Outcome after complex neurosurgery: the caregiver's burden is forgotten


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Object. The goals of this study were twofold: 1) to determine outcome, including quality of life, in patients who have undergone surgery for petroclival meningioma in which a standard skull base approach was used; and 2) to assess the impact of the patients' surgical treatment on their caregivers.

Methods. Seventeen patients (13 women and four men ranging in age from 29 to 63 years) who underwent a transpetrosal approach for a petroclival meningioma during a 5-year period were prospectively included in this study. Pre- and postoperative data including adverse events were noted. The patients were assessed at 3, 6, and 12 months postoperatively, and annually thereafter, and they completed a postoperative SF-36 questionnaire. In addition, each patient's caregiver was interviewed to determine the effect of the patient's illness on the caregiver's life and responsibilities.

Twenty-two operations were performed. A new permanent neurological deficit developed in five patients and in eight a temporary deficit or exacerbation of existing deficits occurred. Two patients underwent surgery to create a facial-hypoglossal nerve communication; five required a temporary percutaneous gastrostomy and/or tracheostomy; three required a shunt; and one underwent successful squint surgery. At 1 year postoperatively 13 patients had made a good or moderate recovery, three were severely disabled, and one had died--outcomes in keeping with other studies. By contrast, responses to the SF-36 questionnaire showed that, in all eight of its categories, between 43% and 75% of surviving patients were functioning below accepted norms. Fifty-six percent of caregivers experienced a major change in lifestyle and 38% experienced a major change with respect to their work.

Conclusions. After transpetrosal excision of a petroclival meningioma, the quality of life for the patient is worse than that indicated in surgeons' reported results. The impact on the patient's caregiver is profound--a burden perhaps not fully appreciated by the surgeon.

Key Words * petroclival meningioma * transpetrosal approach * caregiver * outcome

The patient's perception of the effects of their illness on daily living and health status--their quality of life--is recognized as being important in measuring outcomes of management modalities, including surgery. The neurosurgical literature is much concerned with outcomes after complex surgery. However,
too often this outcome is determined according to the surgeon's perspective, concentrating on rates of morbidity and mortality, rather than being concerned with the patients' perceptions of factors such as pain, mood, functional impairment, cognitive function, and the ability to cope with personal and family responsibilities. Surgery for skull base tumors raises these issues because the pathological lesion is often benign and not immediately life threatening, and the postoperative neurological deficit may be disabling. In these circumstances, the process of informed consent for surgery, in which the risks of surgery are balanced against the likely natural history of the disease, is particularly important.

In general, outcome is related to various preoperative factors: the type, size, and location of the tumor, and the age, general medical status, and preoperative neurological disability of the patient. There are a number of outcome assessment scales in use, such as the Karnofsky Performance Scale (KPS), the Glasgow Outcome Scale (GOS), and The Medical Outcome Study 36-Item Short-Form Health Survey (SF-36), and most publications focus, quite understandably, on the effect of surgery on the patient. Although measures of patient satisfaction may be insensitive to variations in medical practice and surgical methods and may be invalid as measures of performance, they do provide some indication of expected results of management. Therefore, they are important in an evaluation of information given to the patient when obtaining consent for operations. Unfortunately, little attention has been paid to the reliance that the disabled patient has to place on a caregiver, usually a close relative, to achieve the expected or actual outcome status. Similarly, and equally important, little attention has been paid to the effect that the patient's disability has on the caregiver's own life and career, including employment.

In this paper we record the effects of surgical treatment of patients on caregivers following one type of neurosurgical operation for which indications are often debatable. From these effects flow implications for informed consent.

**CLINICAL MATERIAL AND METHODS**

**Patient Selection**

All patients undergoing a transpetrosal approach for petroclival meningiomas--those arising medial to the fifth cranial nerve--between 1992 and 1997 at the Wessex Neurological Centre were prospectively included in this study. All preoperative, operative, and postoperative data, including adverse events, were entered into a database. The patients were observed at 3, 6, and 12 months postoperatively, and annually thereafter. The patients completed a postoperative SF-36 questionnaire at 1 year postoperatively, and the questionnaires were analyzed by a research nurse. At this time patient GOS scores were recorded.

The SF-36 is a short questionnaire containing 36 items that measure eight multiitem variables covering: physical functioning, social functioning, role limitations due to physical problems, role limitations due to emotional problems, mental health, energy and vitality, pain, and general perception of health. The questionnaire can be self administered and completed within 10 minutes. For each variable item, the scores were coded, summed, and transformed onto a scale ranging from 0 (worst possible health state measured by the questionnaire) to 100 (best possible health state). The data were then compared with averaged normative data. The questionnaire used was the validated modified version for British citizens.

The SF-36 was used because it is a generic quality-of-life measure that can be used to compare directly
the lives of patients with those of the general population. In addition to being reliable, valid, and widely accepted, it is able to discriminate various stages and severity of illness and is not limited to retrospection over long periods of time because it only focuses on a 4-week recollection period.\textsuperscript{[25]} Treatment effects can be detected across a broad range of health-related areas, and a comparison of outcomes across a range of different interventions, diseases, and populations is allowed. There is much literature on the SF-36 assessment tool, including normative data to enable interstudy comparisons.\textsuperscript{[18]}

In addition, the patients' caregivers were contacted and interviewed by the research nurse to determine the effects of patients' illnesses on caregivers' lives and responsibilities.

**RESULTS**

Seventeen patients, 13 women and four men ranging in age from 29 to 63 years, underwent 22 operations; staged procedures were performed in five patients. The clinical features at presentation included: elevated intracranial pressure in seven patients, lower cranial nerve palsies in five patients, other cranial nerve palsies in 15 patients, other focal neurological deficits in 12 patients, and endocrine disturbance in one patient.

The surgical approach was via transpetrosal routes. In three patients preoperative embolization was performed, and total removal of the tumor was achieved in nine patients (53%). In four patients, focused radiosurgery was used postoperatively. During the course of surgery, technical problems were encountered because of the relationships between tumors and vertebrobasilar arteries and their branches, the brainstem, the cranial nerve, and/or the cavernous sinus. The transpetrosal approaches that were used included the retrolabyrinthine, translabyrinthine, transcochlear, transpetrosal-transzygomatic, and anterior petrosal. The transpetrosal approaches were favored because the major operative work is within the bone, the line of access and view is usually straight, there is minimal retraction of neural structures, and there is usually reasonable protection of neurovascular structures.

Despite this, five patients experienced a new permanent neurological deficit and eight experienced a temporary new neurological problem or exacerbation of existing deficits. Of these 13 patients, two underwent surgery to create a facial-hypoglossal nerve communication; five required a temporary percutaneous gastrostomy and/or tracheostomy to support respiratory function/nutrition in the presence of lower cranial nerve palsies; three required a shunt to control hydrocephalus; and one underwent successful squint surgery at 1 year postoperatively.

Table 1 displays the overall outcomes based on scores from both the GOS and the SF-36. Although the GOS scores appear good, the SF-36 scores indicate that, in the majority of patients, there is a considerable effect on quality of life. The other significant feature is the impact on the patient's caregiver with respect to both lifestyle and work.
DISCUSSION

The main consideration in this paper is the plight of the caregivers and the implications of this for preoperative advice, counseling, and decisions about surgery. Therefore only brief reference will be made to the purely technical aspects of the neurosurgical procedure. These form the basis for another communication.

Preoperative Status

The preoperative status and neurological deficits and disabilities in our patients appear to be similar to those recorded in other series.[1,7,14,19,20,23,26] As we expected with a tumor in this location, the most common deficits were cranial nerve palsies and other focal neurological deficits. All patients had progressive symptoms. In seven patients, the tumors had advanced to a stage at which intracranial pressure had become elevated. That proved to be a more definite indication for surgery than did the cranial nerve palsies or other neurological deficits. Indeed, when there was definite evidence of elevated intracranial pressure, decisions concerning whether surgery should be advised were easier.

Surgery and Outcome

The type of surgery and its technical problems were described earlier. Although the term "minimally invasive" has been used to describe the transpetrosal approach to these tumors, with respect to brain retraction and protection of neurovascular structures, that term was certainly never used in talking to patients or relatives. At the start of discussion, it was pointed out that the procedure was a major one that carried a significant risk of disability. Preoperative embolization was considered essential in some patients. Because of the location and size of the tumor and the operative difficulties encountered, in five patients the procedures were staged. It was believed that this made surgery safer. In eight patients (47%) the tumor was not removed totally. This is in conformity with other reported series and is an indication of the surgeon's relatively cautious approach and readiness during surgery to appreciate anatomical difficulties and, thereby, the added risks of complications. It was believed at the time that to attempt a

| Table 1: Overall outcomes in patients and effects on caregivers* |
|----------------------------------|-----------------|
| **Outcome**                      | **No. of Patients (%)** |
| GCS score (17 patients)          |                  |
| good                            | 11 (65)          |
| moderate                        | 2 (12)           |
| poor                            | 3 (18)           |
| dead                            | 1 (6)            |
| below accepted norms on SF-36 (16 patients) |                  |
| physical functioning            | 8 (50)           |
| role limitations — physical     | 9 (56)           |
| mental health                   | 7 (44)           |
| vitality                        | 12 (75)          |
| general health perception       | 8 (50)           |
| social functioning              | 9 (56)           |
| role limitations — emotional    | 9 (56)           |
| pain                            | 7 (44)           |
| impact on caregiver (16 caregivers) |                  |
| major change in lifestyle       | 9 (56)           |
| major change in employment      | 6 (38)           |

* At minimum of 1 year postoperatively.
total removal in such circumstances would place patients at unwarranted risk of severe postoperative disability and, indeed, of death. Despite this cautious approach and the considerable experience of the surgeons in skull base surgery for different types of lesions, there were only four occasions in which significant postoperative complications did not occur. All patients required intensive postoperative management in the neurosurgical intensive care unit.

In the assessment of outcome, it was clear that the overall GOS score for individual patients gave a more optimistic picture of the patients' functional and social levels than the SF-36 assessment. However, the most significant findings were that nine caregivers experienced a major change in lifestyle and six a change in employment.

Methods of Assessing Outcome and Accuracy of Outcome Scales and Measures

In determining the potential benefits of surgical interventions that can influence a wide number of variables such as physical mobility, emotional well being, and socioeconomic factors, the traditional measures of morbidity and mortality are too narrow.

Reference has already been made to other series in which results following surgery for similar tumors were reported. On the basis of GOS scores, our results appear to be similar to those of other series.[5,7,14,19,20,26] Nevertheless, there is great difficulty in comparing different series, not only because of the wide variation in deficits observed both pre- and postoperatively, but also because of the difficulty encountered when comparing outcome measures. Many papers focus on technical success and incidences of morbidity and mortality, but with little reference to the effects of surgery on functional ability and health status.[1,3,7,14,17,19,23,26] Known achievable and accurately assessed outcome standards should strongly influence the choice of treatment in the individual patient. It is not sufficient simply to offer a particular strategy, especially surgical, and to accept that as the main factor affecting outcome.

The GOS is widely used and has much to commend it. Nevertheless, significant deficiencies and difficulties are encountered in its use such as its failure to address activities of daily living and the ability of the patient to cope with family, home, employment, and social activity. In addition, the effect on the patient's cognitive ability and its impact on domestic activity, including family responsibilities, complex social interactions, leisure pursuits, and employment are not considered.

The SF-36 questionnaire is one of the few outcome measures currently available for routine use that satisfies the criteria of validity, reliability, and sensitivity to changes in health status. It is a shortened version of a battery of 149 health status questions designed to understand how specific components of the American health care system affect outcomes of treatment.[21,22] The SF-36 questionnaire was developed as a practical tool for monitoring patient outcomes in a busy clinical setting. The validity and reliability of this tool when used in patient populations has been confirmed in the United States and the United Kingdom.[4,9,15,16]

The SF-36 is a more complex assessment tool than the GOS generally encompasses important factors that the GOS does not. Of importance, the SF-36 is also used to compare the status of the patient with normative data. The application of this scale has its difficulties and deficiencies. Ideally, subjective quality-of-life indices should not be influenced by patient characteristics that are outside the domain of disease and health care. The major criticism is that this type of quality-of-life measurement tool can be influenced by personality factors, marital status, education, income, race, and geographic location.[2,24]
There is also a view that some patients give answers that they believe to be socially acceptable or reflect favorably on themselves.[6] Nevertheless, assessment of the patient's experience of the disease and treatment is, in our view, an essential component of outcome measurement.

The KPS was introduced primarily to assess the response to chemotherapy in a patient with malignant disease.[11] The scale has been widely used; however, there is no direct mention of any effect on caregivers and no allowance for recognition of the range of normality. This is despite the fact that careful examination of the definitions and criteria used reveals that, from scores 70 down to 40, it is clear that assistance is needed. This includes a range in which help equivalent to that given in a hospital situation is required before hospitalization is indicated (a score of 30).

It is therefore clear that the KPS and, to a lesser extent, the GOS have major deficiencies compared with the SF-36 with respect to overall and detailed assessment of outcomes following complex surgery.

**The Neurosurgeon's Interpretation and Comparison of the Results of Surgery**

In light of the findings reported in this paper, there is clearly a major limitation in the surgeon's appreciation of adverse effects of surgery that extend far beyond the patient alone. This problem does not appear to have been considered in other reported series of such cases. In some series, especially when the details of the KPS are carefully examined, the results appear to be far too optimistic, even without consideration of the caregiver's plight. It would certainly be instructive to reexamine the material in some of these series with this in mind. For example, a patient who has a preoperative KPS score of 10 (moribund, fatal process progressing rapidly) and who postoperatively achieves, at best, a score of 50 (requires considerable assistance and frequent medical care) can hardly be considered a success.[20] Indeed, this particular severity of disability will affect the lifestyle and potential employment of any caregiver, often with disastrous results for the caregiver, to whom attention is rarely drawn.

**Effects on Caregivers**

The effects on caregivers have already been indicated in Table 1. The types of caregivers and their occupations are important in this respect. At the most favorable extreme is the spouse who either works at home or is retired, although age and infirmity may become relevant. The caregiver who cannot afford to relinquish an occupation that takes him or her away from home is in a very difficult position. In many cases the caregiver's occupation and employment is essential for maintaining the home for both caregiver and patient. In this series, the situation was seriously disruptive for a number of caregivers and, therefore, for the patients. A careful perusal of the KPS and the SF-36 reveals that the level of outcome claimed by the patient depends, to a large extent, on the availability of support (in a hospital environment or in the patient's home) and on the ability of the caregiver. Unfortunately, this essential qualification of patient outcome following surgery and, therefore, the success claimed after surgery, has not been stressed sufficiently in the neurosurgical literature. Any assessment and comparison of the efficacy of different surgical approaches and methods should certainly include details of the long-term postoperative care required and available. The wide variation in social structure and habits in different milieus and in different countries can vitiate conclusions about surgical success or failure.

Notwithstanding these factors, it is clear that, despite the degree and rate of clinical deterioration of patients preoperatively, the caregivers' lifestyle may not have altered, but, in time, the natural history of the disease in these patients would necessarily precipitate a change. Surgical intervention accelerated the inevitable course of events, resulting in an untimely alteration in domestic and socioeconomic status for
the relatively unprepared caregivers.

**Informed Consent**

In the present state of law in the English jurisdiction, the only requirement is to inform the patient of the nature and possible complications of the operation; it is only the patient who is in a position to accept or decline advice concerning surgery. There are certain circumstances in which incompetence to understand what is said may qualify the responsibility of the patient. Nevertheless, in general the patient is perfectly able to disregard other considerations when deciding whether to accept or decline surgical advice.

In light of our findings and the details provided by the KPS and SF-36, the availability of postoperative support and a caregiver must be one such consideration. Whether, from the patient's point of view, it is incumbent on, or obligatory for, the surgeon to draw attention to this aspect must be a matter of opinion. However, it could easily become a matter for dispute, at least in an intellectual form if not in a litigious environment.

**The Caregiver's Rights**

Considerations of the issue of informed consent must inevitably raise important questions about the caregiver's rights if, indeed, such rights exist at all. Some may regard this as either too farfetched or too controversial to merit consideration by surgeons, even though it is the surgeon who is ultimately responsible for ensuring that consent to undergo surgery is fully informed. However, as surgical complexity and endeavor grow, not always wisely and with an increasingly aged population, the caregiver's rights will probably become a greater issue. Here we can only pose a number of questions that, as surgeons, we certainly cannot answer at present. The implications are wide ranging and will involve the law, departments of social services, employment statutes, and government policy. Inevitably, ethical aspects will carry weight. 1) Does the caregiver have a right to be involved in the process of informed consent? 2) May the caregiver indicate to the patient or department of social services that he or she will not/cannot afford to give up employment to care for the patient? 3) Can the caregiver either prospectively or retrospectively place the department of social services on notice for financial support for the patient and caregiver? 4) What is the stance of the caregiver's employer concerning the level of support and employment to which the caregiver who is affected by another person's disability should be entitled?

**FUTURE IMPLICATIONS AND CONCLUSIONS**

Our examination of the serious effect on caregivers of "high-tech" neurosurgery, albeit in a specialized field, calls for a reexamination of the criteria on which informed consent for surgery has usually been based. It is beyond the scope of this paper and our experience to answer questions that should be asked of lawyers, social workers, and employers. Nevertheless, our findings are sufficient to indicate that potential caregivers--usually close relatives--should very definitely be brought into discussions about prognosis, the risks of disability, or increased disability following surgery. The extent to which potential caregivers should influence the patient's acceptance of surgical advice and, likewise, the extent to which surgeons' advice should be influenced by potential caregivers' circumstances and wishes are delicate and debatable points.

The issues are essentially those of traditional sympathetic and caring medical practice. However, the current climate of public inquiry into the basis of medical practice and the climate of litigation will cause neurosurgeons to consider more carefully the wider effects of surgery.
In speaking of caregivers recently, the Archbishop of Canterbury drew attention to their plight, stating that they "often paid a high price." "Their gift to others can be a profound personal deprivation--loss of job and livelihood, independence and esteem, the erosion of a self that has been built and nurtured and expected to flourish."[9] There could be no more relevant comment for neurosurgeons who embark on what might be described as heroic skull base surgery.

References


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