

Epidemiology of Tenosynovial Giant Cell Tumor in the United States

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Objective

- To estimate the overall and gender-specific annual incidence and prevalence of localized tenosynovial giant cell tumor (L-TGCT) and diffuse tenosynovial giant cell tumor (D-TGCT) in the United States

Conclusions

- The results of this study suggest that, in the United States, the estimated prevalence of L-TGCT and D-TGCT is 113,377 and 29,511, respectively. Therefore, the estimated prevalence of tenosynovial giant cell tumor (TGCT) in the US adult population is 142,888

- These estimates reveal that a large population of patients with TGCT exists in the United States, with a significant unmet need
- Surgery, repeat surgery due to recurrence, and pexidartinib (systemic therapy) are the only treatment options available for these patients
- In the United States, pexidartinib is the only drug approved by the US Food and Drug Administration for the treatment of adult patients with symptomatic TGCT associated with severe morbidity or functional limitations and not amenable to improvement with surgery
- Further efforts are needed to identify and develop additional treatment options for this underserved patient population

Introduction

- TGCT is a rare, nonmalignant neoplasm involving the synovium and tendon sheaths that typically presents in young and middle-aged adults¹
- TGCT is usually a monoarticular disease that involves the bone, soft tissue, synovium, or tendon sheath of small or large joints. Initial symptoms are often minimal due to the slow progressive nature of the disease, but as the tumor mass grows within the intra-articular space and surrounding tissue, symptoms can progress from mild to debilitating
- Commonly reported symptoms include pain, stiffness, swelling, and reduced range of motion of the affected joint, which can become severe and result in marked functional limitation²
- L-TGCT is usually a benign neoplasm, most commonly occurring in the digits³
- D-TGCT is a locally aggressive, nonmalignant neoplasm composed of synovial-like mononuclear cells, multinucleate giant cells, foam cells, siderophages, and inflammatory cells that may be intra-articular or extra-articular. D-TGCT most commonly occurs in large joints, particularly in the knee, as well as in the ankle and hip⁴

Methods

- To estimate the annual incidence of TGCT in the United States, subtype- and gender-specific TGCT incidence rates reported by Mastboom et al¹ in The Netherlands were extrapolated to the gender-specific US population based on 2020⁵ census estimates
- To estimate the adult prevalence of TGCT in the United States, subtype- and gender-specific prevalence reported by Ehrenstein et al³ in Denmark were extrapolated to the gender-specific adult (≥18 years) US population census estimates for 2020⁵

Results

- The estimated overall annual incidence (new cases) of:
 - L-TGCT of the digits in the United States is 11,028 (female, n = 6663; male, n = 4365; **Table 1**)
 - L-TGCT of the extremities in the United States is 3610 (female, n = 2155; male, n = 1455; **Table 1**)
 - D-TGCT in the United States is 1646 (female, n = 999; male, n = 647; **Table 1**)
 - TGCT in the United States is 16,284 (L-TGCT, n = 14,638; D-TGCT, n = 1646)

Table 1. Estimated Annual Incidence of TGCT by Subtype and Gender in the United States

	US population	L-TGCT: digits		L-TGCT: extremity		D-TGCT	
		Incidence	IR ^a	Incidence	IR ^a	Incidence	IR ^a
Overall	325,268,000	11,028	34 (33-35)	3610	11 (11-12)	1646	5 (4-5)
Female	165,807,000	6663	40 (39-42)	2155	13 (12-14)	999	6 (5-6)
Male	159,461,000	4365	27 (26-29)	1455	9 (9-10)	647	4 (3-4)

TGCT, tenosynovial giant cell tumor; L-TGCT, localized tenosynovial giant cell tumor; D-TGCT, diffuse tenosynovial giant cell tumor; IR, incidence rate.

^aEstimates from Mastboom et al.¹

- The estimated prevalence* of:
 - L-TGCT in US adults is 113,377 (female, n = 69,482; male, n = 43,895; **Table 2**)
 - D-TGCT in US adults is 29,511 (female, n = 15,833; male, n = 13,678; **Table 2**)
 - TGCT in US adults is 142,888 (female, n = 85,315; male, n = 57,573)

*Estimated for the year 2020.

Table 2. Estimated Prevalence of TGCT by Subtype and Gender in US Adults

	US population	L-TGCT		D-TGCT	
		Prevalence	Prevalence/10 ⁶ (95% CI) ^a	Prevalence	Prevalence/10 ⁶ (95% CI) ^a
Overall	255,200,373	113,377	44.3 (42.4-46.3)	29,511	11.5 (10.6-12.6)
Female	130,851,717	69,482	53.1 (50.1-56.2)	15,833	12.1 (10.7-13.6)
Male	124,348,656	43,895	35.3 (32.9-37.9)	13,678	11.0 (9.6-12.5)

TGCT, tenosynovial giant cell tumor; L-TGCT, localized tenosynovial giant cell tumor; D-TGCT, diffuse tenosynovial giant cell tumor; CI, confidence interval.

^aEstimates from Ehrenstein et al.³

References

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Disclosures

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