Psychological distress in patients with soft-tissue tumors: Uncertainty is as detrimental as malignancy

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Background
Not only malignancy of tumors but also other factors influence the level of psychological distress in patients. For example, uncertainty evokes anxiety. Uncertainty can be reduced by a clear diagnosis and stringent therapy which gives patients a feeling of control (de Ridder et al., 2008). We examined the impact of uncertainty on distress and compared distress levels of 4 different rare kinds of soft-tissue tumors (STT, only 1% of all adult cancers): Sarcoma & GIST (both malignant) and lipoma & desmoid (both benign). Importantly, desmoids are associated with especially high uncertainty for the patients as their exact diagnosis occurs relatively late. This makes desmoids a perfect candidate to investigate the influence of uncertainty.

Methods
From May 2016 to December 2017 169 in- and outpatients with STTs filled out the standardized Hornheider Screening Inventory (HSI, Strittmatter et al. 2002), which consists of 7 items. A sum score >3 indicates relevant distress and the need for psychological counseling.

Statistics
We performed a Kruskall-Wallis Rank Sum test with the factor STT-type and the HSIsumscore as dependent variable. The significant effect of tumor type was followed-up by individual comparisons between the different tumors. In addition, as rather exploratory analyses, we computed a two-way ANOVA STT-type x Gender with follow-up Wilcoxon-Tests and computed regression analyses of HSIsumscore on age and duration of disease.

Results
Maineffect:
HSIsumscore differed significantly between STT-types: χ²=13.07, df=3, p=.004*.

Individual comparisons:
Desmoid vs. Lipoma: χ²=7.71, df=1, p=.006*.
Desmoid vs. GIST: χ²=3.71, df=1, p=.054
Desmoid vs. Sarcoma: χ²=1.98, df=1, p=.159
Lipoma vs. Sarcoma: χ²=9.41, df=1, p=.002
Lipoma vs. GIST: χ²=2.22, df=1, p=.136
GIST vs. Sarcoma: χ²=2.15, df=1, p=.142

Additional exploratory analyses:
After a non-significant Levene-Test for non-homogeneity of variances (F(7,134)=1.17, p=.32) an exploratory ANOVA was calculated. The significant main effect for STT-type from above was replicated: F(3,134)=2.9, p=.04*. In addition, a significant interaction for STT-type and gender was observed: F(3,134)=3.03, p=.02*.

Results of the Wilcoxon-Tests of gender differences for the different tumor types were: Lipoma W=14, p=.21, Desmoid: W=4, p=.03*, GIST W=67, p=.28, Sarcoma W=1090, p=.43.
The regressions on age (t=-0.32, p=.75) and duration of disease (t=0.69, p=.49) were not significant.

Conclusions
- Psychological distress in STT patients cannot be predicted by malignancy, duration of disease or age alone.
- Desmoids, although being benign per definition, seem to evoke relatively high levels of distress. We assume that uncertainty (e.g. different hypothesis during the diagnostic process, no peers to talk about the experiences associated with this illness) is driving this effect.
- Exploratively, women seem to be especially susceptible to distress by uncertainty. The higher resilience of men may be explained by their tendency to „passive information gathering“ behavior compared to „active information seeking“ (Saab et al., 2018) which might confront with stressful information.
- Doctors should be more sensitive to these effects and show empathy to signs of distress in patients even when the diagnosis does not seem to be „bad news“ from the professional perspective.

Limitations: Our sample is quite small so far, due to the nature of this research. The importance of patients’ well-being stresses the need for further research, though. This is especially important when dealing with rare cancers that are associated with higher uncertainty.

Acknowledgment
We thank Jan Zwickel for help with data analysis.

Literature