ADOLESCENTS IN PALLIATIVE CARE: A STUDY BASED ON THE THEORY OF CALLISTA ROY

ADOLESCENTES EM CUIDADOS PALIATIVOS: UM ESTUDO FUNDAMENTADO NA TEORIA DE CALLISTA ROY

ADOLESCENTES EN CUIDADOS PALIATIVOS: UN ESTUDIO FUNDAMENTADO EN LA TEORÍA DE CALLISTA ROY

Patrícia Peres de Oliveira¹, Carolina Eloí Miranda², Eduardo Henrique de Oliveira Lima³, Marina Bueno Dias⁴, Edilene Aparecida Araújo da Silveira⁵, Andrea Bezerra Rodrigues⁶

ABSTRACT

Objective: to operationalize the Nursing process for adolescents in palliative care, based on the Roy Adaptation Model, using NANDA, Nursing Outcomes Classification and Nursing Interventions Classification. **Method:** a qualitative study, in which the case study, was adopted, as a methodological strategy, carried out with two adolescents and families, through home visits. As a theoretical reference, the Callista Roy Adaptation Model was used. **Results:** it was observed that the care to the adolescents and their families favored the adaptation, since the young showed a significant improvement in front of the stimuli; the identified socioeconomic conditions interfered with the well-being of the female family and adolescent, and consequently, the generated impact was perceived. However, one should propose interventions as guidelines on the management of the presented symptoms and sessions of music therapy, contributing to the improvement in the environment reduction of anxiety. **Conclusion:** the interventions implemented were important for the substitution of ineffective responses by adaptive responses. **Descriptors:** Palliative Care; Neoplasm; Adolescent health; Nursing Process.

RESUMO

Objetivo: operacionalizar o processo de Enfermagem para adolescentes em cuidados paliativos, baseado no Modelo de Adaptação de Roy, utilizando NANDA, Classificação dos Resultados de Enfermagem e Classificação das Intervenções de Enfermagem. **Método:** estudo qualitativo, no qual se adotou, como estratégia metodológica, o estudo de caso, realizado com dois adolescentes e famílias, por meio de visitas domiciliares. Como referencial teórico, foi utilizado o Modelo de Adaptação de Callista Roy. **Resultados:** observou-se que os cuidados aos adolescentes e suas famílias favoreceram a adaptação, pois os jovens apresentaram melhora significativa frente aos estímulos; as condições socioeconômicas identificadas interferiram no bem-estar da família e da adolescente do sexo feminino e, conseqüentemente, percebeu-se o impacto gerado. Todavia, deve-se propor intervenções como orientações sobre o manejo dos sintomas apresentados e sessões de musicoterapia, contribuindo para a melhora no ambiente familiar, além da redução da ansiedade. **Conclusão:** as intervenções implementadas foram importantes para a substituição de respostas ineficazes por respostas adaptativas. **Descritores:** Cuidados Paliativos; Neoplasias; Saúde do adolescente; Processos de Enfermagem.

RESUMEN

Objetivo: operacionalizar el proceso de Enfermería para adolescentes en cuidados paliativos, basado en el Modelo de Adaptación de Roy, utilizando NANDA, Clasificación de los Resultados de Enfermería y Clasificación de las Intervenciones de Enfermería. **Método:** estudio cualitativo, en el cual se adoptó, como estrategia metodológica, el estudio de caso, realizado con dos adolescentes y familias, por medio de visitas domiciliarias. Como referencial teórico, se utilizó el modelo de adaptación de Callista Roy. **Resultados:** se observó que los cuidados a los adolescentes y sus familias favorecieron la adaptación, pues los jóvenes presentaron una mejora significativa frente a los estímulos; las condiciones socioeconómicas identificadas interfirieron en el bienestar de la familia y de la adolescente femenina y, conseqüentemente, se percibió el impacto generado. Sin embargo, se debe proponer intervenciones como orientaciones sobre el manejo de los síntomas presentados y sesiones de musicoterapia, contribuyendo para la mejora en el ambiente familiar, además de la reducción de la ansiedad. **Conclusión:** las intervenciones implementadas fueron importantes para la sustitución de respuestas ineficaces por respuestas adaptativas. **Descriptor:** Cuidados Paliativos; Neoplasia; Salud del Adolescente; Procesos de Enfermería.

¹Nurse, PhD, Professor, Federal University of São João del-Rei. Divinópolis (MG), Brazil. E-mail: pperesoliveira@ufsj.edu.br; ²Nurse, Federal University of São João del-Rei. Divinópolis (MG), Brazil. E-mail: celoimiranda@gmail.com; ³Nurse, Federal University of São João del-Rei. Divinópolis (MG), Brazil. E-mail: eduardo.henry@gmail.com; ⁴Nurse, Federal University of São João del-Rei. Divinópolis (MG), Brazil. E-mail: marinabueno26@gmail.com; ⁵Nurse, PhD, Professor, Federal University of São João del-Rei. Divinópolis (MG), Brazil. E-mail: edileneap@ufsj.edu.br; ⁶Nurse, PhD, Professor, Federal University of Ceará. Fortaleza, Brazil. E-mail: andreadrodrigues@gmail.com

INTRODUCTION

Adolescence is an exciting time when everything seems incredible. Young people are on the threshold of love, and often of professional life. They are meeting the most interesting individuals in the world, themselves.¹⁻³ It is a phase of life known to the developmental impulses that affects the physical, sexual, cognitive and emotional aspects and the beginning of actions that aim to reach the cultural expectations of the society in which they live. It is defined as the period of transition and change between childhood and adult life. The young man begins to search for his independence, defining the things that he likes and the projects of life, starts to look outside the family, looking for the coexistence and integration with the social group in which it is inserted. Such changes generate conflicts necessary for the maturation of the person.¹⁻²

Including, the exposed scenario, the experience of cancer, considered one of the most overwhelming diseases for the vast majority of people. Adjusting to the new reality, in the face of the daily disease and the context of therapeutic care, is a complex task.^{1,3} The diagnosis of malignant neoplasm in adolescence is confronted with the discovery of the body, the construction of identity, the search for autonomy and in addition, they often, cause a devastating effect not only on the adolescent's life, but also on the family, since they believe it to be an incurable disease related to death and painful treatments where the adverse effects of cancer treatment may quality of life, causing disorders not only during the treatment period, but, also, late.³⁻⁴

Given this, it is essential to plan support care for these youngsters and their families, which demands the mastery of health professionals about specific theoretical information and sensitivity to deal with this clientele. Including, studies indicate that adolescents and young adults are a vulnerable population,⁴⁻⁵ in addition to stressing that there is a vacuum in the care of children and adults oncology⁴ and it becomes an abyss when it comes to palliative care for these people.⁵ Another research suggests that as a group, young people with malignant neoplasms tend to experience more severe and longer-lasting

suffering than children, adults, and the elderly with similar diagnoses.⁶

Palliative care has, as main objective, the relief of symptoms, whether physical, social, spiritual or psychological, generated by the chronic disease itself or by the experience of it. The patient's family is also included in this mode of care, as it is characterized as an extension of the same. Palliative care does not have protocols but principles, so, that, the individuality of the patients who are seen in a holistic way, taking into account their momentary desires and desires, can be worked out, thus, generating, the main focus, the quality of life.^{3,5}

For the family, recognizing palliative care is an arduous task because of the uncertainty and apprehension about the future and the possibility of death.^{3,7} Recognizing the benefits of palliative care does not mean accepting death, because this is a reality that the family will never accept, but it is their way of dealing with losses along the way and maintaining their hope and perseverance to focus on managing child care. This means that the family experiences a sense of loss in the course of the illness and not only after the child's death, which must be acknowledged by the caregiver.⁷

As previously mentioned, adolescents with malignant neoplasia tend to become more sensitive and vulnerable to stimuli caused by the cancer situation and non-response of the treatment, interfering in the promotion of an effective response to these stimuli, which contributes, in a negative way, to their adaptation. Therefore, it is up to the health professionals, especially the nurse, as it remains longer alongside the patient and his family, to plan the integral care of these individuals and their families, in an orderly and scientific way, using the Nursing Process, based on a theoretical reference that in this study, will be the Callista Roy's Adaptation Model (CRAM).⁸

The Nursing Process (NP) is based on five interrelated phases: research; diagnosis; planning; implementation and evaluation. It is a systematic and dynamic way of performing Nursing care, with evidence-based Nursing being essential, as well as providing humanized care.⁹ Nurses have working tools that allow agile interaction during the application of the PE, among

they are: NANDA Nursing Diagnostic classification systems,¹⁰ Nursing-NOC¹¹ Results and Nursing Interventions-NIC.¹² The PE is based on phases that can modify according to the Nursing theory to be applied.⁹

According to Roy's Adaptation Model, NP is divided into six phases: the first stage is where behavioral assessment occurs, which is conceptualized as adaptive or ineffective. The second step involves identifying the internal and external stimuli that are influencing behaviors. The third stage of the process is the identification of Nursing diagnoses, which reflects the nurses' judgment about the level of adaptation of the person. The fourth step involves setting goals, at which point the nurse lists the behaviors resulting from Nursing care. The fifth is intended for the planning of interventions that must be selected, according to the previously established goals, with a view to promoting adaptation through stimulus change.¹³⁻⁴

The sixth phase of the NP, according to CRAM, is the evaluation, where the effectiveness of the Nursing intervention in relation to the human behavior of adaptation is judged.⁸ Its system concentrates on adaptive behaviors and the set of processes by which a person adapts to the stress environments.^{8,13} Stimuli that occur with individuals and families are responsible for generating coping mechanisms, described as innate or acquired mechanisms to respond to changes in the environment. Such mechanisms will trigger responses, such as: adaptive responses and ineffective responses.^{8,14}

Nursing aims to enable effective responses in the four adaptive modes (physiological, self-concept, role function and interdependence) and interventions need to stimulate adaptive reactions in health and disease situations.⁸ The nurse should be attentive to the management of focal stimuli, contextual, residual of the person and in the promotion of the adaptation reaction.¹²⁻⁴

It is emphasized that focal stimuli refer to the central problem that causes changes in the person. The contextual ones are the signs and symptoms that can be evaluated, observed and/or reported by the individual. And residual stimuli are conditions that are significant for a person's situation but are not measurable.¹⁴ The coping mechanisms

used for adaptation are the regulator, which comprises chemical, neuronal, or endocrine transmitters, and the cognitive, that involves perceptions, emotions, and judgment.¹²⁻³ Mechanisms, regulator and cognoscent, act in adaptive modes.^{8,14}

In this study, malignant neoplasm generates stimuli requiring the individual to respond, which may be either adaptive or ineffective, through home care that includes the family as an interactive and collaborative element in health care, thus, addressing, complex needs and using a range of institutional, community and family resources for the effectiveness of adaptive responses.

The relevance of this research is, mainly, the fact of contemplating three themes with distinct specificities and that requires management as: adolescents, malignant neoplasms and palliative care. In addition to scarce studies in palliative care with adolescents with malignant neoplasia and no publication, addressing the Nursing Process for this population, palliative care for adolescent cancer patients is challenged by the diversity of young people's needs, ages, and treatment settings.^{2,4,6} It should be emphasized that palliative care begins at the time of diagnosis and can be offered concurrently with disease-directed therapy of base.^{3,5}

The choice to implement the Nursing Process in adolescents in palliative care was given, in view, that it constitutes a differentiated group, both in terms of social conditions, and in the aspect of the care necessary for their health and a state of well-being. It is considered fundamental that young people be better approached to identify the Nursing care that best meets their needs, seeking to improve their quality of life and, consequently, the individualization of care. Thus, this study may contribute to the knowledge of Nursing professionals caring for adolescents with cancer.

OBJECTIVE

- Operationalising the Nursing Process for adolescents in palliative care, based on Roy's Adaptation Model, using the NANDA (North American Nursing Diagnosis Association), Nursing Outcomes Classification (NOC) and Nursing Intervention Classification (NIC) -Nursing Interventions Classification).

METHOD

A qualitative study, in which the case study was adopted, as methodological strategy. It refers to a broad method that can be applied to a multiplicity of problems and can be used in multiple fields of research, in order to provide greater involvement and knowledge of the researcher with a real conjuncture observed.¹⁵ As a theoretical reference, Callista Roy's Model of Adaptation was used.⁸

The study scenario was the domicile of two adolescents with malignant neoplasms, one young male with relapsed Hodgkin's Lymphoma (HL) refractory to antineoplastic chemotherapy, diagnosed at 18 years of age, and a 16-year- with hypercalcemic small cell carcinoma of the right ovary. Home visits were performed from March 2016 to May 2017. These adolescents were intentionally chosen because they were in palliative care and registered in a philanthropic entity located in the city where they reside, profit organizations whose goal is to provide assistance to people with cancer, improving their quality of life and social inclusion.

Initially, a data collection script was developed, elaborated by the first author, based on Roy's Theory of Adaptation, divided into four adaptive modes. In the part related to the function mode of paper, data related to identification and to the social role were considered. In the interdependence mode, data regarding affective adequacy, solitude and interpersonal relationships. In the self-concept mode, the psychological, spiritual and self-physical aspects (self-image) were emphasized; and in the physiological mode aspects, related to neurological function, oxygenation, senses, nutrition, protection, bladder and intestinal elimination, activity and rest.

It should be emphasized that this instrument was evaluated by six Nursing judges to analyze the topics regarding relevance, clarity and applicability with experience. These professionals should have expertise in the subject and profiles that meet the following criteria: being a nurse, with proven performance in the Curriculum Lattes (database of the National Council for Scientific and Technological Development) in the field of oncology of at least five years

and publications with the referential of Callista Roy. The judges, were asked, to indicate suggestions of items and modifications that they considered pertinent.

At the first home visit (HV), the script was designed to evaluate focal, contextual and residual behaviors and stimuli. Nursing diagnoses were then established using NANDA.¹⁰ Afterwards, the goals and interventions were established in order to promote a better adaptive response among adolescents. In view of the objective of acting on the identified ineffective behaviors, results and interventions and Nursing were defined according to NOC11 and NIC.¹²

In other HV interventions were implemented and evaluated. A process of judgment was made on the responses of adolescents regarding the stimuli that generated these responses.

The Project was approved by the Ethics and Research Committee of the Federal University of São João del-Rei, according to CAAE: 1210915.5.0000.5545, opinion number: 1,409,673. The study participants accepted the invitation voluntarily by signing a Free and Informed Consent Term (FICT) and the teen signed the Informed Consent Form and the person responsible signed the Free and Informed Consent Form for Minors. To preserve their identity, they were identified with fictitious names.

RESULTS

The following data, will be presented regarding behavioral research, that is, the collection of responses or behaviors of the individual as an adaptive system in relation to each of the four adaptive modes: physiological mode, interdependence mode, social mode or self-concept mode.

The data were collected by script, based on CRAM, physical and medical examination of the charity where the adolescents were registered, as well as results of exams and reports that they found in their residence. This process led to the history of the young.

◆● Adolescent history with relapsed and refractory Hodgkin's lymphoma to anti-neoplastics in palliative care

Male, diagnosed at age 18, single, white skin color, complete elementary education, from Igaratinga, Minas Gerais, Brazil, referred to a High Complexity Care Unit (UNACON) due to enlarged lymph nodes in

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the cervical region, axillary and inguinal, painless, without local inflammatory signs, progressive increase for seven months, presented inappetence and weight loss of approximately ten kilos in seven months, in addition to excessive sweating and sporadic evening fever. Computed tomography (CT) of the thorax revealed a tumor in the anterior mediastinum, pulmonary nodule on the left, right hilar lymph node enlargement, and CT concluded cervical lymph node enlargement. Laboratory tests showed no abnormalities. Abdomen CT showed hepatomegaly and hepatic lymphadenopathy. Diagnosis of HL stage IVB due to the presence of disease in lymph nodes in different non-contiguous chains and involvement of extralymphatic organs (lung and liver). He underwent three cycles of MVC (metoclosetamine, vincristine, procarbazine, and prednisone) with ABVD (doxorubicin, bleomycin, vinblastine and dacarbazine) three cycles, associated with external mediastinal radiation therapy. I did all the protocol, I did not get a vacancy in a CACON or UNACON that did TCTH through the Unified Health System (UHS). The first HV was carried out in March/2016, the other RV in May/2016, July/2016, October/2016, February/2017, April/2017 and May/2017. He resided with his mother (from home), father (mason), and his 15-year-old sister, who has mental deficiency (accompanied by the mother on a Monday to Friday treatment), home with basic sanitation and six rooms. She said she was dating a neighbor two years ago. On the latter date, he was suffering from staged IV disease, used UHS for hospital admissions, communicative, depressed, bleached, emaciated, reported moderate to severe throbbing abdominal pain (from five to eight by the analogue pain scale) seven months ago, in addition to dyspnea at bedtime, sleeps about seven o'clock at night, but waking up several times. It makes use of strong opioids of schedule and for rescue. Body weight 25% below the ideal, however, presented an increase of three kilos between the first and last HV. The physical examination showed dyspnea on medium exertion, preserved bilateral thoracic expandability, diminished vesicular murmurs, without adventitious noises. Regular heart rhythm in two-times, normal heart sounds, without murmurs. Globose abdomen, painful to superficial and deep palpation, active intestinal sounds, referred

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to evacuate daily, hardened stools, unchanged diuresis. Preserved body and oral hygiene, with the frequency of a bath/day before bed. Respiratory rate: 14 ipm at 22 ipm; heart rate from 68 bpm to 74 bpm; blood pressure from 100 x 60 mmHg to 110 x 70 mmHg; temperature from 36.2 ° C to 37.8 ° C. In the penultimate DV, he said that being without treatment is difficult and his parents are very upset by the reserved prognosis. He reported lack of energy all the time, and said:

I'm looking for strength in spirituality, in the affection of my friends and my girlfriend, I do not want to bring more weight to my parents [...]] it's amazing how a hug and a friendly word can do for you [...]] I'm alive today, tomorrow I do not know, I am trying to understand a little more the meaning of life and love [...]]. I'm not going to the hospital to suffer anymore, I do not want to be accompanied by this kind of palliative. (Teen with HL).

In relation to finitude reported:

Death, there is a day that I am afraid to die (prolonged silence) other days I pray and I am calm [...]] very good to be speaking clearly to someone about my feelings about death and my desires and fears until the day comes, I feel alone many hours of the day. (Teen with HL).

◆◆ Adolescent history with right ovary small cell carcinoma in palliative care

A 16-year-old female, white skin color, from the city of Feira de Santana, Bahia, Brazil, finished elementary school, the youngest daughter of three siblings. She had diagnosis of mixed germ cell ovarian cancer and initially referred for treatment in a High Complexity of Oncology Center (Cacon). His family decided to move to a city near the capital of Minas Gerais due to relatives and place of residence in order to perform diagnostic confirmation and treatment. The initial complaint was abdominal volume increase (adnexal masses) and weight loss of more than five kilos in three months. As gynecological antecedents, menarche at 11 years, regular cycles, with moderate dysmenorrhea and without beginning of sexual life. No relevant personal or family history. Physical examination revealed a painless mass that was palpable up to the umbilical level. In abdominal ultrasound

there was a description of a massive mass of 16 cm. To clarify the origin, an abdomino-pelvic magnetic resonance was performed in which a large pelvic mass was measured median measuring 18 cm of longitudinal axis with a volume of 800 cc. This lesion was compatible with a primary lesion of the right ovary, with regular contours, a heterogeneous constitution, with a peripheral solid component, adenomegaly without pelvic region and ascites. Laboratory tests: Hemoglobin from 10.2 g/dl (October 2017) to 11.6 g/dL (May 2017), hematocrit from 28% to 33%, hypercalcemia from 15.5 mg/dL to 10.0 mg/dl (May 2017), and other laboratory tests within the parameters of normality, thus, tumor markers CA 125, CA19.9, CEA, AFP and HCG negative. She underwent an exploratory laparotomy with right adnexectomy in January 2016 and an examination that revealed a poorly differentiated malignant neoplasia. A fertility-preserving staging procedure was then performed, performing pelvic lymphadenectomy, multiple peritoneal and contralateral ovary biopsies, and cytology of the diaphragmatic domes. The histological and immunohistochemical findings revealed a hypercalcemic small cell carcinoma (HSCC) of the right ovary. The tumor had positive peritoneal and inguinal lymph nodes (tomography was performed), corresponding to a stage IIIC. After the multidisciplinary evaluation, adjuvant treatment with cisplatin and etoposide D1 to D5 was decided, due to factors of poor prognosis, age, pre-surgery hypercalcemia, tumor size and staging. Eleven months later, the adolescent was in a wheelchair, due to the loss of muscle turgor, transferred to bed with the mother's help, jaundice, distended abdomen, liver metastasis was diagnosed. He started a palliative antineoplastic regimen (Paclitaxel and Irinotecan D1 to D8), made four cycles, and interrupted treatment twice because of transfusion necessity and pulmonary infection. Finalized in April 2017; was hospitalized for 15 days, three times, from December to February, 2017. The first HV was performed in March/2016; the other RVs in May/2016, July/2016, November/2016, April/2017 and May/2017. It is noteworthy that in the third DV she was tearful and sad, she reported lack of energy all the time and said she was disgusted with life for not attending school in 2016 and knowing that she will not attend in 2017. In the last HV, in May/2017, was

staging IV, using the Unified Health System for hospital admissions. He resided with his mother, father, brother, and uncle at home in the masonry (by the employer of his uncle and his father), with basic sanitation and four rooms. In the examinations during the HV, it was verified that the adolescent was conscious, oriented, halo and heteropsiquicamente, and communicated little. Emagrecida, body weight 25% below ideal, presented increase of three kilos between the first and last HV. Skin and mucous membranes were dry and discolored. There was a decrease in skin dryness throughout the body from the third HV. He sleeps for about eight hours, waking up several times at night for bodily discomfort. Initially, the patient presented decreased fluid intake, decreased appetite, with poor dietary acceptance, globose abdomen, painful palpation with palpable masses, reported moderate to severe pain and abdominal pressure (five to ten times the analogue pain scale) reported for nine months. It makes use of strong opioids of schedule and for rescue. Preserved body and oral hygiene, with the frequency of a bath/day before bed. He reported medium fatigue, fatigue and fatigue when walking with the help of one of his relatives, with normal thoracic expansion, pulmonary auscultation with vesicular murmurs present without adventitious sounds and respiratory rate of 14 ipm at 18 ipm. Heart auscultation: normal rhythmic rhythmic sounds, pulse of 64 bpm at 72 bpm, preserved peripheral perfusion, blood pressure within normal parameters (120 x 70 mmHg at 130 x 70 mmHg). Spontaneous bladder elimination, with normal characteristic and frequency, daily intestinal elimination, active intestinal sounds. As for recreation and leisure, refers to watching television and not having friends:

You know, I feel alone for hours[[...]] I also miss talking to my friends, I do not have friends here, I came to the treatment [[[...]]]. (Teen With CPH Of Ovaries).

As far as finitude reported:

I see my mother suffering (sadness), for my mother it is much more difficult, she cries at night, thinks that I am sleeping [[[...]]] I can not talk to my family that I am tired and I want to leave, that I believe in God

and I have faith, but I know that my day is near. (Teen With CPH Of Ovaries).

◆● The Nursing Process and the Adaptation Model of Callista Roy

The PE can be observed according to the CRAM. The components of PE were behavioral and stimulus assessment, Nursing diagnoses, goal setting, interventions and evaluation. The center of Nursing care was the adolescents with malignant neoplasia in palliative care and their relatives, taking into account their beliefs, values and hopes.

The aspects that affected adolescents, called stimuli, caused an ineffective or adaptive response and represented the interaction of the adaptive system with the environment. Neoplastic malignant cells and metastases were the focal stimuli that confronted the young in the four adaptive modes, namely: physical changes, such as weight loss, abdominal pain, anemia, dyspnea on exertion, use of strong opioids and rescue which affected the physiological mode. Concurrently, these transformations

have brought with them feelings of hopelessness, fear and insecurity, which affects self-concept. The solitude manifested by both adolescents reaches interdependence and the role of role is impaired in the family. As an example, the deficit in communication and social issues, evidenced in the adolescent who reported missing the friends that are far, related to the absence of significant people.

Contextual stimuli are the signs and symptoms that can be assessed, observable and reported by the person, such as, in adolescents' age, reduction of oxygenation to tissues, lymphadenopathy. They exert influence over the effect of the focal stimulus. Residual stimuli, which include previous attitudes and experiences, were not detected in young people's reports.

Figure 1 shows the Nursing Process with the modalities of physiological adaptation, diagnoses, results and Nursing interventions for adolescents with malignant neoplasia in palliative care, based on CRAM, using NANDA, NOC and NIC.

Roy's Modes of Adaptation	Nursing Diagnostics (NANDA code)	Nursing Results (NOC code)	Nursing Interventions (NIC code)
Physiological mode: nutrition.	Unbalanced nutrition: less than bodily needs (00002), characterized by lack of interest in food, pale mucous membranes, abdominal pain and body weight 25% below ideal; related to biological factors.	Nutritional status (1004). Appetite (1014). Weight: body mass (1006).	Nutritional monitoring (1160). Diet planning (1020). Weight control (1260).
Physiological protection mode.	Ineffective protection (00043), characterized by dyspnea, fatigue, weakness and insomnia related to cancer and inadequate nutrition.	Energy Conservation (0002) Sleep (0004).	Power control (0180). Improvement of sleep (1850).
Physiological mode: protection.	Risk of falls (00155), related to anemia and the use of strong opioid.	Behavior of fall prevention (1910).	Fall prevention (6490).
Complex physiological mode: senses.	Chronic pain syndrome (00255), characterized by report of pain, fatigue, impaired sleep pattern, activity intolerance, related to advanced cancer.	Pain level (2102). Control of pain (1843). Level of discomfort (2109).	Pain control (1400). Music Therapy (4400). Administration of analgesics (2300).

Figure 1. Nursing process with Roy's physiological mode for adolescents with malignant neoplasia in palliative care. Minas Gerais, Brazil, 2017.

Figure 2, shows the Nursing Process with the modes of interdependence, social and self-concept, diagnoses, results and Nursing interventions for adolescents with malignant neoplasia in palliative care based on CRAM using NANDA, NOC and NIC.

Roy's Modes of Adaptation	Nursing Diagnostics (NANDA code)	Nursing Results (NOC code)	Nursing Interventions (NIC code)
Interdependence mode.	Provision for improved resilience (00212) characterized by expression of desire to improve the use of coping strategies and improve communication skills.	Personal resilience (1309). Confrontation (1302). Family resilience (2608)	Resilience promotion (8340). Improvement in coping (5230). Family support (5250).
Social mode.	Impaired social interaction * (00052), characterized by the report of missing friends that are far away, related to the absence of significant people.	Quality of life (2000). Communication (0902).	Art Therapy (5100). Active listening (4920).
Self-concept mode: Physical self.	Anxiety related to death (00147), characterized by impotence and concern about the impact of death itself on a significant person related to discussions about death and the perception of imminent death.	Anxiety level (1211). Personal well-being (2002). Resolution of regret (1302). End of life with dignity (1307)	Reduced Anxiety (5820). Assistance at death (5260). Visits for listening (5220). Presence (5340).

Figure 2. Nursing process with the modes of interdependence, social and self-concept in the light of Roy for adolescents with cancer in palliative care. Minas Gerais, Brazil, 2017.
*Only for adolescence with ovarian carcinoma

DISCUSSION

Chronic diseases, such as malignant neoplasms, have a strong influence on the functional capacity of adolescents. So, care must be directed to the implementation of interventions aimed at maintaining this functional capacity, since it has implications for the quality of life of these youngsters.^{2,4}

The young female had the diagnosis of small cell carcinoma of the ovary, hypercalcemic form. It is a rare, highly malignant cancer, with a reserved prognosis in which young women with this malignant neoplasm appear to have a more aggressive clinical course. All recently reported cases of this cancer in adolescents have shown a similar clinical course, with death within two years after diagnosis.¹⁶⁻⁷

The male adolescent was diagnosed with Hodgkin's lymphoma. It is a potentially curable malignant neoplasm and, in recent years, remarkable advances in diagnosis, staging and treatment have been observed. However, it is known that up to 10% of

patients will fail to achieve complete response, 18 as the case of the adolescent in this study. It is known that hematopoietic stem cell transplantation (HSCT - intravenous infusion of hematopoietic stem cells with the objective of restoring marrow function) is the gold standard therapy for those who did not respond after treatment, 19 however, the young man failed vacancy in a UHS transplant unit in Brazil.

According to the Center for International Blood and Marrow Transplant Research, approximately 13 thousand autologous TCTHs were performed, in the United States, in 2016.²⁰ In Brazil, data from the Brazilian Transplant Registry in 2016 showed that 2,187 TCTHs were performed (donor is a brother or family member), allogeneic not related (donor is not family) and autologous or autogenic (stem cells originate from the patient himself).²¹

Adolescents who are compelled to face the experience of a chronic disease, which coincides with the peculiar alterations of their development phase, leading to a

change from a healthy condition to the disease condition and, in the young of this study, the experience of the process of death and death, which brings with it from the uncertainty, the fear of the unknown to the resilience, and changes their designs and dreams.^{5,21} Palliative care is responsible for offering services that are appropriate for these young people and, thus, improves their quality of life and their families. However, the World Health Organization (WHO) and the World Wide Palliative Care Alliance in the year 2014 published a global Atlas to assess the provision of palliative care, which reported that only 14% of those in need are receiving palliative care around the world.²²

Thus, in order to implement PE for these adolescents in palliative care, the analysis and grouping of the signs and symptoms present during the evaluation and the clinical judgments made on the human responses, based on Roy's frame of reference, allowed the researchers to use well defined terminologies such as NANDA,¹² NOC¹³ and NIC¹⁴, to systematize Nursing care.

After grouping the clinical data, the human responses, raising the Nursing diagnoses, and establishing the results, together with the adolescents, was intended to be achieved. The care plan was developed and implemented during home visits and the researchers assessed whether the goals were being met or whether they needed to be modified by adjusting the diagnoses, outcomes and/or interventions as appropriate. Nursing interventions involved the manipulation of stimuli with the purpose of providing adaptive responses within home palliative care.

The modes of adaptation of Callista Roy committed were: physiological (nutrition, and protection), physiological complex (senses), self-concept (physical Self), interdependence and social.

◆● Physiological mode

The physiological mode is described in five basic physiological needs (oxygenation, nutrition, elimination, protection, activity and rest), besides four complex physiological needs (senses, neurological function, fluids and electrolytes and endocrine).

Nursing diagnoses, considered by the authors, in the care of adolescents, in the physiological way, were: unbalanced

nutrition, less than body needs (nutrition), ineffective protection, risk of falls and chronic pain syndrome (senses).

The diagnosis of unbalanced nutrition, less than body needs is defined as: insufficient intake of nutrients to meet metabolic needs.¹² In the present study, this diagnosis was evidenced by lack of interest in food, pale mucous, abdominal pain and body weight 25% below ideal; related to biological factors (malignant neoplasm in the advanced stage). The results of the NOC,¹³ established with adolescents and their families, were: appetite, nutritional status, swallowing status and body weight-to-weight ratio. The initial appetite score was two (very compromised) and the score was four (slightly compromised). Regarding the other results, the starting score was two (substantial deviation) and, as a target score, three (moderate deviation).

The interventions established with adolescents and their families to achieve the established results, were, weight control, diet planning and nutritional monitoring, through the following activities: adapting the diet to the adolescents' lifestyle; guide food intake according to preferences; stimulate creativity in the preparation of colored dishes in order to become more "appetizing"; keeping the meal environment fresh and airy.²³ It is emphasized that initially the ability of each family to meet the needs and ensure colorful food and preference for each young person was determined.

The diagnosis of ineffective protection is defined as: a state in which the person has a decreased ability to defend himself against external and internal threats, such as illness or injury.¹² It was characterized by dyspnoea, fatigue, weakness and insomnia related to malignant neoplasia and inadequate nutrition. The result of Nursing, energy conservation and sleep, was classified in four (very compromised) and the goal was established in two (slightly compromised). The activities performed to achieve the interventions, energy control and sleep improvement were discussed with the family, being established: assisting in stressful situations before bedtime; discuss comfort measures with the patient/family; monitor sleep and changes in lifestyle; teaching, to the patient, relaxation techniques; encourage a routine at night, facilitating the transition from alert to

sleep; observe physical circumstances - dyspnoea, obstructed airway, pain/discomfort; provide a quiet and safe environment.

The label risk of falls, which is thought to be an increased vulnerability to falls that can cause physical damage,¹² is related to anemia and the use of strong opioids. The established goal was to prevent falls, whose initial score was two (not adequate) and the target score was set at five (fully adequate). As an intervention, fall prevention was established, and as activities agreed with the adolescent and his family: installing a bedside lamp; removing the carpets from the circulation areas; installation of anti-slip tapes on mats; wear suitable footwear; keep a seat in the box if you decide to bathe yourself.

The diagnosis of chronic pain syndrome has been defined as: recurrent pain for more than three months and that significantly affects the activities of daily living and well-being.¹² It was characterized by reports of pain, fatigue, impaired sleep patterns, intolerance to advanced cancer-related activity. The Nursing result, pain level, was classified as intense and the goals were established, on an analogue scale of ten-point pain, between three and four in the movements and zero to two at rest. The interventions performed to achieve pain relief were discussed with the family, being established: the pain control, the administration of analgesics and the level of discomfort.

It should be emphasized that the activities listed for the diagnosis of chronic pain syndrome included the instruction of body positions and movements to avoid pain increase, including sleep counseling for adolescents on the principles of pain control, such as administration of painkillers before bathing, to ease the sensation of pain, stimulating the distraction through music of the young's preference. Thus, we obtained well-being, evidenced by the absence of pain after the analgesia and the musical hearing and the report of improvement in the sleep pattern.

Studies have clinically recognized the effects of music on biological responses, including: blood pressure, heart and respiratory rate, immune system, cardiac output, muscle tone, and endorphin production.²⁴⁻¹⁵ Music can have analgesic effect, decrease anxiety effects, pain,

tension and stress, allowing less use of anesthetics.²⁴

◆● Autoconcept Mode

The self-concept mode is circumspect of beliefs and feelings about oneself at a particular moment. Its components, are the physical self and the personal self. The physical self includes: bodily sensation (non-assertive behavior, sadness, feeling of death) and body image. The personal self is an individual assessment of one's own characteristics, expectations, values, and merits.⁸

The label of anxiety related to death has been raised that is conceptualized as the state in which the person presents concern or fear related to the process death and dying.¹² Characterized by impotence and concern about the impact of death itself on significant person related to discussions about death and perception of imminent death. The results listed were: personal well-being, whose starting scores were determined to be one (not at all satisfied), and the target scores were three (moderately satisfied). The initial scores for resolution of grief and end of life with dignity were two (little evidence) and the desired score, five (extensive evidence), and; for the established goal and achieved level of anxiety was moderate (3) to mild (4).¹³ To reach the goals, the researchers established the interventions: anxiety reduction, visits for listening, assistance in dying and presence.¹⁴

The activities developed were aimed at allowing the person and family members to share their perceptions about the situation; encourage the individual and family members to share their conflicts and concerns; explore the person/family relationship between spirituality; explore the interpretation of the individual/family about suffering; Encourage the reporting of life stories and reminiscences; attract reflective activities such as family prayers and meditation; encourage friends and family members to be emotionally and spiritually honest; explain the anticipated arrangements and assist in the death process, if desired; allow them to express feelings about the meaning of death; recognize your struggle.^{3-4,14}

◆● Interdependence mode

The mode of interdependence focuses on interactions related to giving and receiving affect, respect, and value.⁸ The provision

for improved resilience, has been diagnosed as the standard of positive responses to a situation or adverse crisis that is sufficient to optimize human potential and may be reinforced.¹² In this study, expression of desire to improve the use of coping strategies and improve communication skills. The selected results were: personal and family resilience and coping, whose starting scores were determined as three (sometimes shown), and the target scores remained at five (consistently demonstrated).¹³

To reach out, the researchers established interventions: promoting resilience, improving coping and family support, and establishing established activities: keeping prayers and prayers; sit a little in front of the residence; take the young person to take some of the morning sun or late afternoon; establish assertive and sincere communication; to help the family to face the disease and the finitude of its relative; provide support to help the family face the moment of death; avoiding pathological mourning; to guide families in relation to adolescent care; adapt the routine of all to the situation acquired; promote sharing of feelings; helping young people find relief from suffering.^{15,26} It is noted that the adolescents and their respective mother received an emergency hotline where they could call two nurses at any time of distress.

Studies indicate that death, is almost always repelled by parents. However, this moment is one of the most critical.^{7,21} In this study, it was verified that the possibility of finitude and the development of a consciousness of death came to exist in a real way in the thoughts. Consequently, the need for support and support was a constant.

◆● Social mode

The social mode is the set of expectations about how an individual plays a role in society.⁸⁻⁹ The diagnosis of impaired social interaction (only for adolescence ovarian carcinoma), which is insufficient or excessive or ineffective, of social exchange characterized by inability to receive a satisfactory sense of social involvement related to the absence of significant people.¹² It was characterized by the report of missing friends who are far away related to the absence of significant people.

The goals established were: quality of life and communication with an initial score of one (severely compromised) and a target score of three (moderately compromised).¹³ The interventions to achieve the results were: art therapy and active listening,¹⁴ as well as activities. They were: performing art therapy exercises to deal with emotions; evidence perception and sensitivity to emotions; being attentive to the physical posture that transmits non-verbal messages; listening to unspoken messages and feelings; determining the meaning of the message, reflecting on attitudes, past experiences and current experience; to be attentive to the tone, the time, the volume, the height and the inflection of the voice; identify prevailing issues; give answers in a timely manner, so as to reflect understanding of the message received; avoid barriers by listening carefully (offering easy solutions, minimizing feelings, interrupting, talking about oneself, and terminating prematurely).^{21,26}

Most of the time, illness, even being a fact, only acquires the condition of fact by the way it is apprehended by the conscience. It is in the consciousness that certain prognostic diagnoses and overpowering gain meaning of irreversibility, of transformation.²¹ The adolescent has difficulties to understand the dimension that is passing,^{3,27} may not accept the illness, manifestations of the disease and refusal to follow up palliative care in an institution, as happened with the adolescent with HL of this study.

Achieving the complete well-being that every human being craves is certainly impossible, because he experiences different demands during development, which also lead to stress, but with palliative care at home can ease the suffering and favor the resilience.²⁷

◆● Evaluation

At this stage, the behavioral goals were compared with the person's exit responses, and the movement towards the goals was verified. The readaptation to the targets and the interventions made on the basis of the evaluation data.

When a trial of the adolescents' responses was carried out, after the implementation of the Nursing interventions, as observed, during the HVs, and, as the interventions were implemented and evaluated, the

adolescents showed improvement in the stimuli, which goals of an improvement of the appetite, conservation of energy, absence of pain at rest. They began to pray in the family and talk openly about finitude, increasing the resilience of the adolescents and their families. In this way, there was the manifestation of behaviors that demonstrated the possible adaptation for each person. It can be concluded that the established goals were achieved, demonstrating the importance of palliative care in the context of the domicile.

CONCLUSION

Nursing care, in the light of Roy's theory facilitated dialogue with adolescents and their families in achieving goals and behavioral changes through the implementation of interventions. Gradually, young people and family members have progressed satisfactorily.

It can also be verified that, the care implemented with the NP allowed the researchers to act in a directed way to the adolescent's adaptive problems in palliative care, through clinical judgment in the quest to better promote the tranquility and resilience so necessary in this process.

Despite being in agreement with the criteria stipulated in the method, one of the limitations of the study was to be performed with two adolescents with malignant neoplasia in palliative care, not allowing generalization. However, this limitation does not invalidate the study and respond satisfactorily, to the research proposal. The results stimulate the continuity of this type of study with cases not described in the literature, because, in this way, it will provide a continuous care, reduce the suffering in this vulnerable population as adolescents.

REFERENCES

- Oliveira PP de, Santos KL, Silva FL, Dias ACQ, Silveira EAA da, Guimarães EAA. Evaluation and intervention in the family of adolescents with sickle cell disease. *J Nurs UFPE on line* [Internet]. 2017 Apr [cited 2017 Apr 30];11(4):1552-64. Available from: <http://www.revista.ufpe.br/revistaenfermagem/index.php/revista/article/view/10732>
- Kristanti MS, Setiyarini S, Effendy C. Enhancing the quality of life for palliative care cancer patients in Indonesia through family caregivers: a pilot study of basic skills training. *BMC Palliative Care* [Internet]. 2017 Jan [cited 2017 Apr 16];16(1):4. Available from: <https://www.ncbi.nlm.nih.gov/pmc/article/PMC5240385/>
- Day E, Jones L, Langner R, Bluebond-Langner M. Current understanding of decision-making in adolescents with cancer: A narrative systematic review. *Palliat Med* [Internet]. 2016 Dec [cited 2017 Apr 25];30(10):920-34. Available from: <https://www.ncbi.nlm.nih.gov/pmc/article/PMC5117127/>
- Zebrack BJ, Corbett V, Embry L, Aguilar C, Meeske KA, Hayes-Lattin B, et al. Psychological distress and unsatisfied need for psychosocial support in adolescent and young adult cancer patients during the first year following diagnosis. *Psychooncology* [Internet]. 2014 Mar [cited 2017 Apr 28];23(11):1267-75. Available from: <http://hdl.handle.net/2027.42/109318>
- Clark JK, Fasciano K. Young adult palliative care: challenges and opportunities. *Am J Hosp Palliat Care* [Internet]. 2015 Feb [cited 2017 Apr 28];32(1):101-11. Available from: <http://journals.sagepub.com/doi/pdf/10.1177/1049909113510394>
- Sansom-Daly UM, Wakefield CE, Bryant RA, Butow P, Sawyer S, Patterson P, et al. Online group-based cognitive-behavioural therapy for adolescents and young adults after cancer treatment: a multicenter randomised controlled trial of Recapture Life-AYA. *BMC Cancer* [Internet]. 2012 Aug [cited 2017 Apr 29];12:339. Available from: <https://www.ncbi.nlm.nih.gov/pmc/article/PMC3503656/>
- Misko MD, Santos MR, Ichikawa CRF, Lima RAG, Bousso RS. The family's experience of the child and/or teenager in palliative care: fluctuating between hope and hopelessness in a world changed by losses. *Rev Latino-Am Enfermagem* [Internet]. 2015 June [cited 2017 Apr 30];23(3):560-7. Available from: http://www.scielo.br/pdf/rlae/v23n3/pt_0104-1169-rlae-23-03-00560.pdf
- Roy C, Andrews HA. *The Roy Adaptation Model*. 3rd ed. Upper Saddle River, New Jersey: Pearson; 2009.
- Pereira CFD, Tourinho FSV, Miranda FAN, Medeiros SM. Ensino do processo de enfermagem: análise contextual. *J Nurs UFPE on line* [Internet]. 2014 [cited 2017 Mar 15];8(3):757-64. Available from:

<http://www.revista.ufpe.br/revistaenfermagem/index.php/revista/article/view/5473>

10. Heardman TH, Kamitsuru S, editors. NANDA International Nursing Diagnoses: Definitions & Classification, 2015-2017. Oxford: Wiley Blackwell; 2014.

11. Moorhead S, Johnson M, Maas M, Swanson E. Classificação dos Resultados e Enfermagem (NOC). 5th ed. Rio de Janeiro: Elsevier; 2016.

12. Bulechek G, Butcher H, Dochterman J, Wagner C. Classificação das Intervenções de Enfermagem (NIC). 6th ed. Rio de Janeiro: Elsevier; 2016.

13. Bastos R, Fernandes M, Soares M, Costa M, Sousa F, Almeida F. Physiological adaptation of elderly in hemodialysis treatment: an analysis in the light of the Roy Model. J Nurs UFPE on line [Internet]. 2014 Jan [cited 2017 Jan 12];8(4):834-41. Available from:

<http://www.revista.ufpe.br/revistaenfermagem/index.php/revista/article/view/4743>

14. Campiño-Valderrama SM, Duque PA. Afrontamiento y adaptación de cuidadores de niños y niñas com cáncer. Rev Univ Salud [Internet]. 2016 May/Aug [cited 2017 Jan 11]; 18(2):302-11. Available from: <http://www.scielo.org.co/pdf/reus/v18n2/v18n2a11.pdf>

15. Yin RK. Estudo de caso: planejamento e métodos. 5th ed. Porto Alegre: Bookman; 2015.

16. Kascak P, Zamecnik M, Bystricky B. Small cell carcinoma of the ovary (hypercalcemic type): malignant rhabdoid tumor. Case Reports in Oncology [Internet]. 2016 [cited 2017 Apr 12];9(2):305-11. Available from: <https://www.ncbi.nlm.nih.gov/pmc/article/s/PMC4939673/>

17. Witkowski L, Goudie C, Foulkes WD, McCluggage WG. Small-cell carcinoma of the ovary of hypercalcemic type (malignant rhabdoid tumor of the ovary): A Review with Recent Developments on Pathogenesis. Surg Pathol Clin [Internet]. 2016 June [cited 2017 May 12];9(2):215-26. Available from: <https://link.springer.com/article/10.1007%2Fs10689-016-9957-6>

18. Passweg JR, Baldomero H, Bader P, Bonini C, Cesaro S, Dreger P, et al. Hematopoietic stem cell transplantation in Europe 2014: more than 40 000 transplants annually. Bone Marrow Transplant [Internet]. 2016 June [cited 2017 Apr

11];51(6):786-92. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4895175/>

19. Araujo DD, Rodrigues AB, Oliveira PP de, Silva LS, Vecchia BP, Silveira EAA. Nursing diagnoses and interventions for patients with graft-versus-host disease submitted to hematopoietic stem cell transplantation. Cogitare Enferm [Internet]. 2015 Abr/June [cited 2017 Apr 09];20(2):305-13. Available from: <http://dx.doi.org/10.1155/2015/710543>

20. D'Souza A, Zhu X. Current uses and outcomes of hematopoietic cell transplantation (HCT): CIBMTR Summary Slides [Internet]. 2016 [cited 2017 Apr 15]. Available from: <http://www.cibmtr.org>

21. Associação Brasileira de Transplante de Órgãos (BR). Dimensionamento dos transplantes no Brasil e em cada estado (2009-2019). Registro Brasileiro de Transplantes [Internet]. São Paulo; ABTO; 2016 [cited 2017 May 10]. Available from: <http://www.abto.org.br/abtov03/Upload/file/RBT/2016/RBT2016-leitura.pdf>

22. Yeager A, LaVigne AW, Rajvanshi A, Mahato B, Mohan R, Sharma R, et al. Can Support: a model for home-based palliative care delivery in India. Ann Palliat Med [Internet]. 2016 July [cited 2017 May 11]; 5(3):166-71. Available from: <http://apm.amegroups.com/article/view/11024/11568>

23. Worldwide Palliative Care Alliance. Global Atlas of Palliative Care at the End of Life. Geneva: WHO, 2014 [cited 2017 May 10]. Available from: <http://www.who.int/nmh/GlobalAtlasofPalliativeCare.pdf>

24. Dias VCC, Andrade SQ de, Santos CF, Oliveira PP, Rodrigues AB. Cuidado ao idoso com duas neoplasias primárias e metástases fundamentado na Teoria de Callista Roy. J Nurs UFPE on line [Internet]. 2015 June [cited 2017 May 10];9(6):8285-94. Available from: http://www.revista.ufpe.br/revistaenfermagem/index.php/revista/article/view/7648/pdf_8025

24. Firmeza MA, Rodrigues AB, Melo GAA, Aguiar MIF, Cunha GH, Oliveira PP, et al. Control of anxiety through music in a head and neck outpatient clinic: a randomized clinical trial. Rev Esc Enferm USP [Internet]. 2017 Mar [cited 2017 May 12];51:e03201. Available from:

<http://www.scielo.br/pdf/reeusp/v51/1980-220X-reeusp-51-e03201.pdf>

25. Pichler A, Pichler M. Music therapy in cancer patients: fact or fiction?. *Future Oncol* [Internet]. 2014 [cited 2016 Mar 25];10(15):2409-411. Available from: <http://www.futuremedicine.com/doi/full/10.2217/fon.14.181>

26. Hermes HR, Lamarca ICA. Cuidados Paliativos: uma abordagem a partir das categorias profissionais de saúde. *Ciênc saúde coletiva* [Internet]. 2013 [cited 2016 Mar 30];18(9): 2577-88. Available from: <http://www.scielo.br/pdf/csc/v18n9/v18n9a12.pdf>

27. Donovan KA, Knight D, Quinn GP. Palliative care in adolescents and young adults with cancer. *Cancer Control* [Internet]. 2015 Oct [cited 2017 Apr 27];22(4):475-9. Available from: <https://moffitt.org/media/4652/475.pdf>

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Corresponding Address

Patrícia Peres de Oliveira
Universidade Federal de São João del-Rei -
UFSJ
Rua Sebastião Gonçalves Coelho, 400
Bairro Chanadour
CEP: 35501-296 – Divinópolis (MG), Brazil