

# **Patient Reported Outcomes on Quality of Life in Neurofibromatosis Patients Undergoing Surgery**

Presenter: Eduardo Gonzalez, MD

Co-Authors: Jordan D Frey, MD; Z-Hye Lee, MD; Sheel Sharma, MD

Affiliation: Hansjorg Wyss Department of Plastic Surgery, New York University Langone Health

## **BACKGROUND:**

Surgical excision of dermal neurofibromas and peripheral nerve sheath tumors in neurofibromatosis patients represent a therapeutic challenge since no evidence-based guidelines exist on criteria for undergoing surgery. Treatment is considered to be symptomatic, focused primarily on pain management. We report our neurofibroma center's experience with surgical excision of neurofibromas and peripheral nerve sheath tumors.

## **METHODS:**

Patients with neurofibromatosis type-1, type-2, and Schwannomatosis undergoing surgery for excision of neurofibromas or peripheral nerve sheath tumors were enrolled in a prospective database. Demographic and clinical data was collected and a survey was applied, which consisted of 10 questions on interference of symptoms with daily activities (e.g., dressing, ambulating), pain scale, impression of overall state of health, and experience with surgery. Primary outcome was comparison of these quality of life survey questions before and after surgery. Secondary outcomes were post-operative complications (e.g., wound complications, hematoma, re-operations). Student's t-tests were used to analyze binary data sets. Statistical significance was predetermined at  $p < 0.05$ .

## **RESULTS:**

Ninety-six patients were enrolled in the study with a mean age of 32 years, 51% of the patients were female. A diagnosis of NF type 1 was carried in 80% of patients, NF type 2 in 11% of patients, while Schwannomatosis in 9%. Surgical pathology reported tumor histology as neurofibromas (84%) (of which 29% were plexiform), Schwannomas (10%), mixed tumors (4%), and malignant peripheral nerve sheath tumors (2.7%). The most common indication for surgery was symptoms other than pain interfering with daily activities (49%), followed by pain (24%), interval growth of lesion (21%) and other concerning features (5%). Patients' reported state of health improved from an average of 2.9 (of 5)(pre-operative) to 3.9 (of 5)(post-

operative)( $p < 0.05$ ), interference of symptoms with daily activities improved from 4.1 (of 5)(pre-operative) to 2.0 (of 5)(post-operative)( $p < 0.05$ ), 95% responded that they would undergo surgery again. A post-operative complication was reported in 9.7% of patients, with wound complications (e.g. delayed wound healing, surgical site infection) being the most common.

## **CONCLUSIONS:**

This large case series of patients undergoing surgical excision of neurofibromas and peripheral nerve sheath tumors support patient-reported symptoms as an indication to undergo surgery. Such intervention translates into significant improvement of daily activities, pain scores, and patients' perception of their state of health. The post-operative complication rate is comparable to that of other soft tissue surgeries, maintaining these interventions under a "low risk" category. These data can guide clinicians caring for neurofibroma patients on counseling them when considering surgery.