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CASE REPORT ARTICLE

ROLE OF THE NURSE IN RELATION TO OSTEOSARCOMA PATIENTS AND THEIR FAMILY

PAPEL DO ENFERMEIRO JUNTO AOS PACIENTES COM OSTEOSSARCOMA E FAMILIARES PAPEL DEL ENFERMERO JUNTO A LOS PACIENTES CON OSTEOSARCOMA Y FAMILIARES

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ABSTRACT

Objective: to identify the role of nurses in the health education process among osteosarcoma and family patients. **Method:** this is a qualitative, descriptive study, case report, with the empirical incursion next to the routine of the nurses of the National Cancer Institute (NCI). Twenty nurses are considered to be directly related to the care routine of patients with osteosarcoma. A questionnaire with 11 objective inquiries was used as instrument of data collection. **Results:** it is necessary to offer the understanding of reality in the practice of health education in the routine of NCI nurses. **Conclusion:** it is concluded that, among the NCI nurses and the patients and their families, there is a real practice of health education, precisely when it is established the transmission of knowledge and the improvement in the quality of life of the young people assisted with osteosarcoma. **Descriptors:** Osteosarcoma; Health education; Nursing; Adolescent; Neoplasia; Nurse.

RESUMO

Objetivo: identificar o papel dos enfermeiros no processo de educação em saúde junto aos pacientes com osteossarcoma e familiares. **Método:** trata-se de estudo qualitativo, descritivo, relato de caso, com a incursão empírica junto à rotina dos enfermeiros do Instituto Nacional do Câncer (INCA). Consideram-se que participaram 20 enfermeiros que possuem relação direta com a rotina de cuidados dos pacientes com osteossarcoma. Usou-se como instrumento de coleta de dados um questionário com 11 indagações objetivas. **Resultados:** ressalta-se que é necessário oferecer o entendimento da realidade na prática da educação em saúde na rotina dos enfermeiros do INCA. **Conclusão:** conclui-se que, entre os enfermeiros do INCA e os enfermos e seus familiares há a verdadeira prática da educação em saúde justamente quando se estabelece a transmissão de conhecimentos e a melhora na qualidade de vida dos jovens assistidos com osteossarcoma. **Descritores:** Osteossarcoma; Educação em Saúde; Enfermagem; Adolescente; Neoplasia; Enfermeiro.

RESUMEN

Objetivo: identificar el papel de los enfermeros en el proceso de educación en salud junto a los pacientes con osteosarcoma y familiares. **Método:** se trata de un estudio cualitativo, descriptivo, relato de caso, con la incursión empírica junto a la rutina de los enfermeros del Instituto Nacional del Cáncer (INCA). Se considera que participaron 20 enfermeros que tienen relación directa con la rutina de atención de los pacientes con osteosarcoma. Se utilizó como instrumento de recolección de datos un cuestionario con 11 indagaciones objetivas. **Resultados:** se resalta que es necesario ofrecer el entendimiento de la realidad en la práctica de la educación en salud en la rutina de los enfermeros del INCA. **Conclusión:** se concluye que entre los enfermeros del INCA y los enfermos y sus familiares hay la verdadera práctica de la educación en salud justamente cuando se establece la transmisión de conocimientos y la mejora en la calidad de vida de los jóvenes asistidos con osteosarcoma. **Descriptor:** Osteosarcome; Educación en Salud; Nursing; Adolescente; Neoplasia; Enfermero.

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INTRODUCTION

It is believed that health education has different aspects of action, with preventive and curative approaches or those for coping with diseases.¹⁻² It is observed that in the case of the confrontation of diseases, the thematic focus of the article, the goal is to offer well-being to the patient by accommodating them in the best way to their illness and providing them with quality of life in their health-disease process. It is seen that when it comes to dealing with diseases, there is usually a reference to Non-communicable Diseases (NCD) encompassing diseases such as: heart attacks, cancers, stroke, diabetes and respiratory diseases.¹⁻³

It is observed that in addition to the characteristic of not being transmissible, such diseases are also characterized by the long-term incidence in their involvement and, therefore, chronic. According to the Non-communicable Diseases Country Profiles study, published in 2014 and prepared by the World Health Organization (WHO), 975,320 (74%) of the total of 1,318,000 deaths per year are related to NCDs. It is observed that, among deaths related to NCD, cancer is the second disease to cause more deaths appearing after cardiovascular diseases.³

This study is, for research purposes, a carcinogenic NCD, in the case of osteosarcoma, a disease seen as a primary malignant bone tumor that is more frequent in children, adolescents and young adults. It is considered that the peak incidence of the disease occurs in the second decade of life representing approximately 5% of the malignant diseases of the child and the adolescent.⁴ It is noted that these tumors preferentially affect the appendicular skeleton; in 75% of cases, the predominance occurs through the metaphysis of the long bones adjacent to the epiphyseal plate, with a predilection for the end of the distal femur. It is seen about the cause of the disease, there are no direct specifications in addition to family genetic tendencies.⁵ It is estimated to occur in 8.7 cases/million followed by Ewing's sarcoma, with 2.9 cases/million.⁶ It is observed that some of the initial symptoms of the disease are: previous trauma in the region affected by the neoplasia; pain in the area; local volume increase; pathological fracture; fatigue and night pain and limitation of movement. The time between the initial symptoms is determined and the diagnosis can be up to five months.⁷

It can be stated that the prognosis of patients with osteosarcoma depends on the

size of the tumor, the surgical margins achieved in the procedures and the presence of pulmonary metastases.⁴ Survival is up to 70% in five years, this is for non-metastatic patients, with overall survival being up to 80%. It is observed that when there are relapses, this survival reaches 20% in a year, and can reach 40% in five years, when it is possible the complete resection of pulmonary metastasis.^{4,8}

During the last two decades, there have been significant advances in the quality of orthopedic prostheses and in the increasingly frequent use of conservative surgeries. It was seen that these advances represented an important contribution to the quality of life of these patients. It is emphasized that although the disease still has a very important stigma of death, the information and observation of the emotional domains are of vital significance⁴, and, in addition, there is a risk of relapses of the disease making the patient remain apprehensive for the possibility back for at least five years of their life.^{4,8}

OBJECTIVE

- To identify the role of nurses in the health education process among patients with osteosarcoma and family members.

METHOD

This is a qualitative, descriptive study, case report, with the empirical incursion next to the routine of the nurses of the National Cancer Institute (NCI). It was reported how nurses use speech as a practice of health education among patients and their families. The National Cancer Institute (NCI) was considered as the scenario of the study, more specifically NCI II.¹⁹

It is the NCI of the center of reference in the treatment of cancer in Brazil, with its history started in 1937, currently counting with five units in the city of Rio de Janeiro.²⁰

It is considered the NCI advisory body to the Ministry of Health, has 413 beds in its hospital units for UHS users including those of hospital admission, intensive care and prompt care.²¹ The study subjects were chosen by the NCI II nurses who had the following routine:

- ♦ To plan, organize, supervise, perform and evaluate all nursing activities in clients submitted to anti-neoplastic chemotherapy treatment, categorizing it as a highly complex service based on Nursing care methodology;
- ♦ To elaborate therapeutic protocols of Nursing in the prevention, treatment and minimization of the side effects in clients submitted to the treatment;

- ◆ Conduct consultation based on the Nursing process directed at clients in anti-neoplastic chemotherapy treatment;
- ◆ To provide full assistance to clients and their families based on the Code of Ethics of Nursing Professionals and current legislation;
- ◆ To administer anti-neoplastic chemotherapy according to the pharmacokinetics of the drug and the therapeutic protocol;
- ◆ Promote and disseminate risk and injury prevention measures, through the education of clients and families, aiming to improve the patient's quality of life;
- ◆ Participate in quality assurance programs in service of anti-neoplastic chemotherapy in a sectoral and global way;
- ◆ To provide conditions for the improvement of nursing professionals working in the area through courses and internships in related institutions;
- ◆ To participate in the elaboration of programs of internship, training and development of Nursing professionals in the different levels of training related to the area of performance;
- ◆ To participate in the definition of the human resources policy, the acquisition of material and the provision of the physical area necessary for integral client care;
- ◆ Comply and enforce the norms, regulations and laws pertinent to the areas of operation;
- ◆ Establish technical-scientific relations with related units by developing investigative and research studies;
- ◆ Promote and participate in the integration of the multi-professional team seeking to guarantee integral assistance to the client and family;
- ◆ Record information and statistical data relevant to Nursing care highlighting performance and quality indicators and interpreting and optimizing their use;
- ◆ Formulate and implement operational technical manuals for the Nursing team in the various sectors of activity;
- ◆ Formulate and implement educational manuals for clients and their families, adapting them to their social reality;
- ◆ To maintain the technical and scientific updating of individual, collective and environmental biosafety that allows for effective professional action in routines and emergency situations in order to interrupt and/or avoid accidents or occurrences that may cause physical and/or environmental damage.

English/Portuguese

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Based on the routine of the NCI II nurses, the study was conducted in October 2017, when there was an incursion with the hospital professionals. The study consisted of a sample composed by 20 nurses, the data collection instrument being a questionnaire with 11 objective inquiries. The Ethical Approach was adopted with the participants of the sample using the Free and Informed Consent Term (FICT), with the approval of Resolution 510, of 2016.²² The limitation of the study in regionalization was found, being a reference for the city of Rio de Janeiro and not a national survey.

HEALTH EDUCATION

Health education is understood as the promotion and preservation of the well-being of individuals. It is considered a blessing in the health sector with increasing appreciation over time, because in the context of health, there is the understanding that education is an instrument of social transformation to stimulate the acceptance of new values with society.⁹ Health can be understood as a compendium of knowledges, as a symbolic product, that can be passed on to society or individuals of a particular group through education^{1,9} and transmitted in the form of a message, which must be strategically planned for due assimilation. Thus, one arrives at the Transmitter-Receiver model, considered as a unilinear model, and placed as Lasswell's paradigm, exemplified in synoptic representation:¹⁰⁻¹

Health communication should be promoted, based on scientific knowledge and ethical precepts, allowing one to explore the logical reasoning for the attainment of the art of retention, the art of thinking and the art of communicating information. It can be used to practice the art of communicating: grammar as a tool of discourse; rhetoric as a quality of discourse; criticism as literary messages; pedagogy with ways of teaching and philology.^{1,9-11}

Thus, through the discourse, communication practice is allowed in the context of health education, establishing a link between the sender and receiver of knowledge. Discourse is understood¹² as an event of communication with historical roots, being an element for the dissemination of ideas and/or knowledge. It is the transformation obtained with the discourse of finite, limited, desirable and useful good.¹² It is seen that the practice of discourse requires its mediation which, when used for the purpose of offering knowledge in education, can occur through pedagogical praxis,

including in it the dialogical model, a literary antagonist of reality. It can be said that speech has the characteristic of encompassing simplicity of expression and dialogue in the promotion of learning, providing greater freedom for the emission and absorption of knowledge. Thus, discourse transmission can embrace the alternative (or popular) pathway involving horizontal format participations in a group of individuals and influencing the social context of it. It is verified that in such conjuncture, there is the valorization of the web of relations linked to the group, being a route of propagation of the discourse. It is possible through the educational process, through the alternative way, the dialogue between individuals potentiating the discourse as mediator of the emission and reception of the message of knowledge. Thus, informal discourse is accommodated in discourse, which, in turn, establishes itself as a solution in coping with and overcoming problems, such as an oncological disease such as osteosarcoma.¹³

It is understood in the treatment of the osteosarcoma, the orthopedic oncologic surgery (resection), in conjunction with the use of chemotherapy (adjuvant), is a way to avoid amputation of the patient's limb, an action taken as a last resort, since the use of osteosarcoma radiotherapy is ineffective in combating the disease. It is the early diagnosis factor to attenuate the severity of the treatment. Because it is a disease with great potential for recurrence, the patient, even after a successful treatment of osteosarcoma, should maintain continuous monitoring of health changes at periodic visits, ^{4,8} therefore, it can be established that patients with metastatic osteosarcoma and recurrent patients constitute a large group, which can

be subdivided by means of differentiation of characteristics, such as: those with the potential to cure by chemotherapy, surgery or long interval of relapse and those with rapid evolution to death.¹⁴ At this juncture, the nurse is a piece of support regardless of the treatment chosen, including, above all, their role of educator through discourse.¹⁵

It is the discourse of nurses, in their working environment, together with patients with osteosarcoma, of an informal way of dialogue allowing the practice of health education, especially with family members, due to the patient's age.¹⁶ It should be emphasized that when providing care, nurses are close to both the patients and their families, being a kind of continuous connection with the treatment. They are allowed to have such proximity to act as a transmitter of messages about the disease and its coping, such as: daily care; an explanation of the collection effects of chemotherapy and their identification; guidelines on how to cope with lack of appetite; to highlight the benefit of using orthopedic prostheses and to emphasize the importance of maintaining medical follow-up (even after successful treatment) due to the possibility of recurrence.^{1,9-11,15,17-8}

RESULTS

The presentation of the results was divided into two stages, namely the first one regarding the profile of nurses and the second with reference to the process of health education in the routine of nurses. Tables 1, 2, 3 and 4 present the variables referring to the profile of the nurses in the sample.

Table 1. Age of the sample nurses. Rio de Janeiro (RJ), Brazil, 2017.

Age	N	%
22-25	0	-
26-31	7	35%
32-35	11	55%
Over 35	2	10%
Total	20	100%

Table 2. Sex of the sample nurses. Rio de Janeiro (RJ), Brazil, 2017.

Sex	n	%
Male	6	30%
Female	14	70%
Total	20	100%

Table 3. Nursing graduation mode of the sample. Rio de Janeiro (RJ), Brazil, 2017.

Type	N	%
Specialist in oncology	11	55%
Master	7	35%
Doctorate	2	10%
Total	20	100%

Table 4. Time of operation at NCI. Rio de Janeiro (RJ), Brazil, 2017.

Type	n	%
2-3 years	5	25%
4-5 years	12	60%
More than 6 years	3	15%
Total	20	100%

It is observed in the profile of the majority of the nurses in the sample was found to be 32-35 years old, female, with specialty in Oncology Nursing and working in NCI for four and five years. However, there are interesting points related to the sample profile: even in the minority, there are male nurses; all the nurses in the sample have education above

the upper level, and all the nurses in the sample have worked at NCI for more than two years.

The positions are highlighted, regarding the health education process in the nurses' routine of the sample, in Tables 5, 6, 7, 8, 9, 10 and 11.

Table 5. Dialogue time. Rio de Janeiro (RJ), Brazil, 2017.

In their routine with patients with osteosarcoma and their families, what is the average time spent with the dialogues?	n	%
Less than 10 minutes	1	5%
Between 11 and 15 minutes	14	70%
Over 16 minutes	5	25%
Total	20	100%

Table 6. Level and knowledge about osteosarcoma. Rio de Janeiro (RJ), Brazil, 2017.

When you give information about osteosarcoma to family members, you realize that most:	n	%
Had no knowledge of the disease	3	15%
Had some knowledge about the disease	16	80%
Had full knowledge of the disease	1	5%
Total	20	100%

Table 7. Capture of information about osteosarcoma by family members. Rio de Janeiro (RJ), Brazil, 2017.

In your experience at NCI II, do you notice that the relatives of the sick young people capture the information offered about the pathology and its treatment?	n	%
Yes, they learn from them and improve the patient's quality of life	16	80%
More or less, because they have difficulty understanding, little improving the quality of life of the patient	3	15%
There is no understanding of them, being indifferent to the improvement in the patient's quality of life	1	5%
Total	20	100%

Table 8. Information with the greatest effect on patients' daily

lives. Rio de Janeiro (RJ), Brazil, 2017.

Based on your experience, among the information below, which has a greater effect on the daily transformation of the patients?	n	%
Attention to food care	0	-
Care of side effects of chemotherapy	12	60%
Periodicity in the medical follow-up for recurrences	8	40%
Total	20	100%

Table 9. Election of receivers and way of transmitting information. Rio de Janeiro (RJ), Brazil, 2017.

When you pass on knowledge about disease and treatment, how do you do it?	n	%
Communicate with family members only, away from the patient	3	15%
Communicates with family members and patients separately	7	35%
Communicates with family and patients together	10	50%
Total	20	100%

Table 10. Ease of communication and transmission of information. Rio de Janeiro (RJ), Brazil, 2017.

It is easier to communicate and transmit information about the disease and treatment:	N	%
With family members	16	80%
With the young (patients)	4	20%
Total	20	100%

Table 11. Facility to receive and assimilate information. Rio de Janeiro (RJ), Brazil, 2017.

Who is easier to receive and assimilate information about the disease and the treatment?	n	%
The family members	10	50%
The young (patients)	10	50%
Total	20	100%

The results show some of the major positions in the health education process in the routine of the sample nurses, such as: 70% of the sample emphasized spending between 11 and 15 minutes dialoguing with patients and their families; 80% of the sample realized that there is some knowledge about the disease by the relatives; 80% of the sample understands that the information offered in dialogues with family members is assimilated by assessing the quality of life of the patient; 60% of the sample emphasize that information on care with the side effects of chemotherapy is the most assimilated; 50% of the sample prefer to talk with their families and patients together to communicate information about the disease and 80% of the sample find it easier to communicate and provide information about the disease to family members. The sample still showed a curiosity, since the result of one of the issues is a tie in the case of non-precision in defining who better assimilates the information about the

disease and treatment and the relatives and young people are sick at the same level.

DISCUSSION

According to the empirical incursion, it is assumed that NCI counts on graduated nursing professionals, all established through LGB and NCG. In addition, it was verified that the majority of the professionals possessed specialization, being also those with Masters and PhD.²³⁻⁴ Another important factor in the research was the time taken by the professionals of the sample in NCI, all of them older than two years, giving a margin of safety to their opinions on the subject at hand, that is, health education within the scope of the osteosarcoma, considering that the nurse is a health agent with routine close to the young patients and their relatives, therefore, being able to be the agent that gives them knowledge about the disease for the same ones.^{1,9-11,15} Nurses are considered to be conducive to the practice of speech, which is

a link between the sender of the message and its receptor, a communicational instrument relevant to coping with oncological diseases,¹³ see most nurses in the sample spend 11 to 15 minutes in dialogues with the sick and their families.

It is understood that osteosarcoma is not so unknown, since only 15% of the sample considered a total lack of knowledge on the part of the relatives, 85% of the sample emphasized that there is total or partial knowledge of the relatives about the disease, different positioning of the topic of unknown disease by relatives.¹⁷

It can be seen that health education is an instrument of social transformation by the acceptance of new values, as seen in the research⁹, in which 80% of the sample considered that the relatives of the sick young people capture the information offered about the disease, improving the quality of life of the patients corroborating, thus, the verification of the efficiency of the practice of the discourse in the relation emissary-receptor in the communication in health in unilinear model, according to basements.^{1,10-2} This situation was checked in the research by the positive influence of the offered information about the care with the side effects of the chemotherapy and with the need of periodicity in the medical follow-up in case of relapses; the ease of the sample nurses to communicate about the disease with the patients and their relatives was also investigated, where informal communication establishes the communication solution in health for the confrontation in the health-disease process of osteosarcoma.^{13,16-8}

CONCLUSION

It is attentive, through the study undertaken, to the best way for nurses to play their role in the context of health education, that is, to ally the practice of discourse in their routine of patient care. It can be understood that, based on the proximity of nurses to patients and their families, the discourse in the informal format of dialogue may be the link between the sender of the message about the osteosarcoma and its receptor.

It was found that in this study, such a unilinear communicational approach in the routine of the NCI nurses, who take advantage of this moment to offer the knowledge about osteosarcoma to the patients and their relatives and advise the improvement of patients' quality of life. This study is based on the importance of the role of dialogue in the involvement of nurses in the health education

process among patients with osteosarcoma and their families.

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