgical intervention was not a possibility either. The RMS located in the head and neck regions are barriers to effective surgical treatment due to their complex anatomy, thus preventing extensive resections that have safety margins. In surgeries in these regions, physiological, functional and esthetic sequelae are involved, forming a worse prognosis.³³

It was planned, before the evidences of the physiopathological and clinical challenges of the treatment, the assistance based on the assumptions of the extended clinic, which encompasses the particularities of the health-disease process with the characteristics of the subject, extending the object of clinical intervention to disease-subject-context. It was sought, in its totality, that the patient had autonomy over his health-disease condition, independence and that he was able to develop skills for self-management. It is known that the constitution of a reference multiprofessional team is an integral part of the desired quality of care, and this team must be prepared to receive, guide, make viable the healing process or guarantee the quality of life in all the steps of the journey.^{16,34}

It is understood that the actions developed by the reference team, especially the nurses, go beyond the management of signs and symptoms. It becomes the nurse, by supervising the treatment process, building self-management in patients and family members, providing information and support,^{15,34} besides the important task of being the main link between them and the other health team professionals, an essential professional.

During the care, members of the Multiprofessional Residence in Oncology and the Acolhe-Onco used the Nursing process, the conceptual assistance models of communication of bad news from SPIKES,¹⁰ the construction of skills for self-management¹¹ and the principles of humanized care: welcoming and extended clinic.¹⁶⁻⁷

The main caregivers of the patient affected by the disease were identified in order to carry out quality care and promote self-management for decision making: the mother and the maternal aunt, and these were the ones who performed the main cares and were the focus of the health team for the strengthening of decision making and for the adoption of care practices that generated safety and well-being to the patient. In practice, it is observed that strengthening patients and caregivers

to possess cognitive, operational and attitudinal mastery of contents related to the illness process is fundamental for therapeutic adherence and for the perception of improvement of physical and psychosocial symptoms.¹⁵

The advantages of using the SPIKES¹⁴ protocol are: knowing what the patient and his/her family are understanding of the situation as a whole (it helps the health professional to know where to start); providing information according to what the patient and his/her family can hear; welcoming any reaction that may happen and, finally, having a plan, through which it was possible to maintain quality and effective communication, facilitating the process of communication with the patient and family.¹⁴

It was verified, in the construction and professional experience of the assistance plan of the reported patient and his relatives (mother and aunts), that the diagnostic classification NANDA,¹⁸ as well as the classification of results (NOC)²⁰ and interventions (NIC),²⁴ favored the NP¹² in the perspective of adopting theoretical-conceptual and methodological references.

The chain of actions undertaken by the bad news communication technique¹⁴ was facilitated and, since the beginning of the implementation of the plan, it was perceived that the adoption of skills for the decision making of the patient and his family members was improved over time. It is certainly admitted that this case report cannot attest to the efficiency of the assistance plan at levels of evidence capable of categorically guiding the practice, this being the greatest fragility of this study.

However, the description of the clinical case and the detailing of the assistance plan can favor a clinical reflection in a health professional during the life of a similar case.

CONCLUSION

This case report highlights the importance of studies that contextually explain the Nursing care plan for patients with advanced cancers, in age groups that are usually more rare in diagnoses. The complexity of the process of getting sick from cancer must be considered and scientific resources must be raised to determine the attitudes and procedures adopted by the professional, in the particular case of the nurse.

The results of this study are intended, in general, to stimulate the assumptions of the construction of self-management, the expanded clinic and the capacity of effective and affective communication generated by the technique of communication of bad news in cancer disease. It is concluded that, through the systematic use of theories, models and techniques scientifically proven to be effective, nurses will be able to advance in the construction of knowledge of the profession and the quality of care provided to cancer patients.

CONTRIBUTIONS

It is informed that all authors contributed equally in the conception of the research project, collection, analysis and discussion of the data, as well as in the writing and critical review of the content with intellectual contribution and in the approval of the final version of the study.

CONFLICT OF INTERESTS

Nothing to declare.

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