

A Facebook based survey on psychosocial distress levels in patients with Osteo-, Ewing- and Liposarcoma

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Introduction

Psychosocial distress is an important problem in cancer patients. Routinely applied screenings can help to identify vulnerable patients and provide them with an appropriate therapy. However, differences between distress levels in orthopaedic patients with different sarcoma entities are hard to identify due to the low incidence of these diseases. 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 psychosocial distress levels in patients with Osteo-, Ewing- and Liposarcoma with a self-assessment screening via Facebook.

Methods

A psychometrically tested questionnaire with 10 items (answer categories: 0 = no distress to 5 = high level of distress) for self-assessment of psychosocial distress (QSC-R10) (Book et al., Psychooncology, 2011) was compiled to an online survey. A result above 14 points indicates a relevant level of distress requiring psychooncological treatment. A link to the survey and all necessary informations were posted in specific Facebook groups regarding Osteo-, Ewing- and Liposarcoma. After 1 month all surveys were closed and data was statistically analyzed according to distress levels in different sarcoma entities and psychooncological therapy offered.

Results

A total of 43 patients with Osteo-, Ewing and Liposarcoma participated in our study. In either group a high amount of patients suffered from psychosocial distress (Liposarcoma: 78%; Osteosarcoma 91%; Ewing Sarcoma: 100%). In patients with Liposarcoma the results of the questionnaire averaged 24,5 points. Patients with Osteo- or Ewing Sarcoma attained an increased but statistically narrowly not significant average value of 30,4 ($p=0,14$) and 32,0 ($p=0,07$) compared to patients with Liposarcoma. Psychooncological treatment was offered in 34% of the cases. 41,7% were satisfied with the psychooncological treatment when offered.

Conclusion

Our study could confirm the high demand of additional psychooncological treatment of sarcoma patients as previously experienced in daily clinical routine. In this context a correlation between psychosocial distress and the mortality associated with the different sarcoma entities could be shown. However, to date no sufficient psychooncological treatment is offered to orthopaedic tumor patients. Additionally, a social network as a modern communication medium was successfully used for collection and analysis of epidemiologic data of rare diseases.