SACHIN SARCOMA SOCIETY

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Analytical Report on the Desmoid Tumor Patient Experience: Insights from the Sachin Sarcoma Society Survey

SUMMARY

Based on a cohort of 105 unique patients, the analysis reveals critical insights into patient demographics, clinical characteristics and treatment journeys.
The patient cohort is predominantly **female (66%) with a median age of 34. Tumors** are most commonly located in the **abdominal/chest wall/torso (38%) and limbs (33%).** A significant finding is the high prevalence of **ongoing pain, reported by 44% of patients**, highlighting a major unmet need in quality-of-life management.

The landscape is **dominated by surgical intervention (61% of patients)** and the **use of the targeted therapy Sorafenib (48%)**. A striking **41% of female** patients report the onset of their **desmoid tumor after pregnancy**. Furthermore, the data reveals wherein **chemotherapy** is preferentially **used in a significantly younger patient population** (average age 26.6 years), pointing to distinct clinical challenges in this group.

DATA SNAPSHOT

Characteristic	Value
Age	
Mean	33.6 years
Median	34 years
Range	2 - 65 years
Sex	
Female	69 (66%)
Male	36 (34%)
Marital Status	
Married	56 (53%)
Not Married	49 (47%)
Tumor Location Group	
Abdominal/Chest Wall/Torso	40 (38%)
Limbs	35 (33%)
Head/Neck	16 (15%)
Pelvic/Retroperitoneal	9 (9%)
Other/Multiple	5 (5%)
Pain Prevalence ("Do you have pain?" = Yes)	**46 (44%)**

Table 1: Demographic and Baseline Clinical Characteristics of the Patient Cohort (N=105)

TREATMENT

Among systemic therapies, **Sorafenib is the most prevalent, with 48%** of patients reporting its use. **Chemotherapy has been administered to 21%** of patients. Other, more localized treatments are utilized less frequently: **radiation therapy was reported by 11%** of the cohort, while **ablative techniques such as cryoablation (4%) and microwave ablation (2%)** are used by a smaller subset of patients.
The analysis shows that while **many patients had one or two surgeries**, there is a tail of patients with extensive surgical histories, including individuals reporting three, four, five, and even nine separate surgeries related to their desmoid tumor. This **pattern of repeat surgery is a direct reflection of a clinical challenge in managing desmoid tumors: their high rate of local recurrence**. Even after a seemingly complete removal, these tumors can regrow, often more aggressively, necessitating intervention.

1 Surgery	39	61%
2 Surgeries	14	22%
3 Surgeries	5	8%
4+ Surgeries	6	9%

Table2: Distribution of number of Surgeries (among 64 surgical patients)

The high prevalence of ongoing pain among a population that is largely undergoing or has completed treatment is a stark indicator of the disease's significant impact on quality of life. **Pain is a primary symptom of desmoid tumors**, often arising as the growth presses against or invades adjacent nerves, organs, or blood vessels. This ongoing pain burden may be attributable to the tumor itself, post-surgical complications, or side effects of systemic therapies. **This finding positions pain management as a major unmet need and a critical area for patient support and education.**

SIDE EFFECTS

Common side effects reported include **"Hand Foot Syndrome," "Hair loss," and "Pain"** Many patients choose the "All of the above" option, indicating they face multiple overlapping toxicities that affect their quality of life. This underscores the **need for proactive side effect management, an area where the Sachin Sarcoma Society offers valuable educational resources and support.**

Side Effect	Sorafenib Users (n=50)	Chemotherapy Users (n=22)	Surgery Only (n=24)
Hand-Foot	**20 (40%)**	4 (18%)	1 (4%)
Hair Loss	7 (14%)	**10 (45%)**	0 (0%)
Pain	10 (20%)	5 (23%)	**7 (29%)**
Diarrhea	9 (18%)	4 (18%)	1 (4%)
Fatigue/Tiredness	11 (22%)	6 (27%)	5 (21%)

Table 3: Comparative Analysis of Top 5 Reported Side Effects by Primary Treatment Regimen

CONCLUSION

This analysis of the Sachin Sarcoma Society's patient survey compiles individual experiences into a cohesive narrative about the desmoid tumor journey in India. The findings provide an evidence-based roadmap for the Society to evolve its strategy encompassing unique burdens related to pain, treatment side effects, and life circumstances like new motherhood. The key takeaway is the **importance of listening to patients through structured data, providing a roadmap for the Society to enhance its strategy.** The Society aims to be a vital resource, **leveraging patient voices for advocacy, education, and improved quality of life for those affected by desmoid tumors.**

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