#2145039: Real-World Management of Symptomatic vs Asymptomatic TGCT from an Observational Registry

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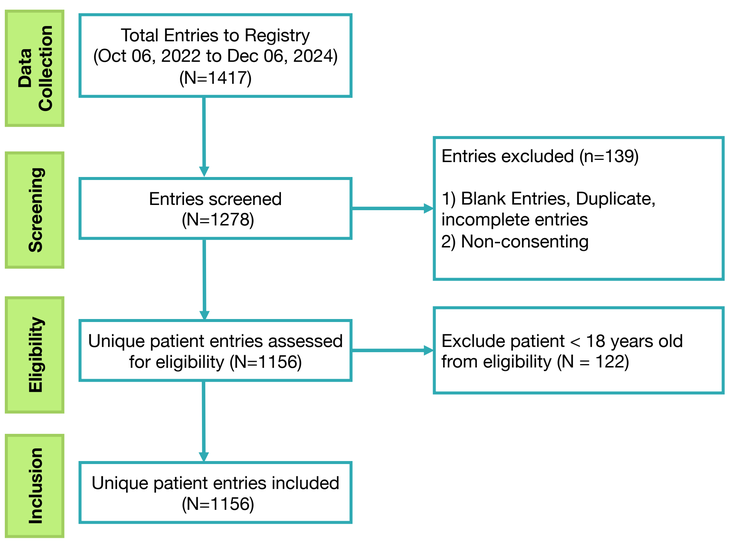
Background

Tenosynovial giant cell tumor (TGCT) is a rare, locally aggressive tumor originating in the synovial lining of the joint, bursa, and tendon sheath. TGCT presents with a wide range of clinical symptoms and severity. Treatment decisions should balance the possible curative nature of surgery with the benign, potentially indolent, nature of TGCT, the risk of recurrence and the potential for surgery-related morbidity.

Methods

The TGCT Support Registry is an international, patient-reported registry initiated in 2022 by TGCT Support, a program of The Life Raft Group. This analysis included adults with TGCT, classified as symptomatic or asymptomatic using pain inference and physical function derived from validated patient-reported outcomes tools (e.g., PROMIS-PF).



TGCT management is complex, and must balance symptom burden, treatment timing, tailored approaches, and patient perspectives.

Results

Table 1. Characteristics of patients stratified by symptom status

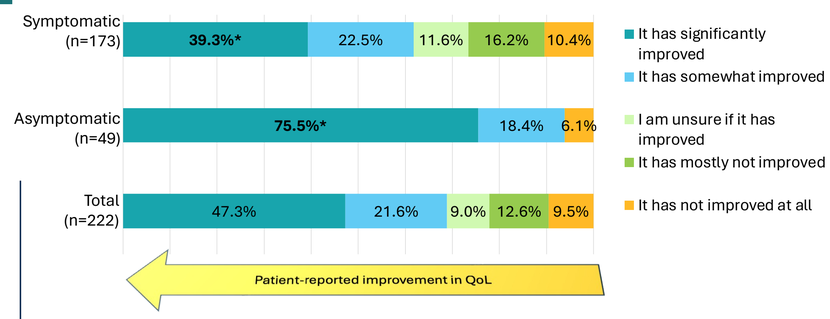
	Symptomatic (n=893, 77.2%)	Asymptomatic (n=263, 22.8%)	Total (n=1156) (n, % column)
Female sex, n (%)	681 (74.5)	152 (57.8)	833 (72.1)
Median age at Diagnosis, years (range)	43.2 (18–84)	47.8 (18–81)	44.0 (18–84)
Diffuse TGCT	632 (70.8)	163 (62.0)	795 (68.8)
Located in the US, n (%)	423 (47.4)	151 (57.4)	574 (49.7)
Location of disease, n (%)			
Knee	616 (69.0)	167 (63.5)	783 (67.7)
Hip	84 (9.4)	28 (10.6)	112 (9.7)
Ankle	104 (11.6)	32 (12.2)	136 (11.8)
Other	89 (10.0)	36 (13.7)	125 (10.8)

Table 2. Patient treatment journey by symptom status

	Symptomatic (n=893, 77.2%)	Asymptomatic (n=263, 22.8%)	Total (n=1156) (n, % column)
Treating HCP, n (%)			
Orthopedic Surgeon	679 (76.0)	187 (71.1)	866 (74.9)
Orthopedic Oncologist	511 (57.2)	138 (52.5)	649 (56.1)
Medical Oncologist	235 (26.3)	62 (23.6)	297 (25.7)
Academic Treating HCP Affiliation, n (%)	413 (46.2)	119 (45.2)	532 (46.0)
Average surgeries ± SD	2.8 ± 2.7*	1.6 ± 1.2	2.2 ± 1.8
Pexidartinib	85 (9.5)	29 (11.0)	114 (9.9)
Imatinib	82 (9.2)	14 (5.3)	96 (8.3)
Vimseltinib	16 (1.8)**	15 (5.7)	31 (2.7)
Of those with prior surgery	**Symptomatic (n=727)**	**Asymptomatic (n=183)**	**Total (n=910)**
Recurrence(s), n (%)	458 (63.0)**	67 (36.6)	525 (57.7)

*p < 0.01 determined by 2-tailed t test. *** p < 0.01 determined by Mantel-Haenszel χ^2

Figure 2. Patient-Reported Quality of Life Improvement with Systemic Therapies, Stratified by Symptom Status



* p < 0.01 determined by Mantel-Haenszel χ^2 between symptomatic vs asymptomatic patients

Future Directions for Research

This real-world analysis underscores the need for timely diagnosis, early multidisciplinary care, tailored symptom-focused strategies, and integration of physical therapy, supportive care, and thoughtful treatment timing to reduce disease burden and prolong asymptomatic periods. Given the transient nature of symptom status and its influence by repeated interventions, it remains unclear whether sustained dysfunction is driven by TGCT itself or treatment-related sequela.

Acknowledgements

We'd wish to acknowledge patients and families affected by TGCT, as well as the providers and our collaborators.