**BACKGROUND**

- Desmoid tumors (aggressive fibromatoses) are rare, locally aggressive, and potentially motile soft-tissue tumors that infiltrate surrounding structures and can rarely metastasize; in rare cases when vital organs are impacted, desmoid tumors can be life-threatening.
- Patients may experience high symptom burden, including pain, impaired physical functioning, and fatigue, that can cause negative physical, emotional, and social impacts on daily activities, ultimately impacting their quality of life (QoL).1,4
- Generic patient-reported outcome (PRO) tools have been used to evaluate symptom burden, but rarely assess specific desmoid tumors and impact.5

**OBJECTIVE**

To describe real-world, patient-reported symptom severity and impact of desmoid tumors on QoL, using a desmoid tumor-specific PRO tool.

**RESULTS**

**SYMPTOM BURDEN**

- The DTSS mean total symptom score was significantly worse for participants with a current desmoid tumor versus those without (Figure 1a).
- Pain and extra-abdominal symptom domain scores, including item scores for difficulty moving body areas near the tumor, and getting comfortable in bed, were significantly worse for participants with a current desmoid tumor versus those without (Figure 2a and b).
- Participants with a current tumor (versus those without) experienced a significantly worse sense of hopelessness (Figure 2b) – Fear of future diagnostic tests (overall mean, 4.3), fear of tumor recurrence/growth (overall mean, 5.6), and frustration (overall mean, 4.5) were commonly reported regardless of current tumor status.

**IMPACT OF DESMOID TUMORS ON QOL**

- Physical functioning and sleep domain scores, including item scores for difficulty doing moderate activities, difficulty moving body areas near the tumor, and getting comfortable in bed, were significantly worse for participants with a current desmoid tumor versus those without (Figure 2a and b).
- Participants with a current tumor (versus those without) experienced a significantly worse sense of hopelessness (Figure 2b) – Fear of future diagnostic tests (overall mean, 4.3), fear of tumor recurrence/growth (overall mean, 5.6), and frustration (overall mean, 4.5) were commonly reported regardless of current tumor status.

**QOL OUTCOMES BY TUMOR LOCATION**

- Participants with desmoid tumors in joint/extra-locations reported significantly worse scores for total symptoms, pain, and physical functioning (Figure 3) compared with other desmoid tumor locations.

**CONCLUSIONS**

- This analysis of DTSS registry data shows that desmoid tumors have a negative impact on patients’ lives, where patients with a current tumor experience significantly worse pain, physical functioning, and sleep than those without a current tumor.
- Participants reported fear of future diagnostic tests, fear of tumor recurrence/growth, and frustration related to their situation regardless of current tumor status, which suggests that, in addition to physical needs, care for patients with desmoid tumors should focus on emotional support.
- As the DTSS and DTIS surveys solicit participant responses based on the previous 24 hours and 7 days, respectively, symptom severity and impact on QoL may have an association with treatment but may not be solely attributable to the desmoid tumor itself.
- Data collected in this analysis using the GODDESS PRO tool are similar to other published data collected using EORTC QLQ-C30, EORTC-1, and PHQ-9, which show high symptom burden due to pain, fatigue, insomnia, anxiety, and depression.
- Effective care of patients with desmoid tumors depends on understanding the burden and impact of these tumors.