

The Association of Pain With Function for Adult Patients With Desmoid Tumor: Findings From the Desmoid Tumor Research Foundation Natural History Study

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Background: Pain represents a key clinical symptom for adult patients with desmoid tumors (DT) and has been reported to be a prognostic factor for poor outcomes, including potentially negative effects on a patient's function (eg, sleep, physical functioning, or emotional impact). This analysis describes the real-world association of patient-reported, DT-specific pain with function via the global, survey-based Desmoid Tumor Research Foundation (DTRF) Natural History Study from data collected between September 2017 to August 2023.

Methods: Adult patients reported DT symptoms and impact on their lives via a DT-specific patient-reported outcomes (PRO) tool: the GOunder/DTRF-DEsmoid Tumor Symptom Scale (GODDESS[®] DTSS, scale: 0–10) and Impact Scale (GODDESS[®] DTIS, 5-point Likert scale from “None – All the time”, or an 11-point numeric rating scale [NRS] from 0–10). Higher scores indicate worse symptoms or more severe impact (*Qual Life Res.* 2023; 32:2861). The association of DTSS pain scores with DTIS function domain (ie, sleep, physical functioning, and emotional impact) scores was assessed by Pearson Product Correlation; mean function domain scores were compared using ANOVA for patients with pain domain scores ≥ 4 (uncontrolled pain) vs < 4 (controlled pain).

Results: In total, 335 patients (median age: 39 years) completed the GODDESS[®] PRO tool (median pain domain score: 4.0). A significant correlation was found between the scores for pain domain and all function domains ($P < .0001$) with correlation coefficients ranging from 0.47–0.61 (moderate to strong). Similar degrees of correlation were observed across subgroups of DT locations (abdominal wall, intra-abdominal, joint/extremity, or other) and presence or absence of a current DT or a prior DT treatment. Patients with higher (worse) pain domain scores (≥ 4) had significantly higher (worse) function domain scores vs patients with lower pain domain scores (< 4) ($P < .0001$) for sleep (mean: 2.1 vs 1.2 on 0–4 scale), physical functioning (mean: 2.2 vs 1.0 on 0–4 scale), and emotional impact (mean: 5.4 vs 3.0 on 0–10 scale).

Conclusion: Worse pain in adult patients with DT is associated with worse sleep, physical functioning, and emotional impact. This highlights the need for a multidisciplinary approach and development of therapies to effectively reduce pain as a key clinical treatment goal in the management of DT for patients with or without a current tumor.