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The Epidemiology of Desmoid Tumors in Denmark

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Introduction/Aim

We described the epidemiology, demographic, clinical, and treatment characteristics of desmoid tumors (DT) treated at two sarcoma centers in Denmark, and healthcare resource utilization compared with the general population.

Methods

Using Danish health registers, we identified DT patients treated between 2009 and 2018. Data on patients, tumors, and treatments were obtained. For each patient, ten persons from the general population were randomly matched on birth year, sex, and region of residence.

Results

A total of 179 DT patients, mean age was 38, 76% female, were identified. Incidence of DTs was stable and ranged from 2.2 (2011) to 4.1 (2015) per 1,000,000 individuals. Anatomical DT sites included extraabdominal (49%), abdominal wall (40%), and intra-abdominal or retroperitoneal areas (8%). While 73% of patients were initially treated surgically between 2009 and 2014, this was true for only 34% between 2015 and 2018. 56% of patients utilized chemotherapeutic agents, tyrosine kinase inhibitors, NSAIDs, opioids, antidepressants, or steroids at some point during the three years before their DT diagnoses, and 70% of surgically treated and 63% of non-surgically treated patients utilized any of these same drugs in the following three years. The average number of inpatient and outpatient visits, days of hospitalization, and subsequent surgical procedures were higher among DT patients than the comparison cohort.

Conclusion

DTs are rare, but have a large impact on patient's health, healthcare resource utilization, and medication utilization.