

Quality of life, physical and mental status and contentment of patients with localized soft tissue or bone sarcoma: a questionnaire analysis

Saskia M. Sachsenmaier,¹ Ingmar Ipach,² Torsten Kluba¹

¹Department of Orthopedic Surgery, Tübingen University Hospital; ²Ingolstadt Clinic of Orthopedics, Germany

Abstract

Extremity soft tissue and bone sarcomas represent a rare group of bone and connective tissue cancers. In literature, there is little information about psycho-emotional status and impact on quality of life after the diagnosis and treatment of this kind of tumors. The aim of this survey was to define the profile of the patients at risk and their need for psychooncological care. Our self-created questionnaire consists of 71 items related to the individual emotional, mental and physical situation after the diagnosis of soft tissue and bone sarcoma. Sixty-six patients, surgically treated at our department, were included. Only 37.5% of the patients considered themselves to be completely emotional stable. Psychooncological treatment was accepted mostly by female patients, by patients with higher education level and by married patients. Emotional stability and confidence in future were associated with a strong familiar background, with numerous consultations of psychooncological service and also to gender and physical condition. Current quality of life was strongly correlated to physical condition. Thanks to our questionnaire, we disclosed few risk factors for negative emotional outcome after therapy, such as higher age, social isolation, female gender and poor physical status.

Introduction

Extremity soft tissue and bone sarcomas are a rare heterogeneous group of bone and connective tissue tumors.¹ Their growth behavior and the biological grade of malignancy differ markedly between the histological subtypes. The prognosis and therapy options depend on the entity of the tissue. Fast histological diagnosis and grading are therefore essential for treatment decisions and improvement of patient's outcome. The first line therapy for soft tissue sarcomas consists of wide margin

surgery followed by radiotherapy, especially in the case of a primary high grade tumor in a resectable area.¹

Although there are several surveys about quality of life in patients with sarcoma disease, there is little information about how these patients handle the diagnosis of the malignant tumor, and about their arrangement of daily life during and after treatment.^{2,3}

Some international established questionnaires do exist, which are instruments for measurement of life quality.^{4,5} Examples of standardized questionnaires are the Short Form-36 (SF-36), for use in different populations irrespective of disease, the Toronto Extremity Salvage Score (TESS), as a measure of physical disability developed for extremity sarcoma patients and the Musculoskeletal Tumor Society Rating Scale (MSTS), for evaluation of impairment in patients with musculoskeletal tumors.⁶⁻⁸ Most of those questionnaires compare mental and functional outcomes of different treatment groups or are specific for one subtype of sarcoma.

Using our questionnaire, we wanted to gain information about the emotional, mental and physical status of patients after sarcoma diagnosis, and satisfaction with treatment at our Centre for Soft Tissue and Bone Sarcoma at a German University Comprehensive Cancer Centre. We were interested in the methods patients use for handling sarcoma diseases, and how their methods differ one from another. With the new information gained from our questionnaire, we wanted to define a risk profile for new sarcoma patients with the aim of offering early specialized treatment options e.g. psychooncological support in cases with higher demands for additional psychological care.

The influence of a social network, family background, family experiences of tumor disease, educational background, job situation and age at onset of disease should be evaluated, since this had not been performed so far in a larger group of sarcoma patients.

Materials and Methods

The present study consists of a survey with a self-created questionnaire consisting of 71 items, including questions about the individual emotional, social, mental and physical situation after sarcoma diagnosis and about acceptance of treatment (Supplementary Material). All of the 71 questions were classified into seven different sections: in the first one, there were questions to collect general data about patients' living situation, such as their gender, actual age and age at diagnosis, family status, children, about their residential and, working situation and their educational

Correspondence: Saskia Magdalen Sachsenmaier, Orthopädische Klinik, Universitätsklinik Tübingen, Hoppe-Seylerstrasse 3, 72076 Tübingen, Germany. Tel.: +49.07071.2986685. E-mail: saskia.sachsenmaier@med.uni-tuebingen.de

Key words: Bone and soft tissue sarcoma; quality of life; physical situation; questionnaire analysis.

Contributions: SMS, conception and design of the study, organization and delivery of the questionnaire, acquisition of data, analysis and interpretation of data, draft and critical revision of the article for intellectual content; II, conception and design of the study; TK, conception and design of the study, acquisition of data, analysis and interpretation of data, draft and critical revision of the article for intellectual content.

Conflict of interest: the authors declare no potential conflict of interest.

Received for publication: 23 March 2015.
Accepted for publication: 19 April 2015.

This work is licensed under a Creative Commons Attribution NonCommercial 3.0 License (CC BY-NC 3.0).

©Copyright S.M. Sachsenmaier et al., 2015
Licensee PAGEPress, Italy
Orthopedic Reviews 2015; 7:5920
doi:10.4081/or.2015.5920

background. The second section referred more closely to patients' job and the change in their working situation as a result of the disease, including questions about financial income, occupational rehabilitation and about reduction of additional hobbies.

The third section included items about diagnosis and therapy, in particular satisfaction with treatment and diagnosis, information about the disease and personal support during therapy and information about social integration and networking of patients.

Under the topic *psycho-emotional status*, we asked detailed questions about the patients' emotional situation during diagnosis, treatment and after therapy, patients' confidence in the future, changes in their relationships and quality of life. Last but not least, we assessed the physical constitution of the patients after therapy.

Each section consisted of nearly 10 questions. The questionnaire offered 7 possible responses to the majority of questions; the possible answers were arranged in an ascending order scale (e.g., 1 meant *not at all*, 7 meant *highly*). Some items were ranked nominally, such as questions about age, gender or questions about education and living situation, where we proposed seven to ten possible

answers and patients chose one of them.

Patients with localized bone or soft tissue sarcoma, who were surgically treated at our department from January 2009 to June 2012, were included. Age >18 years and full contractual capability were mandatory for enrolment. The survey was approved by the local Ethics committee (036/2013BO2).

The questionnaire was sent to a consecutive series of 169 patients in October 2013. Sixty-six patients were finally included in the statistical analysis after sending back the completed questionnaire within a period of 4 months. Data were collected, saved and analyzed anonymously. Statistical analysis consisted of bivariate analyses using JMP SAS version 10.

Results

The analysis of our survey showed many interesting new findings about the behavior, handling and arrangement of daily life and about the emotional situation of patients after the diagnosis of a malignant tumor of the musculoskeletal system, as well as the impact of the treatment. We collected information about different unknown associations between gender and the environment of patients and satisfaction with treatment or some unfulfilled needs.

The presented results are related to the seven specific classification topics of the questionnaire.

Patients' general data/environment

The mean age of patients was 59 years. More men than women were included in the final analysis of the study. The demographics of the study population are shown in Table 1. The questionnaire was filled out anonymously, so an assignment of the individual questionnaire to the correspondent patient was not possible. The following data concerning the sarcoma entities and the grading refer to the total population of 169 patients who received the questionnaire initially.

Thirty patients suffered from primary bone sarcoma, the other 139 patients had soft tissue sarcomas.

The distribution of the tumors grading in total showed 28% grade 1 sarcomas, 26% grade 2 sarcomas and 38% sarcomas of grade 3. In the total cohort, patients were diagnosed with osteosarcoma (9%), chondrosarcoma (7%), Ewing-Sarcoma (2%), rhabdomyosarcoma (3%), angiosarcoma (2%), myxofibrosarcoma (18%), leiomyosarcoma (8%), liposarcoma (23%) and NOS-sarcoma (28%).

We did not evaluate additional therapies which patients underwent besides surgery.

Working situation

Twenty-three patients (34.9%) were employed before diagnosis of the sarcoma, 20 patients (30%) could continue with their job after treatment without limitations due to the disease or therapy. The attitude to their jobs after diagnosis changed among only 22% of our patients. We asked for the financial impact of the disease, and 27.3% of the patients admitted that they suffered financial strain.

Diagnosis and therapy

This topic contained questions about satisfaction with diagnosis and therapy and background information about sarcoma disease given by our department.

One interesting focus was the main source of information about the disease used by most of the patients in addition to the information given by the hospital staff. Possible options offered were published literature or specialized books, other print media, internet, television or other concerned persons and support groups.

Twenty-nine out of 66 patients (44%) increased their knowledge about the disease with the use of the World Wide Web. Most of the patients who gathered their information about the disease from the internet were under the age of 60 (Figure 1A).

Patients who lived in bigger cities gathered information from friends, neighbors or relatives more often than patients living in villages (n=56, P=0.0155).

Altogether, patients were satisfied with the amount of information about the disease and its prognosis and therapy given by our department.

Employed patients wished to receive more information about therapy of the disease compared to unemployed and retired patients (n=58, P=0.0404).

Further interesting information from the questionnaire referred to patients' opinions about the diagnosis and therapy of sarcoma treated at our department.

Eighty-one percent of patients felt very well treated at our cancer center (n=51) and would repeat the treatment in the same way (n=48). None of our patients would change the treating hospital, some of the patients would make use of additional alternative therapies, for example homeopathic therapies (n=10, 18.9%) or additional pain therapy (n=5, 9.26%).

Other surgical therapies were not favored by our patients (n=0).

We asked patients about their greatest stress factor under therapy, and patients mentioned undesirable effects of therapy as the main stress factor (n=24, 44.44%).

There were different opinions amongst the different patient groups, for example according to their employment situation.

Employed patients declared the loss of hair caused by chemotherapy as a more significant impairment or main handicap during treatment compared to the unemployed group (n=54, P=0.0249).

Other options to answer such as radiation dermatitis after radiotherapy, complications after surgery, fear of therapeutic failure and relapse as well as pain were significantly less commonly chosen in both groups.

Social background

To what extent did patients' social network behavior change after the disease? How did the disease and the therapy influence our patients' relationships?

Retired patients especially felt excluded from their social environment after the onset of the disease (n=64, P=0.0091).

After completion of the treatment, elderly patients (age >60) felt more socially isolated compared to younger patients. Not only can the relationship with friends and neighbors change, but the relationship between patients and their partners and family members may also alter after disease.

We did not ask for the reasons for changing relationships during the disease, but we found some interesting associations between patients' characteristics and change in their relationships.

The relationship between patients and their partners changed more among childless couples after diagnosis compared to patients with children (n=57, P=0.0005). In addition, female patients were of the opinion that their sex life changed markedly after diagnosis, whilst male patients described less change (Figure 1B).

Emotional situation

The current emotional stability of the patients was also part of the questionnaire. Overall, 53% of our patient collective expressed great confidence in the future and 37.5% considered themselves to be completely emotional stable (n=24). With the analysis of patients' emotional situation, it was possible to find some risk factors for poor emotional status after therapy: Patients with two or more children were more optimistic about the future (Figure 1C). Patients' gender also played a role for the emotional outcome, and female patients were more emotionally burdened than males (n=63, P=0.0175). Professional psychological support for oncology patients is offered at our unit, however very few patients made use of this psychooncological service (n=5, 8.47%). Autonomous demand for or use of the psychooncological service varied depending on the gender of the patient. Women consulted the psychooncological service by themselves more often than male patients (n=58, P=0.111). Furthermore, the psychooncological service was used more often by patients with a

higher level of education ($n=59$, $P=0.0148$) and by married patients compared to singles and divorcees ($n=58$, $P=0.024$). Patients who used psychooncological care described their life as being more livable after the disease ($n=58$, $P=0.0040$). These patients were also more confident about the future.

Physical status

There were also questions to evaluate the patients' current physical status and its change under therapy. Twenty-six patients considered their physical condition to be very stable and excellent, the other 26 patients considered themselves to be in only moderate physical condition. Patients in excellent physical condition were less emotionally burdened than patients with a poor physical status ($n=64$, $P<0.0182$) (Figure 1D). We found a significant correlation between current quality of life and physical condition among patients ($n=64$, $P<0.0001$) (Figure 1E). A correlation between good physical condition and confidence in the future was also confirmed (Figure 1F). Those patients who could still practice their job after treatment showed a better emotional status than the others ($n=47$, $P=0.0209$). Patients whose emotional condition was poor wished that they had been supported more by the psychooncological service during treatment ($n=60$, $P=0.0017$). Numerous consultations with the psychooncological service during treatment was positively associated with current happiness ($n=56$, $P=0.0029$). Further evaluated data did not reach statistical significance, and is not shown here.

Discussion

The literature regarding quality of life for sarcoma patients is varied with regard to the focus of the survey. There are some established questionnaires and scores for assessing life quality of cancer patients in general in the literature, for example the Quality of Life-Cancer Specific Scale (QOL-CSS).⁴ The existing questionnaires evaluate quality of life by considering pain scores and the functional situation after tumor therapy, but life quality measurements should also consider mental health and social well-being.⁹ Most of the surveys do not include social background or domestic reorganisation.^{10,11} Novakovic *et al.* compared assessed psychosocial variables with physical function.¹² The assessment of quality of life should include tumor specific items, and the questions should also refer to quantity of life associated with tumor specific treatments.¹³ It is easy to determine physical measurements, but very difficult to obtain objective information about psychological sta-

bility and emotional change in sarcoma patients. Each individual has his own strategies for coping with a life-threatening disease. In these processes, social background, level of educational and financial and family background play an important role. Our patients differ one from another with regard to their social and family circumstances, their physical condition and working environments. It is interesting to examine a large heterogeneous patient group to find some common attributes amongst patients with good or with poor emotional outcome after tumor diagnosis and therapy. For example, patients with a higher level of education are able to understand the course of sarcoma diseases more precisely and make an estimation of prognosis better than patients without such differentiated background knowledge. Some articles hold the view that it is not the physical impairment itself, but the restriction of participation in life roles and situations which mostly influences patients' health related quality of life.¹⁴ Predictive factors for perceiving life quality after sarcoma diagnosis described in the literature are gender, physical status and achievement potential.^{2,3,15} Better physical status is associated with a stable emotional situation, as we were able to confirm in our study. Another factor that influences the emotional status of patients after sarcoma diagnosis is the prognosis of the disease and the trust in treatment processes. In an examination of psychosocial and functional outcomes in long-term survivors of osteosarcoma, researchers found an association between satisfaction with treatment and emotional functioning.³ Furthermore, life quality questionnaires should use patients' expectations of treatment success and patients' satisfaction with treatment decisions.¹⁶ Our questionnaire is a new and non-established survey which reflects the experiences and impressions of a heterogeneous group of 66 patients with bone or soft tissue sarcoma treated in our department. We aim to collect information and criticism about treatment to optimize treatment processes and psychical support mechanisms in the future. The questionnaire was sent to 169 patients who were treated during the last 3.5 years, however only 66 patients could be finally included. The return rate was low, and we can not offer information about the remaining patients. This low return rate restricts the evidence of our study; nevertheless it is the first survey which considers life quality of sarcoma patients with this number of participants. The emotional situation of our patients after therapy differs greatly: we found that gender, the presence of children and early and continuous support from specialized psychologists influences the psychical and emotional stability of sarcoma patients. We were able to confirm what is already known from previous studies: better physical status after ther-

Table 1. Patients' demographics.

Variable	N.	%
Gender		
F	29	43.94
M	36	54.55
NA	1	1.52
Age		
<40	4	6.06
41-60	26	39.39
>60	34	51.52
NA	2	3.03
Employment status		
Working	23	34.85
Housewife	1	1.52
Studying	1	1.52
Jobless	2	3.03
Retired	38	57.58
NA	1	1.52
Sisters/brothers		
No	10	15.15
Yes	55	83.33
NA	1	1.52
Tumor disease in family		
No	23	34.85
Yes	40	60.61
NA	3	4.55
Education		
No education	2	3.03
Secondary school without graduation	30	45.45
Secondary school with graduation	19	28.79
University entrance diploma	4	6.06
Completed studies	9	13.64
NA	2	3.03
Familiar situation		
Unmarried	7	10.61
Married	44	66.67
Divorced	4	6.06
Widowed	9	13.64
NA	2	3.03
Children		
0	15	22.73
1	49	74.24
2	1	1.52
NA	1	1.52
Living situation		
Living alone	13	19.70
With parents	3	4.55
Flat-share	1	1.52
Living with partner	39	59.09
Living with partner and child(ren)	9	13.64
NA	1	1.52
Home		
Village	38	57.58
Small town	23	34.85
City	3	4.55
NA	2	3.03
Able to work after therapy		
Not at all	20	30.30
Possible	7	10.61
Able to fully work	20	30.30
NA	19	28.79

NA, not available.

apy is associated with a higher quality of life. In our clinic, we offer psychological assistance as a specialized psychooncological support service, which can be contacted by cancer patients and their relatives. Our study showed a better psychological outcome in patients who contacted this service. Regarding the evaluation of a patient's risk profile we were able to confirm some results from a study by Hampras *et al.*¹⁷ Most of the sarcoma patients had a low level of education, and most had attended secondary school (n=26).

Conclusions

Thanks to our questionnaire, it was possible to determine patients' physical, psychological and social situation after soft tissue or bone sarcoma diagnosis, and to find risk factors for poor emotional outcome after therapy. Our aim is to improve the existing treatment and to rec-

ognize which patients need more qualified psychooncological support at an early stage. In summary, the results of our questionnaire indicate that elderly patients, retired patients and those who live alone need more intensive psychological care than others. These patients are isolated from society and need early and intensive help and contact with support groups. Older patients are – compared to younger patients – often in a poorer physical condition after therapy and this negatively influences their mood. Another negative predictive factor for coping poorly with the disease is the gender (females). On the other hand, positive influencing factors for emotional stability and confidence in the future after treatment are the existence of children and good physical condition. Physical status could be improved with the help of sport and rehabilitation courses. Furthermore, we found that patients who contacted the psychooncological service during therapy are emotionally more stable. Emotional situation could be positively

influenced during treatment by offering earlier psychooncological support, by informing patients' more exhaustively and by encouraging fast physical rehabilitation.

References

- Hasegawa T, Yamamoto S, Yokoyama R, et al. Prognostic significance of grading and staging systems using MIB-1 score in adult patients with soft tissue sarcoma of the extremities and trunk. *Cancer* 2002;95:843-51.
- Frances JM, Morris CD, Arkader A, et al. What is quality of life in children with bone sarcoma? *Clin Orthop Relat Res* 2007;459:34-9.
- Robert R, Ottaviani G, Huh W. et al. Psychosocial and functional outcomes in long-term survivors of osteosarcoma: a comparison of limb-salvage surgery and amputation. *Pediatr Blood Cancer* 2010;54:990-9.
- Ferrell BR, Dow KH, Grant M. Measurement of the life quality in cancer survivors. *Qual Life Res* 1995;4:523-31.
- Bhatia S, Jenney ME, Bogue MK, et al. The Minneapolis-Manchester Quality of Life instrument: reliability and validity of the adolescent form. *J Clin Oncol* 2002;20:4692-8.
- Ware JE, Snow KK, Kosinski M, Gandek B. SF-36 Health Survey: manual and interpretation guide. Boston: The Health Institute, New England Medical Center; 1993.
- Davis AM, Wright JG, Williams JI, et al. Development of a measure of physical function for patients with bone and soft tissue sarcomas. *Qual Life Res* 1996;5:508-16.
- Enneking WF, Dunham W, Gebhardt MC. A system for the functional evaluation of reconstructive procedures after surgical treatment of tumors of the musculoskeletal system. *Clin Orthop Relat Res* 1993:241-6.
- Langenhoff B, Krabbe P, Wobbes T, Ruers T. Quality of life as an outcome measure in surgical oncology. *Br J Surg* 2001;88:643-52.
- Rouggraff BT, Simon MA, Kneisl JS, et al. Limb salvage compared with amputation for osteosarcoma of the distal end of the femur. A long-term oncological, functional and quality-of-life study. *J Bone Joint Surg Am* 1994;76:649-56.
- Sugarbaker PH, Barofsky I, Rosenberg SA, et al. Quality of life assessment of patients in extremity sarcoma clinical trials. *Surgery* 1982;91:17-23.
- Novakovic B, Fears TR, Horowitz ME, et al.

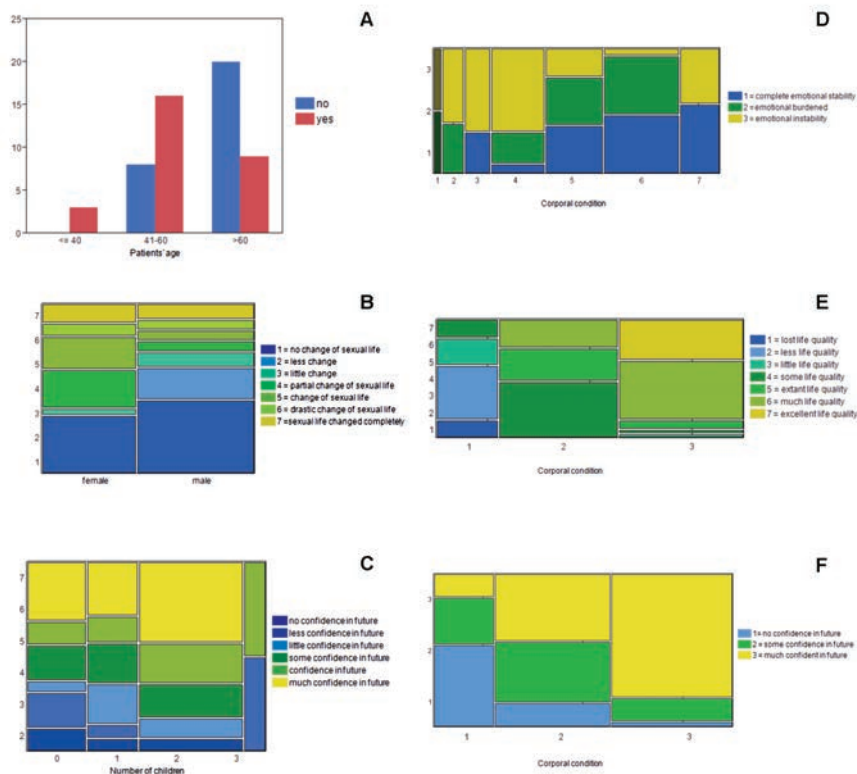


Figure 1. A) The internet as a source of information was especially used by patients under the age of 60 years (n=56, P=0.0073). B) Change in sex life after disease depending on gender (n=58, P=0.0391). C) Confidence in future after disease in association with the number of own children (n=64, P=0.0451). D) Emotional status after disease depending on physical condition (n=64, P=0.0182); 1=poor corporal condition; 7=excellent corporal condition. E) Current life quality associated with physical conduction (n=64, P<0.0001); 1=poor corporal condition, 2=moderate corporal condition, 3=excellent corporal condition. F) Correlation between good physical condition and confidence in the future (n=64, P=0.0002); 1=poor corporal condition, 2=moderate corporal condition, 3=excellent corporal condition.

- Late effects of therapy in survivors of Ewing's sarcoma family tumors. *J Pediatr Hematol Oncol* 1997;19:220-5.
13. Cella DF, Tulsky DS. Quality of life in cancer: definition, purpose and method of measurement. *Cancer Invest* 1993;11:327-36.
14. Schreiber D, Bell RS, Wunder JS, et al. Evaluating function and health related quality of life in patients treated for extremity soft tissue sarcoma. *Qual Life Res* 2006;15:1439-46.
15. Van Riel CA, Meijer-van den Bergh EE, Kemps HL, et al. Self-perception and quality of life in adolescents during treatment for a primary malignant bone tumour. *Eur J Oncol Nurs* 2014;18:267-72.
16. Graves KD, Carter CL. Outcome expectations and self-regulation in cancer patients: reliability, initial factor structure, and relationships with benefit finding. *Palliat Support Care* 2005;3:209-19.
17. Hampras SS, Moysich KB, Marimuthu SP, et al. Socioeconomic factors and the risk for sarcoma. *Eur J Cancer Prev* 2014;23:560-5.