



Trends in the Management of Desmoid Tumors in the Veterans Affairs (VA) National Database



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Background



Desmoid tumors (DT) are rare, locally aggressive, and invasive soft-tissue tumors that infiltrate surrounding structures. In rare cases, these tumors can impact vital organs.¹⁻³



In the past, surgery was the standard approach to primary treatment of DT. However, guidelines have shifted considerably in the last ten years, and surgical resection is now less favored due to high recurrence rates. Active surveillance is recommended for asymptomatic, minimally symptomatic, or non-progressive DT.^{4,5}



Systemic treatment options have expanded with the incorporation of nirogacestat in the treatment guidelines for progressing or symptomatic DT.⁴⁻⁵



This analysis aimed to characterize time from DT diagnosis to surgery in the VA.

Methods

16.4 million pathology reports from 2003 to 2024 retrospectively searched within the National VA Corporate Data Warehouse

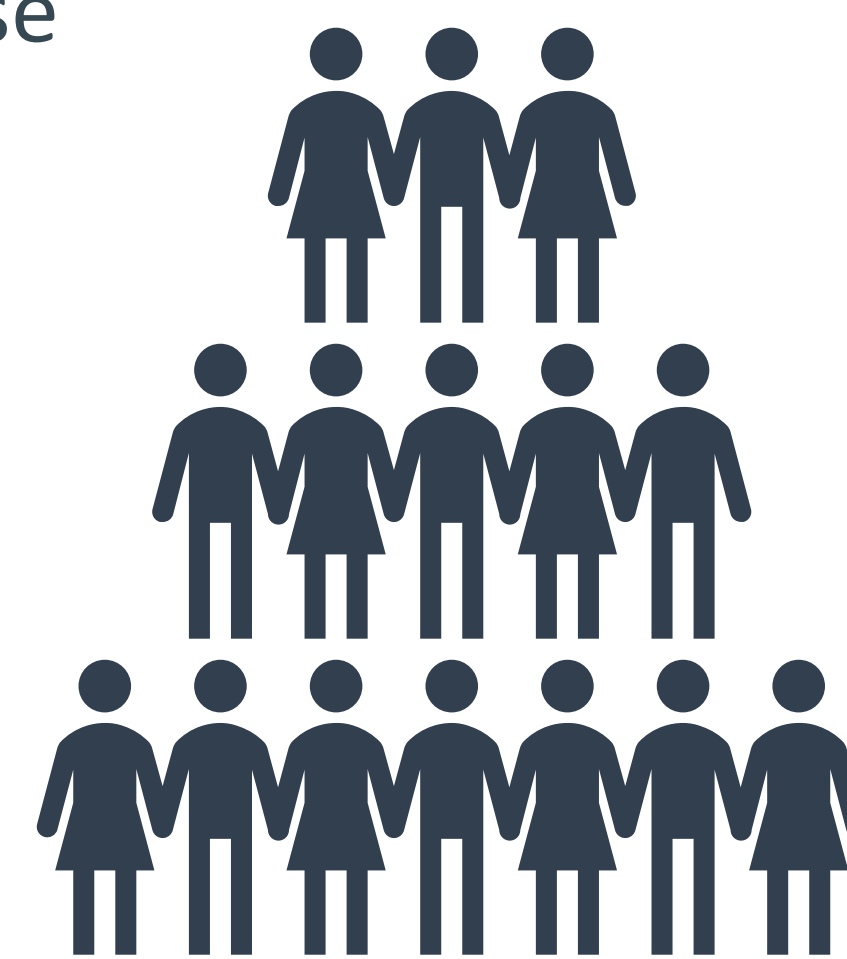
Word search “desmoid fibromatosis”, “desmoid tumor”, “aggressive fibromatosis”

520 pathology reports
426 patients

Manual Review

Gold standard cohort
(confirmed to have true DT)

322 pathology reports
270 patients



Manual review of charts performed to determine whether and when surgery occurred

Results

Time from Diagnostic Treatment until Surgery for Patients with DT

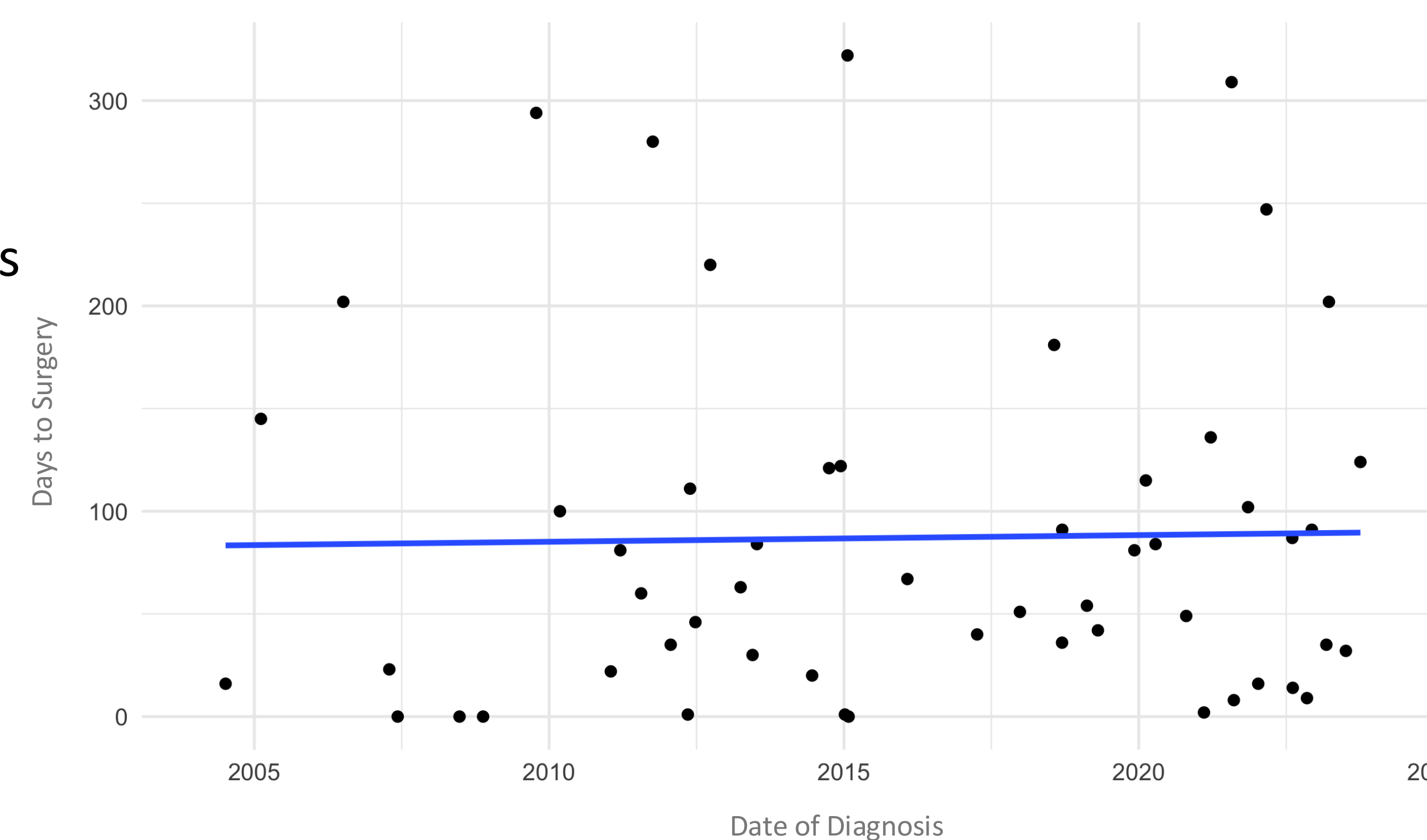


Figure 1: Trends in time between initial diagnosis and subsequent surgery among patients with DT treated with surgery by date of diagnosis. Each dot represents a single patient. The blue line is a linear regression line that demonstrates the trend in surgery over time, showing no significant change over time.

- 65 (24%) patients underwent surgery following diagnosis.
- Anatomic location varied: 34% chest wall; 29% abdominal wall; 27% head/neck; 21% intraabdominal; and 19% extremities/ girdles.
- For those who underwent surgery, 56 (86%) had one surgery, five had two (7.7%), two had three (3.1%), one had four (1.5%), and one had six (1.5%).
- The median number of days between diagnosis and surgery was 84 (interquartile range 32–220).
- Greater than 50% of surgeries occurred within the first three months of diagnosis while more than 75% happened within the first year.

Conclusions

- Despite updated guidelines recommendations shifting away from surgery, there have been no apparent changes from 2003 to 2024 in the time to surgery from diagnosis in the VA system.
- Further work is needed to analyze individual patient and tumor level data better to understand what drives this trend in the VA of patients having surgery so quickly following DT diagnosis.

References

1. Gounder MM, et al. *Cancer*. 2020;126(3):531–539. ; 2. Kasper B, et al. *Ann Oncol*. 2017;28(10):2399–2408.; 3. Sbaraglia M, et al. *Pathologica*. 2021;113(2):70–84.; 4. Kasper B, et al. *JAMA Oncol*. 2024;10(8):1121–1128.; 5. NCCN Clinical Practice Guidelines in Oncology for Soft Tissue Sarcoma (Version 1.2025) May 2, 2025.

