



ORIGINAL ARTICLE

Health care circuit for patients with soft tissue sarcomas of the extremities. A tortuous and slow road to referral units^{☆,☆☆}



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KEYWORDS

Soft tissue sarcoma;
Referral;
Delayed diagnosis;
Referral center

Abstract

Objective: To analyze the waiting periods elapsed since soft tissue sarcomas become symptomatic until their specific treatment in our unit, and to determine new strategies for the improvement of referral circuits.

Material and methods: This is an ambispective observational study of a cohort of 61 patients, with previously untreated soft tissue sarcomas, obtained from our musculoskeletal tumors database. Several variables related to the patient, tumor, and health care circuit were analyzed, as well as the different periods between the initial symptoms of the disease and the first consultation in our unit. The significance level was $\alpha = 0.05$.

Results: The mean size of the sarcomas was 11.3 cm. Thirty-six patients (59%) followed the usual circuit of the National Health System in Spain. The time elapsed since the disease became symptomatic until the first medical consultation was greater than 9.5 months, and nearly another 8.5 months to the consultation in our specific unit. Statistically significant relationships were found between the independent and dependent variables.

Discussion: The study shows that the care of patients with soft tissue sarcomas in our environment is far away from the times of care in our neighboring countries.

Conclusions: It is essential to make the population and health professionals aware of this disease, as well as to remember that there is a referral circuit that must be used.

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PALABRAS CLAVE

Sarcoma de partes blandas;
Derivación;
Demora;
Centro de referencia

Círculo de asistencia a pacientes con sarcomas de partes blandas de las extremidades: un tortuoso y lento camino hasta las unidades de referencia

Resumen

Objetivo: Analizar los tiempos de espera transcurridos desde que los sarcomas de partes blandas (SPB) se hacen sintomáticos hasta su tratamiento específico en nuestra Unidad de Tumores Músculo-Esqueléticos (UTME) para proponer estrategias de mejora en los circuitos de derivación. **Material y métodos:** Estudio observacional, longitudinal y ambispectivo de una cohorte de 61 pacientes con SPB vírgenes obtenidos e identificados de forma continua del registro de pacientes de la UTME. Se analizó la relación entre diferentes tiempos transcurridos desde que la enfermedad se hizo sintomática hasta la primera consulta en la UTME, y diversas variables ligadas a la persona, tumor y circuito asistencial. Se usó un nivel de significación $\alpha = 0,05$.

Resultados: El tamaño medio de los sarcomas fue de 11,3 cm. Treinta y seis pacientes (59%) siguieron el circuito habitual del Sistema Nacional de Salud en nuestro país. El tiempo medio transcurrido desde que la enfermedad se hizo sintomática hasta la primera consulta médica fue superior a 9,5 meses; y el que transcurrió desde esta hasta la primera en nuestra UTME fue de casi 8,5 meses. Algunas variables independientes mostraron relación estadísticamente significativa con las variables dependientes analizadas.

Discusión: El estudio muestra que la asistencia a los pacientes con SPB de las extremidades en nuestro medio está muy lejos de los tiempos que transcurren en los países de nuestro entorno.

Conclusiones: Parece fundamental la necesidad de concienciar a la población sobre la enfermedad y recordarla entre los profesionales sanitarios, al igual que la existencia de un circuito de derivación que es necesario utilizar.

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Introduction

Soft tissue sarcomas (STS) are a heterogeneous group of malignant tumors which derive from mesenchymal tissue originating in the embryonic mesoderm.^{1,2} They account for 1% of all adult tumors and are commonly diagnosed belatedly or treated inadequately at non-specialized centers, which may entail irreparable consequences for patients and physicians. For the former, the limb rescue procedure which may have been possible through an early diagnosis and treatment may become compromised and/or, even worse, the possibility of survival may be reduced. For physicians, in addition to having to bear the burden of feeling they could have done more for the patient, they may become involved in unpleasant malpractice lawsuits.

The objective of this work is to analyze the waiting times elapsed between the start of disease symptoms and specific treatment at our Musculoskeletal Tumor Unit (MSTU). Without going into detail about the consequences of delays, which we take as a given, we aim to identify bottlenecks in the patient referral circuit and propose strategies to improve them.

Materials and methods

Between July 1st 2006 and December 31st 2012, the MSTU of our hospital provided medical care for 112 patients with malignant soft tissue tumors. We carried out an observational, longitudinal and ambispective study of a cohort of 61 patients with previously untreated STS, including some who had undergone prior biopsies at their referring centers. All cases were managed according to the diagnosis, treatment

and follow-up guidelines reflected in the clinical practice guides for the disease.³⁻⁷

Patients were collected and continuously identified from the patient registry of the MSTU. According to the ethical guidelines for research procedures, the information was obtained through revision of medical histories and was gathered over telephone interviews with patients or close relatives (in cases where the patients had passed away) conducted by one of the authors (PCR). The mean follow-up period elapsed from the first consultation at our MSTU until the date of the study or death of each patient was of 2 years (range: 11 days–6 years and 2 months). The dates considered for the calculation of the different periods elapsed in healthcare were those specified in the corresponding official documents, as well as those reported by patients regarding the start of symptoms and initial medical consultations. When this was not clearly specified and was only estimated approximately within a specific month, we considered the 15th of that month. When 2 consecutive months were referred as the approximate time of the investigated episode, we considered the 1st of the second month. All data were collected and registered by one of the authors of the work (PCR) in a data collection form designed for this study.

We analyzed the different times elapsed from the moment the disease became symptomatic in each patient until they were seen and began treatment at our MSTU (Tables 1 and 2, and Fig. 1). These were related to the following independent variables: a) linked to the characteristics of each patient (age above or below 65 years, gender, level of education, resident of a city with a general hospital or not, and referring healthcare area); b) related to the disease (first symptom/sign, location of the tumor in upper or lower limbs, superficial or deep location of tumor

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