

Functional Outcome in the Neurosurgical Patient and Its Impact on Quality of Life

Nicholas B. Levine, M.D.,¹ and Franco DeMonte, M.D., F.R.C.S.C., F.A.C.S.¹

ABSTRACT

Outcomes research has become an integral part of most clinical studies today. Extent of resection, increased median survival, and “time to progression” are no longer the only important end points in need of assessment. Identifying the long-term adverse effects of treatment has become increasingly important as patients try to resume previous activities and an independent lifestyle. The measurement of functional states and health-related quality of life issues are at the forefront of medicine and have become necessary measures of functional outcome following the treatment of a variety of medical and surgical disorders. In this article, we review the most recent studies on the functional outcome of patients undergoing neurological surgeries and its impact on quality of life.

KEYWORDS: Quality of life, skull base surgery, meningioma, acoustic neuroma, paranasal sinus malignancy, craniofacial surgery

The World Health Organization defined health as the presence of physical, mental, and social well-being with the absence of disease and infirmity in 1948.¹ The concept of health-related quality of life (HRQOL) can be defined as the extent to which one’s usual or expected physical, emotional, and social well-being are affected by a medical condition or treatment. Using this paradigm of outcome assessment, it is the patient who ultimately decides what an acceptable outcome is. What is considered acceptable can be vastly different for each patient and very much dependent on the nature of the neoplastic process, the wishes and expectations of the patient, and the point in the time course of the disease in which the patient finds him- or herself. The patient’s perception of his or her outcome can also be adversely affected if family or caregivers do not share the same expectations.

Aaronson felt that quality of life (QOL) could not be measured effectively without dividing it into physical, psychological, social, and functional categories.² Most

HRQOL scales today measure seven basic dimensions of life quality: physical concerns (e.g., pain), functional ability, family well-being, emotional well-being, treatment satisfaction, sexuality/intimacy (including body image), and social functioning. Generic QOL scales allow for comparisons across diseases and have established reliability and validity and the ability to detect treatment effects across a range of different interventions, diseases, and populations.³ Generic scales are not sensitive to a patient’s changing clinical status and do not necessarily focus on specific outcomes for a particular disease. Disease-specific scales or measures are responsive to clinical changes and thus are perceived as more clinically relevant. These scales are most appropriate for clinical trials in which specific therapeutic interventions (like skull base surgery) are being evaluated.

It is insufficient to analyze the HRQOL of patients with skull base tumors using a single modality. The HRQOL in patients with brain injury due to tumor

¹Department of Neurosurgery, University of Texas M. D. Anderson Cancer Center, Houston, Texas.

Address for correspondence and reprint requests: Franco DeMonte, M.D., Department of Neurosurgery, Unit #0442, University of Texas M. D. Anderson Cancer Center, PO Box 301402, Houston, TX 77230-1402 (e-mail: fdemonte@mdanderson.org).

Quality of Life after Skull Base Surgery; Guest Editor, Ziv Gil,

M.D., Ph.D.

Skull Base 2010;20:19–22. Copyright © 2010 by Thieme Medical Publishers, Inc., 333 Seventh Avenue, New York, NY 10001, USA. Tel: +1 (212) 584-4662.

DOI: <http://dx.doi.org/10.1055/s-0029-1242980>.

ISSN 1531-5010.

and treatment must be analyzed with the potential effect of neurocognitive impairment in mind. Patients with frontal lobe dysfunction, such as with large olfactory groove meningiomas or following frontobasal irradiation for paranasal sinus cancers, often have a diminished appreciation of their disabilities and limitations, and thus may report a level of function that is not realistic. Performance-based measures should supplement self-reported information. A three-pronged assessment utilizing measures of (1) functionality and performance, (2) cognition, and (3) self-reported HRQOL is the most telling approach for the evaluation of patients with neurological involvement.⁴

The QOL following resection of vestibular schwannomas has been reported more frequently than other skull base tumors in both the otolaryngological and neurosurgical literature. In 1989, Wiegand and Fickel reported the results of a questionnaire of patient-members of the Acoustic Neuroma Association.⁵ Five hundred forty-one of 832 patient members returned the questionnaire with 90% of the respondents having undergone surgery during the preceding decade, 815 managing their own care, and 70% returning to work within 4 months. Despite the rapid recovery and return to work, 38% reported depression; 35%, anxiety; 26%, sleep disturbance and fatigue; and 10%, sexual dysfunction. Fifteen percent reported a severely negative feeling regarding their posttreatment status, and 40% perceived themselves as permanently changed. The aforementioned data highlight the accompanying negative psychological, social, and functional impact in the setting of successful treatment, demonstrating the disconnection between third-party assessments of outcome and the patient's perception of outcome.

Nikolopoulos et al administered a questionnaire based on the Glasgow Benefit Inventory to patients randomly selected following vestibular schwannoma surgery.⁶ Older patients were found to have a better overall QOL. Younger patients had worse postoperative financial status and were more likely to change professions after surgery, underscoring the reported decreased QOL. Tumor size was not found to significantly affect QOL but it did affect postoperative financial status. Nine patients reported improved; 28 patients, worse; and 15 patients, unchanged QOL.

General health status questionnaires/instruments measure changes in QOL following interventions that alleviate current symptoms, not future symptoms and deficits. Two groups of patients exist: those currently with symptoms and deficits, and those in danger of developing symptoms and deficits. One must recognize that many patients with skull base tumors undergo surgery not to improve QOL but to avoid diminishing QOL due to possible significant complications/deficits or death that may occur if the tumor continues to grow. QOL surveys do not adequately take this into account,

which can dramatically impact outcomes following surgery. When da Cruz et al studied postoperative QOL in vestibular schwannoma patients using the Medical Outcome Study 36-Item Short Form (SF-36) health questionnaire, no difference in QOL was found with respect to operative approach, tumor size, patient sex, and/or age.⁷ Irving et al reported no correlation between degree of facial nerve dysfunction and overall QOL.⁸ The outcomes of both of these studies suggest that the patients were adequately prepared for the varied surgical outcomes that they experienced. Nicoucar et al noted psychological complaints were the most powerful predictive variable for QOL.⁹ Patient perception of facial movements was worse than the clinician's based on the House-Brackman classification. All of these results speak to the need for careful patient selection, thoughtful preoperative counseling, and postoperative counseling if needed to help patients cope with psychological complaints that may overshadow actual physical deficits.

If one looks at untreated vestibular schwannoma patients, the preoperative symptoms are powerful predictors for QOL. Myrseth et al found that vertigo causes the most negative effect on the QOL in patients with vestibular schwannomas.¹⁰ Unilateral hearing loss and tinnitus appear to be less important with regard to a patient's perceived QOL. Therefore, if treatment is planned to relieve vertigo and is successful, the QOL should improve. This, however, to a large extent depends on the patient's preoperative expectations.

Gil et al developed a 35-item questionnaire, which included six QOL domains—(1) performance, (2) physical function, (3) vitality, (4) pain, (5) influence on emotions, and (6) specific symptoms—to address the impact of surgery on patients with anterior skull base tumors.^{11,12} Older patients had poorer scores in performance and physical function domains; patients with malignant lesions had poor scores in specific symptoms, influence on emotions, performance, and physical function domains. Radiotherapy negatively impacted specific symptoms and influenced emotions domains.

The patient's functional status will ultimately be determined by the disease process; however, QOL measures may assist in decision making with respect to primary and adjuvant therapies and provide information that facilitates accurate discussions regarding the disease and its management with patients and their caregivers. Patient care will improve and QOL may improve if patient caregivers' and surgeons' perceptions correlate. Gil et al demonstrated with a triple survey that a surgeon's perception of his or her patient's QOL following anterior skull base surgery does not estimate the patient's QOL status.¹³ Studies have not adequately determined what factors associated with treatment modalities have the greatest impact on patient and caregiver perceptions.

At M. D. Anderson, DeMonte assessed 16 patients after anterior-craniofacial resection of paranasal sinus tumors at 1 to 2 years.³ Patients with significant brain and orbital invasion were excluded in an attempt to look at a more homogeneous group. Fourteen patients had pre- or postoperative radiation therapy and five patients had chemotherapy. Pathologies were typical of paranasal malignancies. The Karnofsky Performance Score (KPS) and the Functional Independence Measure (FIM) were assessed for all of the patients. QOL was studied by patient-generated responses to the Functional Assessment of Cancer Therapy (FACT) questionnaire (generic tool) including its brain and head and neck subscales (both specific tools). Independence was rarely affected with KPS scores of 90 to 100 in 15 patients. Eighty-seven percent of patients had FIM scores >117. All patients had a good QOL with respect to neurological function, and 94% of these had a good head and neck score as well. Despite the aforementioned results, 31% of patients reported a poor QOL based on responses to the FACT general questionnaire. This highlights the need for both specific and general assessments if a full assessment of HRQOL is to be attempted.

Mohsenipour et al investigated the QOL of patients following meningioma resection.² One hundred fifty-five patients were sent two questionnaires, the Nottingham health Profile (NHP) and the Innsbruck Health Dimensions Questionnaire for Neurosurgical Patients (IHDNS). The following parameters are covered in the IHDNS: (1) economic situation, (2) physical complaints, (3) difficulties with activities of daily living, and (4) social and family situations.

The IHDNS responses correlated with the NHP and the overall QOL was good or mildly impaired. Twenty percent of patients documented significant impairment with respect to mobility and energy levels. Many of these patients were older and took antiepileptics, which can reduce the QOL independently. The perception of a globally decreased QOL secondary to specific neurological deficits is a problem with most QOL scales. The IHDNS, a questionnaire specifically designed for neurosurgical patients, attempts to minimize the discrepancy between subjective and objective appraisals of reduced QOL based on neurological deficits, which lead patients to identify these deficits as contributing to a reduction in their overall QOL.

In 2002, Kelleher et al reported on the health-related QOL of patients with skull base tumors using the SF-36.¹⁴ The prospective study of 70 consecutive patients with skull base tumors (a tumor arising from the skull base or excised via a skull base approach) included 54 vestibular schwannomas, 13 meningiomas, two hemangioblastomas, and one hypoglossal schwannoma. A statistically significant reduction in six of the eight domains measured by the SF-36 was found when the skull base cohort was compared with the general pop-

ulation. No significant correlation was found between facial function and any of the SF-36 domains in the vestibular schwannoma patients, which illustrates why generic scales are seen as being not clinically relevant. The 13 patients with skull base tumors other than vestibular schwannomas had a significant reduction in seven of the eight domains when compared with the normal population. Kelleher et al concluded that the surgery caused the impairment in QOL rather than the specific tumor type, because the HRQOL was equally diminished in patients undergoing surgery for both vestibular schwannomas and other skull base tumors.

Any treatment is unlikely to improve excellent QOL, but treatment should decrease or prevent the possibility of significant complications or death. QOL may be better preserved with interval magnetic resonance imaging and avoidance of any treatment, including surgery and/or radiation, until tumor growth is demonstrated or the patient develops deficits.

Lang et al assessed 17 patients with the SF-36 questionnaire and the Glasgow Outcome Score (GOS) following a transpetrosal approach for resection of a petroclival meningioma.¹⁵ The patient's caregiver was also interviewed to ascertain the effect of the patient's illness on the caregiver's life and responsibilities. Thirteen patients had made a good or moderate recovery, three were disabled, and one died by 1 year of follow-up according to the GOS. Forty-three to 75% of patients were functioning below accepted normative values in all eight of the SF-36 categories. The impact on the caregivers was high, with 56% experiencing a major change in lifestyle and 38% experiencing a major change with respect to work. The disparity between the GOS and SF-36 demonstrate the dichotomy between functionality and self-reported QOL, which is subject to patient perceptions.

Skull base surgery as a subspecialty will continue to benefit from technological innovations. However, the pathology and location will always be the limiting factor in avoiding postoperative deficits. We can minimize the potential harm of operative intervention but we cannot eliminate it. Today, much attention is focused on decreasing length of stay and encouraging patients to not see themselves as sick and incapacitated. Minor changes in our practice, such as hair sparing, can dramatically change the patient's perception of themselves as sick.¹⁶ The benefit is short lived with regard to patient's perceptions, as they begin to focus on postoperative deficits and changes in their lives after surgery. Once they are discharged from the hospital setting, many do not have the necessary support from their family and/or caregivers. This represents an area of great potential for improving QOL.

Studies examining the coordination of care between formal providers and informal caregivers demonstrate positive associations with the patient's

freedom from pain, functional status, and mental health when frequent communication occurs.¹⁷ Weinberg et al noted improved clinical outcomes following elective knee replacement when there was effective coordination between health care providers and the patient's caregivers. This theory of "relational coordination" is based on frequent high-quality communication grounded in a philosophy of shared goals, shared knowledge, and mutual respect.¹⁸ Relational coordination leads to effective patient, caregiver, and health care provider preparation, which translates into improved outcome and HRQOL. This represents an important and underutilized avenue for improving QOL in patients with skull base pathology following surgery and other interventions.

REFERENCES

1. World Health Organization Constitution; 1948
2. Mohsenipour I, Deusch E, Gabl M, Hofer M, Twerdy K. Quality of life in patients after meningioma resection. *Acta Neurochir (Wien)* 2001;143:547-553
3. DeMonte F. Functional outcomes in skull base surgery. *Clin Neurosurg* 2000;48:340-350
4. Meyers CA. Issues of quality of life in neuro-oncology. In: Vecht CJ, ed. *Handbook of Clinical Neurology 23, Neuro-Oncology Part 1. Brain Tumors: Principles of Biology, Diagnosis and Therapy*. Amsterdam: Elsevier Science; 1997: 389-409
5. Wiegand DA, Fickel V. Acoustic neuroma—the patient's perspective: subjective assessment of symptoms, diagnosis, therapy, and outcome in 541 patients. *Laryngoscope* 1989;99: 179-187
6. Nikolopoulos TP, Johnson I, O'Donoghue GM. Quality of life after acoustic neuroma surgery. *Laryngoscope* 1998;108: 1382-1385
7. da Cruz MJ, Moffat DA, Hardy DG. Postoperative quality of life in vestibular schwannoma patients measured by the SF36 Health Questionnaire. *Laryngoscope* 2000;110:151-155
8. Irving RM, Beynon GJ, Viani L, Hardy DG, Baguley DM, Moffat DA. The patient's perspective after vestibular schwannoma removal: quality of life and implications for management. *Am J Otol* 1995;16:331-337
9. Nicoucar K, Momjian S, Vader JP, De Tribolet N. Surgery for large vestibular schwannomas: how patients and surgeons perceive quality of life. *J Neurosurg* 2006;105:205-212
10. Myrseth E, Møller P, Wentzel-Larsen T, Goplen F, Lund-Johansen M. Untreated vestibular schwannomas: vertigo is a powerful predictor for health-related quality of life. *Neurosurgery* 2006;59:67-76; discussion 67-76
11. Gil Z, Abergel A, Spektor S, et al. Quality of life following surgery for anterior skull base tumors. *Arch Otolaryngol Head Neck Surg* 2003;129:1303-1309
12. Gil Z, Abergel A, Spektor S, Shabtai E, Khafif A, Fliss DM. Development of a cancer-specific anterior skull base quality-of-life questionnaire. *J Neurosurg* 2004;100:813-819
13. Gil Z, Abergel A, Spektor S, Khafif A, Fliss DM. Patient, caregiver, and surgeon perceptions of quality of life following anterior skull base surgery. *Arch Otolaryngol Head Neck Surg* 2004;130:1276-1281
14. Kelleher MO, Fernandes MF, Sim DW, O'Sullivan MG. Health-related quality of life in patients with skull base tumours. *Br J Neurosurg* 2002;16:16-20
15. Lang DA, Neil-Dwyer G, Garfield J. Outcome after complex neurosurgery: the caregiver's burden is forgotten. *J Neurosurg* 1999;91:359-363
16. Winston KR. Hair and neurosurgery. *Neurosurgery* 1992;31: 320-329
17. Weinberg DB, Gittell JH, Lushenhop RW, Kautz CM, Wright J. Beyond our walls: impact of patient and provider coordination across the continuum on outcomes for surgical patients. *Health Serv Res* 2007;42(1 Pt 1):7-24
18. Weinberg DB, Lushenhop RW, Gittell JH, Kautz CM. Coordination between formal providers and informal caregivers. *Health Care Manage Rev* 2007;32:140-149