

45P “THE PATIENT VOICES: REVEALING THE CHALLENGES FACED BY PERSONS WITH DESMOID TUMORS IN A MIDDLE-INCOME COUNTRY”

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BACKGROUND

Desmoid tumors (DT) present a rare yet significant medical challenge, often leading to substantial morbidity and profound psychosocial impacts on affected individuals. The rarity of these tumors exacerbates the hurdles faced, especially within middle-income countries where resources and awareness may be limited. In an effort to illuminate and comprehend these challenges within the Brazilian context, the Desmoid Tumor patient organization of Brazil - Desmoide Brasil (DB) undertook a qualitative study.

CONTEXT

Desmoid tumors, also known as aggressive fibromatosis, are characterized by their locally aggressive behavior, with a tendency to infiltrate surrounding tissues without metastasizing. Despite their non-malignant nature, they can significantly impair bodily functions and lead to debilitating symptoms, such as pain, restricted mobility, and disfigurement. The psychological toll of living with DTs, often compounded by the uncertainty of their growth patterns, imposes a profound burden on patients and their families.

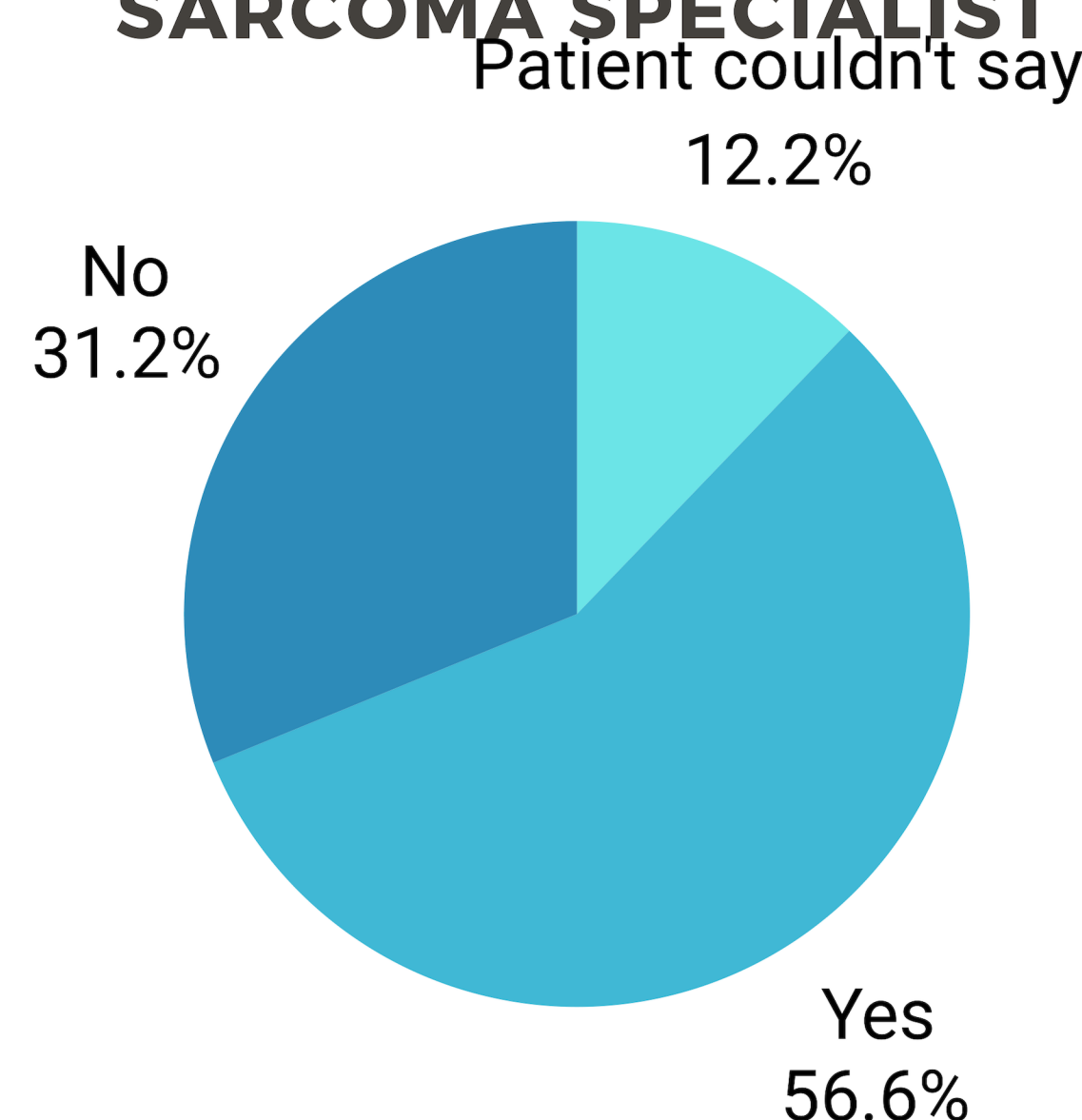
CHALLENGES IN MIDDLE-INCOME COUNTRIES

In middle-income countries like Brazil, the diagnosis and management of rare conditions such as DTs pose distinct challenges. Limited access to specialized medical centers, scarcity of expertise in diagnosing these tumors, and restricted availability of advanced treatment modalities create formidable barriers to optimal care. Additionally, the dearth of awareness campaigns and support networks contributes to the isolation experienced by patients grappling with this uncommon disease.

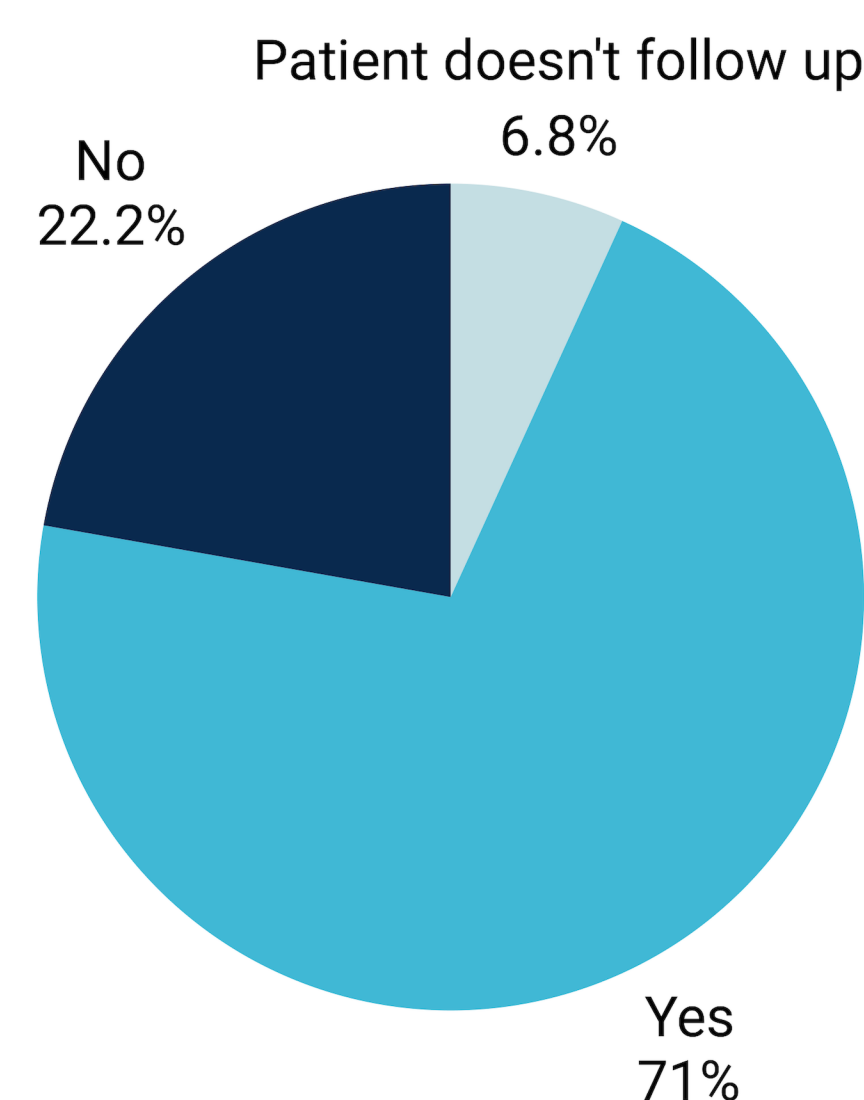
METHODS

Between October/2022 and November/2023, an online questionnaire was distributed using Google Forms among members of Desmoide Brasil. The questionnaire sought information on gender, age at diagnosis, tumor primary site, previous treatments, as well as personal hurdles such as pain management, difficulties in accessing treatment due to travel, and levels of trust in healthcare services. Participants were also invited to share openly their most pressing challenges when diagnosed and viewpoints regarding their condition. All responses underwent meticulous review and were systematically categorized based on recurring themes, facilitating a comprehensive analysis of the gathered qualitative data.

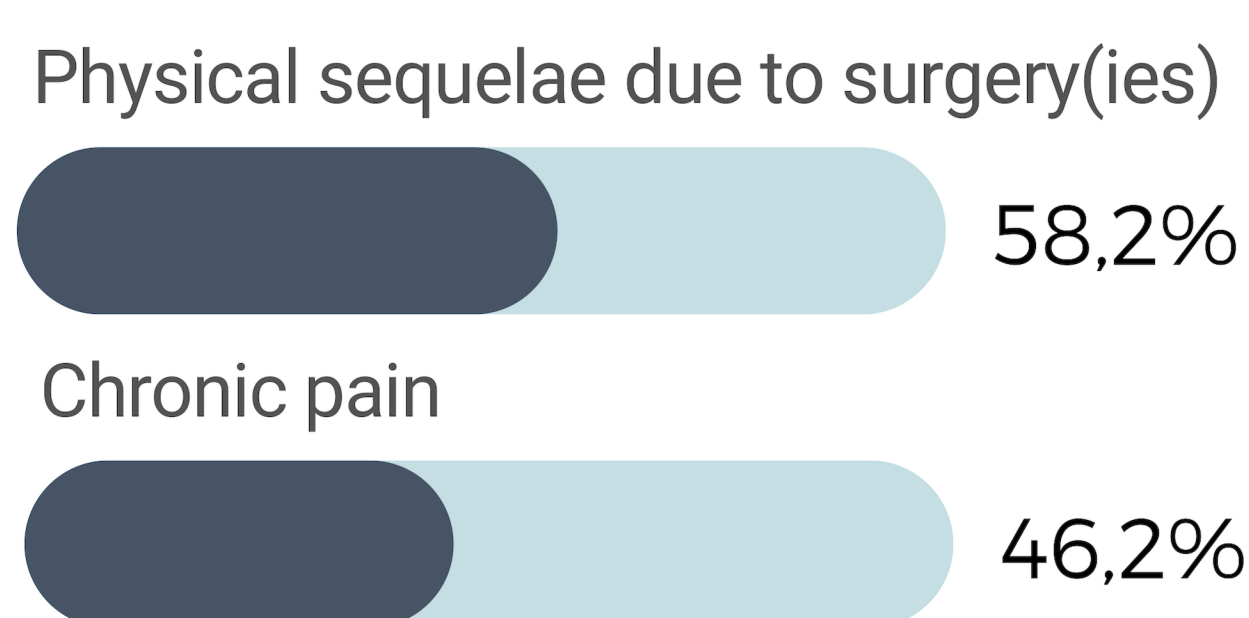
PATIENT DIAGNOSED BY A SARCOMA SPECIALIST



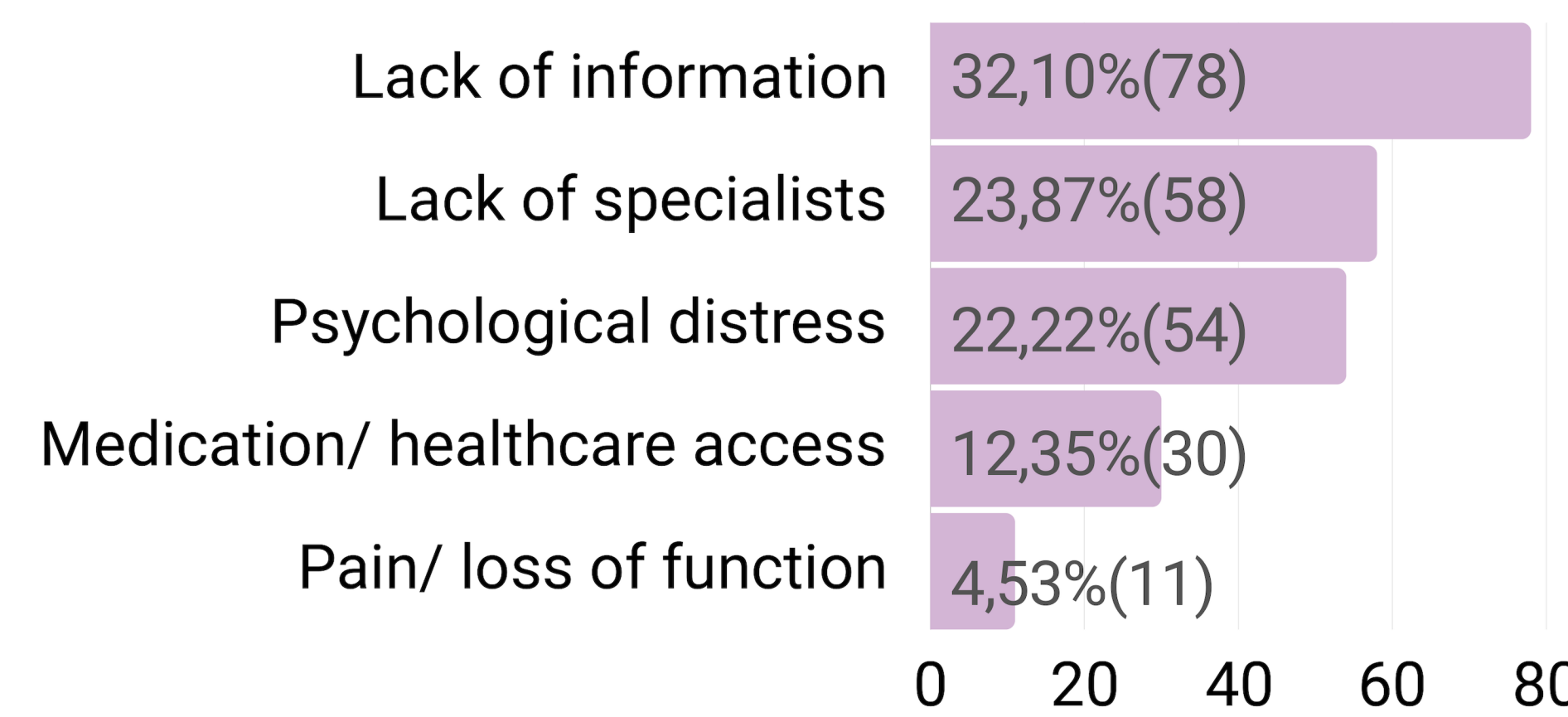
CONFIDENCE IN THE APPROACH CHOSEN BY THE HEALTHCARE TEAM



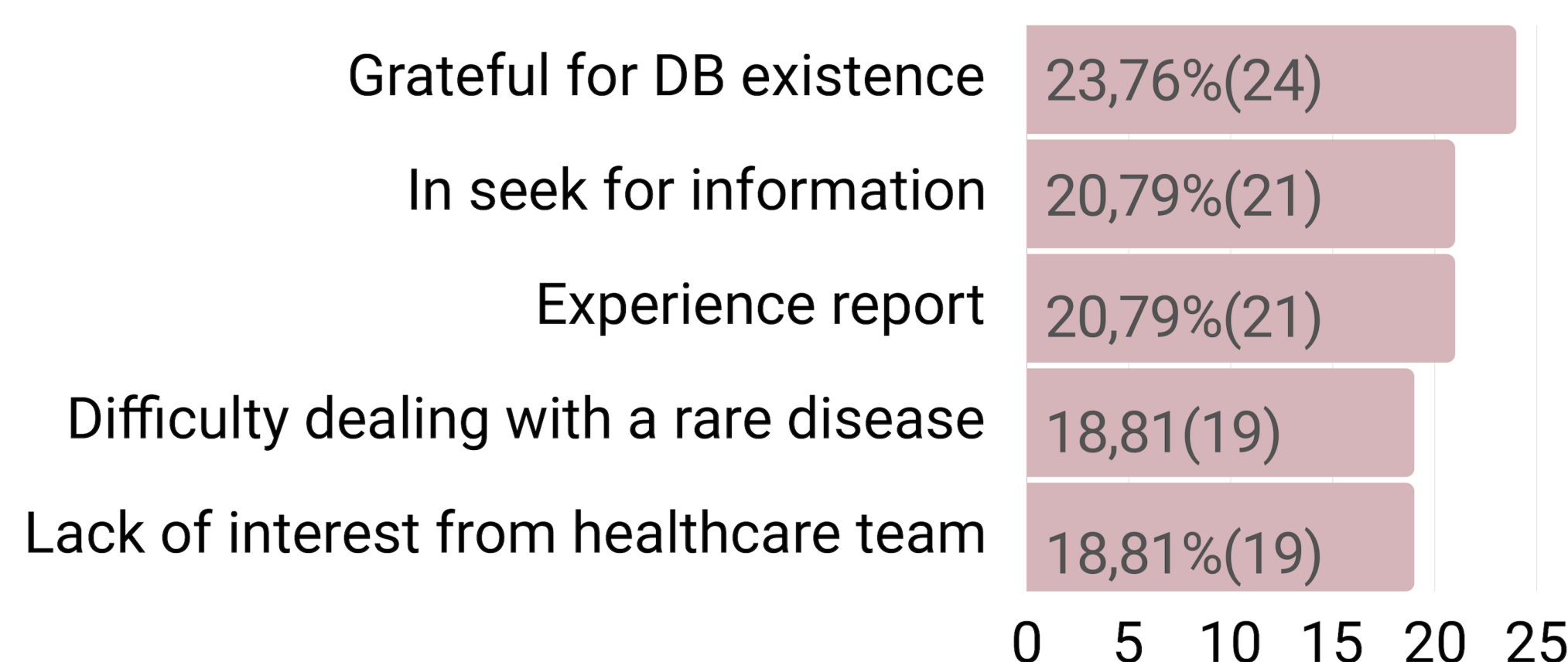
QUALITY OF LIFE



CHALLENGES UPON DIAGNOSIS (243 ANSWERS)



PRIMARY PERSPECTIVES UPON DIAGNOSIS (99 ANSWERS)



RESULTS

A total of **279 patients** completed the form. 86% (240) were female, and 14% (39) were male. Age at diagnosis was 30-49 years in 53%(148), 18-29 in 28%(78), 0-17 in 11.5% (32) and 50-69 in 7.5% (21). DT primary site was extra abdominal in 88.5% (247), while 11.5% (32) were intra-abdominal. **Surgery was performed in 60,9% (170) of patients. Of these, 58.2% (99) reported a chronic decline in their quality of life** as a result, and 59.4% (101) reported recurrence. **46.2% (129) of the patients reported pain, and 22.2% (62) reported insecurity with their healthcare team.** 43% (120) of them reported needing to travel for treatment. Of the 243 (87%) patients who answered the first open-ended question, the most cited challenges were **lack of DT information** in 32.1%(78) of comments, **lack of a specialist team** in 23.8% (58), **psychological distress** in 22.2% (54). The primary perspectives shared by 99 pts on the second open-ended question were: **appreciation for the existence of a patient advocacy organization** in 23.7% (24), and **desire for further information and support** in 20.7% (21).

CONCLUSIONS

This quantitative and qualitative study sheds light on the complex landscape of challenges faced by Brazilian patients upon receiving a desmoid tumor diagnosis. From the initial shock of limited information to the ongoing struggles with psychological distress, medication access, and healthcare coordination, the experiences of DT patients are varied and profound. The findings underscore the urgent need for tailored support services, enhanced medical education, and improved patient-provider communication within the Brazilian healthcare system. Additionally, the voices and perspectives shared by participants highlight the resilience and determination of DT patients in seeking better outcomes and advocating for their needs. Considering the findings, DB has identified its focus for the next 5 years as promoting DT information and facilitating access to specialists. This strategic direction aligns closely with the identified needs of patients, aiming to bridge the gap in knowledge, improve the availability of specialized care, and empower individuals in their DT journey. By addressing these challenges and fostering a patient-centered approach to care, healthcare providers and policymakers can work towards improving the overall quality of life and treatment outcomes for individuals navigating the complexities of desmoid tumors in Brazil.

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