

**PP-100****Delayed diagnosis in osteo- and Ewing's Sarcoma patients: a facebook based survey****F. Pohlig**, U. Lenze, F. Lenze, H. Muhlhofer, H. Rechl, R. von Eisenhart-Rothe*Department of Orthopedic Surgery, Klinikum Rechts der Isar, Munich, Germany*

Introduction: Tumor size and metastases at the time of diagnosis are two of the most significant prognostic factors in patients with Osteo- and Ewing's Sarcoma. Early diagnostic workup is therefore prerequisite to avoid an unfavourable outcome. Regardless, the period until final diagnosis is still more than 3 months in both tumor entities in current literature. These data, however, were usually collected over a long time period due to the low incidence of these diseases lacking timeliness. Social networks like Facebook with their topic-based groups provide a unique potential for collecting and analyzing data of rare diseases like sarcomas. Aim of this study therefore was an internet-based survey on the time to diagnosis and treatment modalities in patients with Osteo- and Ewing's Sarcoma via Facebook.

Methods: An online questionnaire with 10 items regarding general information, treatment modalities and time to diagnosis was developed. A link to the survey and all necessary informations were posted in specific Facebook groups regarding Osteo- and Ewing's Sarcoma. After 1 month all surveys were closed and data was statistically analyzed.

Results: A total of 27 patients participated in our survey. The average time to diagnosis was 2,92 months in Osteo- and 3,27 months in Ewing's Sarcoma patients. Primary tumor site was the lower extremity in both entities. At the time of diagnosis 83% of Osteosarcoma and 73% of Ewing's Sarcoma patients were free of metastases. Surgical tumor resection was performed in 100% of the cases with Osteo- and 91% with Ewing's Sarcoma. Chemotherapy was applied in 92% of Osteosarcoma and 100% of Ewing's Sarcoma patients. Additional radiotherapy was administered in 55% of the Ewing's Sarcoma cases.

Conclusion: Our study could confirm the long time period from first symptoms until the final diagnosis in patients with Osteo- and Ewing's Sarcoma. Nevertheless, only a small percentage of the patients with either tumor entity showed metastases at the time of diagnosis. Therapy was performed in most cases according to international guidelines with surgical resection and chemotherapy. Additionally, a social network as a modern communication medium was successfully used for collection and analysis of epidemiologic data of rare diseases.