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**Patient reported outcomes in patients with Desmoid type fibromatosis**

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**Introduction:** Desmoid type fibromatosis (DTF) is a rare benign neoplasm with infiltrative growth, high local recurrences and inability to metastasize. Due to long disease course, unpredictable growth pattern, and low mortality, using only survival outcomes may be inappropriate. In this study we assessed the impact of DTF on patient reported outcomes.

**Methodology:** This was a cross-sectional study done in patients with DTF and healthy controls. The study participants were asked to fill the EORTC QLQ-C30 (European Organisation for Research and Treatment of Cancer, Quality of Life Questionnaire-Core-30; version 3.0), GAD-7 (Generalised Anxiety Disorder Assessment) and PHQ-9 (Patient Health Questionnaire-9). Outcomes were compared with healthy controls.

**Results:** 204 subjects (102 DTF patients and 102 healthy controls) were recruited for the study. Study parameters have been summarized in Table 1. Mean age of DTF patients was  $32.73 \pm 11.40$  years and 64.7 % were females. Appendicular skeleton (limbs + girdle) was most commonly involved in 59 % patients with equal involvement of upper and lower limbs. Abdominal wall or mesentery was primary site in 22.5 % of DTF patients. Patients have received median of 2 lines of therapy. Mean global health status in DTF patient  $65.58 \pm 22.64$ , was significantly lower than healthy controls. Similarly, DTF patients scored low on all functional scales except cognitive functioning. Symptom scale showed significantly higher symptom burden of fatigue, pain, insomnia and financial difficulties. Anxiety & depression was observed in 39.22 % and 50 % of DTF patients respectively. DTF patients had higher rates of mild, moderate and severe anxiety and depression compared to healthy controls.

**Conclusion:** DTF patients have significant symptom burden, poor functioning, and heightened anxiety and depression. Patient reported outcomes should be routinely used to assess treatment efficacy in DTF patients.

**Table 1. Difference in quality of life between healthy controls & DTF patients.**

<b>Parameter</b>	<b>Healthy controls (n=102)</b>	<b>Fibromatosis (n=102)</b>	<b>p value</b>
Female	58.80 %	64.71 %	0.74
Age in years(Mean $\pm$ SD)	32.54 $\pm$ 9.68	32.73 $\pm$ 11.40	0.54
<b>PHQ9</b>	3.14 $\pm$ 4.34	05.73 $\pm$ 05.25	<b>0.0001</b>
<b>GAD7</b>	2.86 $\pm$ 3.72	04.52 $\pm$ 04.53	<b>0.005</b>
<b>Global health status</b>	81.43 $\pm$ 17.83	65.58 $\pm$ 22.64	<b>&lt;0.0001</b>
<b><u>Symptom scales</u></b>			
Fatigue	15.79 $\pm$ 17.96	31.32 $\pm$ 24.10	<b>&lt;0.0001</b>
Nausea and vomiting	3.7 $\pm$ 13.23	05.70 $\pm$ 12.72	0.08
Pain	10.77 $\pm$ 17.33	34.60 $\pm$ 28.30	<b>&lt;0.0001</b>
Dyspnoea	6.04 $\pm$ 14.40	06.52 $\pm$ 16.25	0.92
Insomnia	9.14 $\pm$ 19.41	21.88 $\pm$ 28.32	<b>0.0002</b>
Appetite loss	7.83 $\pm$ 18.26	12.73 $\pm$ 22.50	0.07
Constipation	7.18 $\pm$ 15.28	09.46 $\pm$ 17.14	0.31
Diarrhoea	2.61 $\pm$ 8.99	03.92 $\pm$ 14.29	0.77
Financial difficulties	6.20 $\pm$ 20.30	29.07 $\pm$ 34.98	<b>&lt;0.0001</b>
<b><u>Functional scales</u></b>			
Physical functioning	90.24 $\pm$ 13.94	76.23 $\pm$ 19.35	<b>&lt;0.0001</b>
Role functioning	87.72 $\pm$ 17.25	72.85 $\pm$ 27.25	<b>&lt;0.0001</b>
Emotional functioning	83.59 $\pm$ 20.35	67.57 $\pm$ 23.98	<b>&lt;0.0001</b>
Cognitive functioning	87.73 $\pm$ 18.47	87.08 $\pm$ 20.17	0.80
Social functioning	91.57 $\pm$ 16.37	79.07 $\pm$ 26.92	<b>&lt;0.0001</b>

DTF-Desmoid type fibromatosis; EORTC QLQ-C30 - European Organisation for Research and Treatment of Cancer, Quality of Life Questionnaire-Core-30; GAD7 - Generalised Anxiety Disorder Assessment -7; and PHQ9 - Patient Health Questionnaire-9. p values < 0.05 suggest statistical significance.

