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## **Vestibular schwannoma treatment : patients' perceptions and outcomes**

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## **Summary and concluding remarks**

Vestibular schwannomas are benign intracranial tumors which generally arise from the Schwann cells of the superior part of the vestibular portion of the eighth cranial nerve. The most common symptoms accompanying vestibular schwannoma (VS) are unilateral hearing loss, tinnitus, vertigo and unsteadiness. For many years, microsurgical treatment of VS has been considered the 'gold standard'. However, the treatment of VS continues to evolve with the advent of alternative treatment options such as wait and scan and stereotactic irradiation. Moreover, advances in MRI techniques have allowed for an early diagnosis and exact measurement of growth, which has led to an increased number of patients with small and minimally symptomatic tumors. As a result, the treatment of VS no longer involves life saving surgery, but prophylactic management of future morbidity. These developments have also created new insights into how vestibular schwannoma can be best treated, as it has become clear that the tumor may remain unchanged for many years. However, the treatment of VS patients still remains a matter of debate with advocates and opponents of each modality. Traditionally, the evaluation of VS treatment was performed using primary outcome measures such as mortality and morbidity. But the subject of quality of life (QoL) has increasingly become an important outcome measure in VS. QoL may provide clinicians valuable information that is not always supplied by traditional outcome measures. This thesis describes how VS patients perceive their QoL at diagnosis and further explores QoL and outcomes in patients treated with observation, microsurgery or radiosurgery.

**Chapter one** gives a general introduction with a short review of the current options and patient's perceptions and describes treatment outcomes in VS. At the end of this chapter, the aim and outline of the study are delineated.

In **Chapter two** QoL outcome, illness perceptions (IPs) and coping behaviour in VS patients at diagnosis are presented. To assess IPs and coping behaviour, the Illness Perception Questionnaire - Revised (IPQ-R) and Utrecht Coping List (UCL) were used. QoL was measured using the SF-36, a validated generic QoL measure. A prospective analysis in 79 patients with small- and medium-sized VS demonstrated that IPs and coping, but especially QoL in VS patients, were not as good as reference values. Untreated VS patients also showed to have poor active and passive coping styles and seek less social support compared to other patients. The results from this study indicate that VS patients are a group of patients that suffer from the moment of their diagnosis. This may have implications for clinical decision making and for optimizing

interaction with patients. Changing IPs and coping by means of an intervention may improve QoL in VS patients.

**Chapter three** investigates how the tumor, the cardinal symptoms, and QoL developed during follow-up in wait and scanned VS patients. A total of 70 vestibular schwannoma patients who were initially included in the wait and scan protocol were followed with a mean observation time of 43 months. All patients had small- or medium-sized tumors when they were included in the protocol. QoL was measured at diagnosis and at the end of follow-up in those patients who were still conservatively treated and by using the SF-36. The study group was characterized by non-growing small tumors and relatively stable symptoms over time. We found that conservative observation did not significantly affect QoL in these patients. Most of the tumors did not grow and useful hearing was preserved in more than half of the patients with useful hearing. Initial conservative observation is therefore a safe option for patients with smaller tumors. There was no significant relationship between cochleovestibular symptoms and QoL. However, progression of hearing loss was observed during follow-up. Patients should be counseled regarding this risk before treatment.

**Chapter four** retrospectively reports on QoL and important clinical aspects in VS patients after radiosurgery. Seventy-two consecutive, newly-diagnosed patients with unilateral VS underwent linear accelerator-based radiosurgery with marginal tumor doses of 1 x 12 Gy. A total of 64 patients filled out the SF-36 questionnaire and scores of these patients were compared with SF-36 scores of the general sample. Local tumor control and symptoms were also studied. The results showed favorable tumor control rates and low posttreatment morbidity after a mean follow-up of 34 months. In general, few patients reported progression of symptoms and QoL did not significantly correlate with any of these symptoms. After treatment, QoL scores were moderately affected when compared to norms. It was concluded that QoL after radiosurgical treatment for VS was impaired. Radiosurgery offered good tumor control and favorable clinical outcome similar to other published reports. This report is one of the few studies that describe QoL in VS patients after low dose radiosurgery. The results may be valuable when counseling patients with small- or medium-sized VSs, for which a radiosurgical treatment has increasingly become a treatment option.

**Chapter five** determines the impact of translabyrinthine (TL) surgery on QoL in VS patients with disabling rotatory vertigo. A total of 18 patients with a unilateral intracanalicular VS, without serviceable hearing in the affected ear and severely handicapped by attacks of rotatory vertigo were prospectively studied. Despite an

initial conservative treatment, extensive vestibular rehabilitation exercises, TL surgery was performed because of the disabling character of the vertigo. Preoperative and postoperative QoL was measured using the SF-36 and DHI. Preoperative QoL was reduced because of the disabling vertigo, but significantly improved after TL surgery. However, QoL was still reduced when compared to the general sample. Until now, evidence for other possible treatment options such as (chemical) labyrinthectomy or radiosurgical treatment in these patients is limited. From our study, it may be concluded that TL surgery significantly improved the patients' QoL and surgical treatment should be considered in patients with small- or medium-sized tumors and persisting disabling vertigo.

In **Chapter six**, we used a new variation of the facial-hypoglossal nerve coaptation to reanimate the paralyzed facial musculature after (surgical) trauma. With this technique 1.5 to 2 cm of the facial nerve is freed from its canal in the mastoid bone to perform a direct coaptation to a restricted part of the hypoglossal nerve. The technique avoids the use of a graft and is thereby a safer procedure because there is only one nerve coaptation site. This factor reduces the potential risk of failure of the reconstructive procedure caused by dehiscence. Another advantage compared to other facial-hypoglossal techniques is that the hypoglossal nerve is only partly incised which reduces the risk of hemiglossal paralysis or hemitongue atrophy. Facial nerve outcome was evaluated using the House-Brackmann grading system, which is widely used by surgeons to grade facial nerve function, but also using the Facial Disability Index (FDI), a frequently used QoL questionnaire related to facial nerve function.

In the majority of our patients, we achieved the main goals of rehabilitative facial surgery: functional oral sphincter musculature and sufficient eye closure to prevent any eye problems. In addition, tongue function was preserved in all patients, and no tongue atrophy was observed. Clinical and QoL outcomes of our technique were similar to published results by other authors. Functional improvements were reported while eating, drinking, or closing the eye, and fewer social limitations related to their facial function were observed.

In **Chapter seven** we hypothesized that postoperative facial nerve function should be significantly better when tumor is deliberately left behind during VS surgery. Second, we aimed to objectively assess the extent of the removal using gadolinium-enhanced MRI scans and compared results with the extent of the removal as intraoperatively estimated by the surgeon. A total of 51 patients with

large VS were operated using the TL approach. The extent of the resection was intraoperatively estimated as complete, near, and subtotal. The amount of residual tumor was measured, and the shape and localization was scored on gadolinium-enhanced magnetic resonance imaging (MRI). Potential growth of residual tumor was documented with frequent MRI follow-up. Postoperative facial nerve function was classified according to the House-Brackmann classification. Tumor control with good facial nerve function could be obtained in most patients. A trend was observed that facial nerve outcome was more favorable when residual tumor was left behind. Intraoperative assessment did not correlate with the amount of residual tumor on postoperative MRI. Objective documentation with postoperative contrast-enhanced MRI to measure the extent of removal is always recommended.

**Chapter eight** comprises the main conclusions and general discussion of the results described in this thesis. Furthermore, clinical implications and future directions of research are discussed.

Finally, with regard to the aims of the study, we may conclude that more insight was provided into patients' perceptions and outcomes in the treatment of VS. Previous knowledge on QoL outcome in the treatment of VS patients was confirmed and new information such as illness perceptions and coping behaviour was added. In general, patients with VS suffer from an impaired QoL and treatment will not necessarily restore the patient's quality of daily life. At present, the choice of treatment in VS is still a matter of debate and probably will remain so for a number of reasons. One of the principal precepts of medicine "primum non nocere", first do no harm, should be kept in mind by both clinicians and patients when discussing the treatment options of VS. The major results of this study can make a valuable contribution to clinical decision making and further optimize management of VS. With awareness regarding this topic, we can help to further elucidate QoL perception and try to improve QoL in VS patients in the future.

