REPORT

THERAPEUTIC STUDY OF TEENS WITH OSTEOSARCOMA: IMPLICATIONS FOR EARLY DIAGNOSIS

ITINERÁRIO TERAPÊUTICO DE ADOLESCENTES COM OSTEOSSARCOMA: IMPLICAÇÕES PARA O DIAGNÓSTICO PRECOCE

ITINERARIO TERAPÉUTICO DE ADOLESCENTES CON OSTEOSARCOMA: IMPLICACIONES PARA EL DIAGNÓSTICO TEMPRANO

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ABSTRACT

Several factors interfere with the delay of diagnosis and treatment of adolescents suffering from osteosarcoma. The purpose of this article was to describe the therapeutic itinerary of adolescents suffering from osteosarcoma. This is a descriptive study of type case report, carried out in a public institution specialized in Oncology in the State of Rio de Janeiro. Three case studies of adolescents suffering from osteosarcoma amputees with the description of the itinerary were conducted. Related issues have identified the difficulties of early diagnosis, as the family relationship with the teenager; the fragility of a health network suitable for the teenager and the difficulty of a diagnosis of childhood cancer. Early diagnosis should be disclosed through a system of integrated health basic attention with the specialized care. It is essential for early detection of osteosarcoma in adolescents, an integrated health system, basic care with specialized care, in order to prevent the discovery of new cases later.

Keywords: Adolescent; Diagnosis; Early Diagnosis; Osteossarcoma.

RESUMO

Vários fatores interferem na demora do diagnóstico e tratamento de adolescentes portadores de osteossarcoma. O objetivo deste artigo foi descrever o itinerário terapêutico de adolescentes portadores de osteossarcoma. Trata-se de estudo descritivo, do tipo relato de caso, realizado numa instituição pública especializada em Oncologia no estado do Rio de Janeiro. Foram realizados três estudos de casos de adolescentes portadores de osteossarcoma amputados com a descrição do itinerário terapêutico. Foram identificadas questões relacionadas a dificuldades do diagnóstico precoce, como a relação familiar com o adolescente, a fragilidade de uma rede de saúde adequada ao adolescente e a dificuldade de um diagnóstico de câncer infantil. O diagnóstico precoce deve ser divulgado por meio de um sistema de saúde integrado da atenção básica com o atendimento especializado. É fundamental, para que ocorra a detecção precoce do osteossarcoma nos adolescentes, um sistema de saúde integrado, da atenção básica com o atendimento especializado, a fim de evitar a descoberta de novos casos mais tardiamente.

Palavras-chave: Adolescentes; Diagnóstico; Diagnóstico Precoce; Osteossarcoma.

RESUMEN

Son varios los factores que interfieren en la demora del diagnóstico y tratamiento de adolescentes con osteosarcoma. El propósito de este artículo era describir el itinerario terapéutico de adolescentes con osteosarcoma. Se trata de un estudio descriptivo de caso llevado a cabo en una institución pública especializada en oncología en el estado de Río de Janeiro. Se realizaron tres estudios de caso de adolescentes con osteosarcoma amputados con la descripción del itinerario terapéutico. Se identificaron problemas relacionados con las dificultades del diagnóstico temprano, tales como la relación familiar con el adolescente; la fragilidad de la red de salud adecuada para el adolescente y la dificultad del diagnóstico de cáncer infantil. El diagnóstico temprano debe ser revelado a través de un sistema de atención básica de la salud integrado con atención especializada. Para la detección temprana del osteosarcoma en adolescentes es fundamental que el sistema de salud sea integrado, de atención básica con atención especializada, para evitar el descubrimiento de nuevos casos más tarde.

Palabras clave: Adolescente; Diagnóstico; Diagnóstico Precoz; Osteossarcoma.

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INTRODUCTION

According to estimates of the incidence of cancer in Brazil, recent changes have been observed in the social and economic context, directly reflected in the health of the population. Based on technological advances and professional development, an increase in life expectancy and the improvement of the diagnosis of cancer in the country is observed.¹

Considering as the most common primary malignant bone tumor, osteosarcoma occurs in any age group but affects mainly children, adolescents, and young adults. The most common signs and symptoms are a progressive bone pain, fatigue and night pain, followed by edema and movement limitation. Respiratory symptoms are rare at diagnosis and are present in cases of advanced lung disease.

Osteosarcoma accounts for 2.6% of all childhood and adolescence tumors, with a peak occurrence at 16 years old, with the incidence of 3.9% of cases per 1 million of the white infant population and 4.5% of cases in relation to the black population in the United States. It presents more frequently in boys and commonly affects the distal portion of the femur and proximal of the tibia and less frequently in the proximal humer.²

Recent studies are expected to cure at least 66% of patients who do not have metastases at diagnosis. These rates are directly influenced by the tumor subtype found. For patients who already have metastasis at diagnosis, the survival rate drops to less than 20%. A portion of patients with pulmonary metastasis (20-30%) may succeed in treatment if all pulmonary nodules are resected and if such treatment is associated with the administration of a more aggressive chemotherapy protocol. It can be considered that the number of pulmonary nodules will determine a better prognosis, directly influenced by the early diagnosis and effective oncological treatment.

Children with metastatic bone disease or with extensive disease in lung present a more reserved prognosis.

Early detection of childhood cancer is of great importance in reducing mortality and morbidity, besides to immediate on-cological treatment.³ Corroborating this assertion, immediate access to specialized centers is crucial to allow timely treatment and it is associated with high survival rates.⁴

Also, the early diagnosis of cancer in childhood and adolescence allows a reduction in treatment time, which may be less mutilating, directly influencing the quality of life of these patients. However, it is necessary for primary care professionals to be trained in the early diagnosis of childhood cancer for quality health care⁴, besides to the need to create a network to access the various levels of complexity of health services, allowing optimization of the diagnosis.

Cancer can be considered a devastating diagnosis, mainly for the adolescent and his family, because the insecurity begins with the indefinition of a diagnosis before a clinical picture of edema and pain in lower or upper limb. The search for various health services and the several disparate and unclear information received from various health professionals determine a period of many indecisions and insecurity. The news of cancer is able to change considerably the relationship between family members and the way they communicate and resolve daily issues.⁵

Another factor that should be considered in delaying the diagnosis of osteosarcoma is the age group of adolescence, which is considered a critical period of the young, with innumerable bodily, emotional and identify changes occurring in the sociocultural context. It is worth mentioning that this period presents other important characteristics when approached within the family nucleus, where it is identified the increase of disagreements and conflicts between parents and children reaffirming that the adolescence is a more challenging period. The difficulty of relationship between parents and children can also be considered a factor hindering the early diagnosis of osteosarcoma due to the difficulty of communication.⁶

Being aware of the therapeutic itinerary of a person or a group with oncological disease facilitates the knowledge of a succession of events and decision making, facilitating the search for a health care, which is built from a detailed trajectory.

Thus, it can be considered that the picture presented in the Pediatric Oncology reference service is of adolescents with osteosarcoma, who present massive tumors associated with marked pain in the affected limb, weight loss and, in most cases, disease with presence of pulmonary metastasis.

In view of this context, the objective of the study was to describe the therapeutic itinerary of three adolescents with osteosarcoma.

DESCRIPTION OF THE EXPERIENCE

This is a descriptive study of a case report type, carried out at a public institution specializing in Oncology in the state of Rio de Janeiro.

The guiding question was: what is the therapeutic itinerary of adolescents with osteosarcoma?

The medical records of three adolescents attending the outpatient clinic of Oncopediatria who presented the diagnosis of osteosarcoma were used.

The eligibility criteria were: to be adolescent, to be between 12 and 18 years old, to present the diagnosis of osteosarcoma, to have performed the treatment in a unit specialized in childhood cancer.

The instrument of data collection was the medical record. This type of collection assisted in the identification of the adolescents, in the collection of the clinical history and in the survey of the therapeutic itinerary. All three cases were identified from the first time nursing consultation, routine nursing activity.

It is noteworthy that the therapeutic itinerary was observed since it is a powerful tool to identify the path traveled by individuals seeking a solution to their health problem. It allows the visualization of the trajectory of the patients and families by the health system, and to their social and cultural aspects, in face of the illness situation.⁷

Data were collected in medical records from May to July 2016. The adolescents were identified by the letter A, B and C to maintain their anonymity.

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CASE REPORT A

G. C., born on April 18, 1999. She was 14 years old in September 2013.

TRAJECTORY BEFORE DIAGNOSIS OF OSTEOSARCOMA

The adolescent had pain in the left knee in September of 2013. Due to the pain complaint, she sought assistance in the emergency room in the region of São Gonçalo. When she was assisted, the doctor diagnosed growth pain. Dipyrone and anti-inflammatory were prescribed for the control of this symptom. Without improvement of the pain symptom, the adolescent returned in October to the same place, presenting left knee edema, receiving the diagnosis of an inflammatory picture. Unresolved, she returned for the third time in November to the emergency room, where she undertook the first X-ray examination of the affected limb. The previously adopted conduit was maintained, and the application of local ice pack was directed. She returned in December again, where she was attended by an orthopedist, this time receiving intravenous analgesic, with release to home after care. In January 2014, she returned to the emergency department, performing a new X-ray examination of the left knee, being referred to the orthopedic outpatient clinic of the region. In the evaluation of the x-ray examination of the left knee, a "benign lesion" was identified. It was requested a tomography of the member, scheduled by the regulation system for July 2014. She sought in February the emergence of São Gonçalo, with severe pain and enlargement of the left knee. The adolescent was medicated with venous analgesic, performed a new X-ray examination of the limb and she was released home. At this stage of the disease development, the adolescent already had a change of gait and her routine, away from daily activities, besides being ashamed of her leg, due to the evolution of the tumor. In March 2014, the adolescent presented an advanced

pain picture, without medication control, being attended in a hospital in the Lagos region, where she received intravenous medication for pain control. In April 2014, the adolescent returned to the São Gonçalo emergency room, being attended by an orthopedist, who worked in a university hospital, where the adolescent was referred. On April 25, 2014, with a previous evaluation and chest X-rays, a biopsy was performed at a reference center for orthopedics in the city of Rio de Janeiro.

DIAGNOSIS TRAJECTORY AT THE START OF OSTEOSARCOMA TREATMENT

After the result, the adolescent was referred to a reference center in Oncology, in May 2014, for osteosarcoma treatment, and she was submitted to amputation on October 16, 2014. At all times, the adolescent was followed by the mother or another family member.

CASE REPORT B

B.D.N.D., age 16, on October 16, 2013.

TRAJECTORY BEFORE DIAGNOSIS OF OSTEOSARCOMA

The adolescent started pain in the knee and right leg during the Physical Education class at the school. One week after the first episode of pain, he continued with local pain and physical activity at school. The pain picture was accompanied by local edema. The mother of B.D.N.D. took him to private medical care and the orthopedist in November 2013 requested X-rays of the affected limb and MRI, being suspicious of muscle damage. The X-ray examination was done on November 25, 2013, showing lytic lesion in the periosteum of the right lower limb. At the beginning of December, the adolescent returned to the orthopedist with the identification of a tumor in the knee region D. In this period, there were tumor growth and an increase in the local pain picture. The mother said that the adolescent was sad and ashamed to leave the house in a wheelchair. He was unable to perform routine activities due to malaise and pain. He was referred to the Municipal Hospital Miguel Couto for biopsy, being attended by an orthopedist who advised not to perform it, and he was referred to a hospital specialized in Orthopedics to perform the biopsy that occurred in December 2013.

DIAGNOSIS TRAJECTORY AT THE START OF OSTEOSARCOMA TREATMENT

After biopsy results, he was referred to the National Cancer Institute (INCA) for confirmation of the diagnosis of right

tibial osteosarcoma with pulmonary metastasis, in February 2014. The adolescent began his chemotherapy treatment and subsequent amputation of the affected limb on June 5, 2014.

CASE REPORT C

M.R.C.O., born on July 12, 1997. He was 17 years old in November of 2013.

TRAJECTORY BEFORE DIAGNOSIS OF OSTEOSARCOMA

The adolescent presented knee and right leg pain after playing soccer at a school in November 2013.

He sought private medical care in November 2013. The orthopedist requested X-rays of the right leg knee and local ultrasound. X-rays were performed on November 25, 2013, and images of the periosteal lytic lesion were obtained. After that moment, the orthopedist sent him to Miguel Couto Hospital for a biopsy. On December 18, 2013, the adolescent was referred from the Miguel Couto Hospital to INCA.

The adolescent performed a biopsy at the National Institute of Traumatology and Orthopedics on December 23, 2013, and had confirmation of diagnosis on January 7, 2014, and subsequent amputation of the affected limb on June 5, 2014.

DIAGNOSIS TRAJECTORY AT THE START OF OSTEOSARCOMA TREATMENT

The adolescent was registered at INCA on December 30, 2013, only returning on January 7, 2014, to check the histopathological report. With a diagnosis of metastatic osteosarcoma for lung and bone, he underwent amputation on June 5, 2014.

DISCUSSION

THE THERAPEUTIC ITINERARY OF ADOLESCENTS WITH OSTEOSARCOMA

The use of the therapeutic itinerary methodology in Brazil is relatively recent. The knowledge of the forms of access for the diagnosis of childhood cancer contributes directly to the consolidation of a cancer care network. Knowing the care devices triggered by the patient and the family in coping with the disease and to suggest an expanded view by health professionals about the users' cultural universe to adapt practices and achieve results are important objectives, among others.⁸ Although there is no consensus regarding the concepts of explanatory models and health care systems developed by Klein-

man, these authors occupy an important role of reference in the researched literature in the explanation of behaviors in the search for care and the routes covered.

ADOLESCENT'S ILLNESS

One of the great challenges faced by family members and health services is to maintain clear and objective communication with adolescents and discuss physical and emotional changes with this group since for seeking identification with their peers, episodes of illness are ignored, silenced or related to the excess of physical activities proper to the age. Early detection of adolescent health has so far not been part of national health policy priorities. However, there is an early diagnosis program for child and adolescent cancer that aims at a decent care of children and adolescents, sharing responsibilities and establishing adequate strategies on adolescent health. It can be considered incipient, which may be a reflection of the national health policy, always prioritized assistance to the maternal and child group.

It is possible to reflect that health programs tend to exclude adolescents from the National Policy on Early Detection of Cancer, reflecting in the difficulty of diagnosis, depersonalized protocols and inadequate therapeutic behaviors, harming adolescents with osteosarcoma and against the goals of the Ministry of Health.

It can be stated that, in the description of the cases, all family members and adolescents sought basic health services to solve their problems. There were comings and goings, without a quick solution, even in the complaints of pain and increase in the volume of the affected limb. The complaint of pain most of the time at night and difficult to control leads to restriction of movement and claudication and limitation of routine activities, that is the exclusion of adolescents from their sociocultural environment.² It should be noted that the signs and symptoms of cancer are very similar to common childhood diseases. Adolescents may often experience dislocations, edema and pain as a result of physical activity or some fall, play or games. It is up to the health service to be able to identify, from examinations, the signs, and symptoms of an oncological disease. Referring to a referral center and reducing social differences, ensuring access to specialized centers for early diagnosis and quality treatment, is of paramount importance for curing the disease.4

In these three cases, it was identified that the mean time since the appearance of signs and symptoms (trajectory prior to the diagnosis of osteosarcoma) until arrival at a specialized service for diagnosis and treatment (trajectory of diagnosis at the start of osteosarcoma treatment) was four months, on average. In the United States and Europe, the average time to diagnosis is around one to three months. The difficulties reported by the

families of adolescents with osteosarcoma in the period preceding diagnosis go beyond the organization of the health system and bureaucratic issues. There is a strong influence of the family subsystem in the decision making on the choice of the therapeutic itinerary of adolescents with suspected bone tumors. However, failures in the different levels of health care contributed to the significant delay in establishing the diagnosis. The diagnosis of the diagnosis.

The family subsystem is responsible for decisions about the health-related practices of these individuals in the search for health services and home-based treatments (self-treatment), probably based on the experiences of family members and beliefs accumulated over the course of their lives. Early diagnosis of childhood and juvenile cancer involves factors such as decisions made by the family when signs and/or symptoms arise, access to health services and professional qualification. Therefore, improvements in the health care system are important, such as the equitable distribution of services by states and integrated reference and counter-referral systems, as well as investments in training qualified professionals to identify childhood and juvenile cancer.

CONCLUSION

The study demonstrated the long course used by adolescents with osteosarcoma, describing their therapeutic itinerary, from the trajectory before the diagnosis of osteosarcoma and then, the trajectory of the diagnosis at the beginning of osteosarcoma treatment. This itinerary highlights the importance of early diagnosis for this disease and the difficulties encountered by adolescents.

The limitations of the study refer to the lack of data in the medical records that would allow a broader description of the identification of adolescents.

The course of the adolescent and his family by the health system, the signs of illness and its sociocultural aspects are observed. Early diagnosis of the adolescent with osteosarcoma involves family decisions, correct assessment of signs and symptoms and appreciation of complaints, access to health services and examinations, and adequate qualification of health professionals in the detection of signs of childhood and juvenile cancer.

It is essential for the early detection of osteosarcoma in adolescents to be integrated, from basic health care to specialized care to avoid the discovery of new cases later.

Table 1 - Demonstration of the cases in the study

| Cases | Date of birth | First symptoms | Diagnosis | Amputation |
|--------|---------------|--|--------------------------------|------------|
| Case A | 04.18.1999 | Left knee pain - September 2013 | May 2014 - 8 Months later | 10.16.2014 |
| Case B | - | Left knee pain and edema - November 2013 | February 2014 - 3 months later | 06.05.2014 |
| Case C | 07.12.1997 | Pain in the knee and right leg - November 2013 | 01.07.2014 - 2 months later | 06.05.2014 |

Source: data from the medical records of the adolescents studied.

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