The Royal College *of* Surgeons *of* England

Ann R Coll Surg Engl 2001; **83**: 215–218

Original article

The realities of postoperative disability and the carer's burden

Glenn Neil-Dwyer, Dorothy Lang, John Garfield

Wessex Neurological Centre, Southampton University Hospitals Trust, Southampton, UK

Outcome after high-risk, complex neurosurgery for progressive skull base pathology, and its effect on carers, has been examined. Two different outcome measures were used. The Glasgow Outcome Score (GOS) assesses overall social capability and dependence of the patient, while the 36 item short-form health survey (SF-36), a generic quality of life measure, can be compared directly with the general population. Overall outcome using the GOS indicated a favourable outcome for 13 of the 17 patients studied. The SF-36 demonstrated that more than half the patients were functioning at a level below the accepted norm. The reasons for this discrepancy and the validity of outcome scales have been analysed. In addition, the effect upon carers, its relevance to assessment of outcome, and the need to involve potential carers in the process of informed consent was stated. Our conclusions are applicable throughout the surgical specialities, and especially to high-risk complex surgery.

Key words: High-risk complex neurosurgery – Skull base – Meningioma – Outcome – Carer's predicament

Surgeons are by nature optimists. Indeed, were it not for this optimism many patients might be denied operations which were justified and which bring considerable benefits. If the surgeon's approach is pessimistic, it is only too easy to marshal sufficient evidence to advise against surgery. Neither the unduly optimistic nor the unduly pessimistic approach is consistent with good medical practice. A balanced approach will depend upon the individual surgeon's personal experience, a critical appraisal of relevant publications dealing with the outcome and also an understanding of the way in which outcome will affect not only the patient, but also the lives of those who will have to support the patient. These are also the facts upon which the process of informed consent for treatment must be based.

These considerations are especially important when advising complex neuorosurgical procedures, which carry risks of serious disability, but when the pathology is not immediately life threatening. Such is neurosurgery for certain skull base meningiomas. The objectives of this paper are: (i) to assess the value of two

---

Correspondence to: Mr Glenn Neil-Dwyer, Consultant Neurosurgeon, Wessex Neurological Centre, Southampton University Hospitals Trust, Tremona Road, Southampton SO16 6YD, UK. Tel: +44 2380 796596; Fax: +44 2380 794148

widely-used outcome scales, and especially their value as measures of quality of life; (ii) to assess the evidence used in previous neurosurgical publications upon which prediction of disability following surgery has been based; (iii) to examine the effect of the patient's disability upon carers, and the extent to which the carer's efforts are a factor in evaluating surgical outcome; and (iv) if carers' lives are significantly affected, should carers be involved in the process of consent for surgery?

Patients and Results

Between 1992 and 1997, 17 patients underwent surgery at the Wessex Neurological Centre for a petro-clival meningioma, a benign skull base tumour. The patients presented with progressive symptoms of raised intracranial pressure (7), lower cranial nerve palsies (5), other cranial nerve palsies (15), other focal neurological deficit (12) and deranged endocrine function (1). Surgical details form the basis of a neurosurgical publication elsewhere. In summary, there were 22 operations using a trans-petrous approach; 5 patients had staged procedures. Total removal of the tumour was achieved in 9 patients. In the other 8 patients, the tumour was partially removed, the surgical decisions being influenced by the extent and relationship of the tumour, especially to the brain stem and the risk of creating severe postoperative disability. Despite this relatively cautious approach, 5 patients developed new permanently neurological deficits. Follow-up assessments were done at 3, 6 and 12 months postoperatively.

In recording outcome of not less than one year after surgery, two scales were used – the Glasgow Outcome Score (GOS)[1] and the Medical Outcome Study 36-Item Short-form Health Survey (SF-36).[2] The results are shown in Table 1. GOS scores were good in 11, moderate in 2, and poor in 4 patients. Using this scale, a good recovery or moderate disability implies independence while a severely disabled patient is not independent. The SF-36, apart from the mental health component and bodily pain demonstrated that more than half of the patients (50–75%) were functioning at a level below the accepted norm.

The impact on the carers was considerable in 6 cases (38%). The carer retired prematurely in order to provide support at home for the patient, thus making a major change in their employment status. In 9 cases (56%), there was a major change in the carer's lifestyle; this included the 6 who retired and a further 3 carers. Of these, two mothers moved into the marital home to allow the primary carers (spouses) to continue to work while there were financial implications for the third carer because the patient (wife) gave up her work.

Table 1 Outcome one year postoperatively using the Glasgow Outcome Scale (GOS) and the SF-36

Glasgow Outcome Score (**GOS**)

Patients			
Good recovery	Moderately disabled	Severely disabled	Dead
11	2	3	1

36-Item Short-form Health Survey (SF-36)

Category	Patients below accepted norms	
Physical functioning	8	(55%)
Role physical	9	(56%)
Mental health component	7	(43%)
Vitality	12	(75%)
General health perception	8	(50%)
Social functioning	9	(56%)
Role emotional	9	(56%)
Bodily pain	7	(43%)

Discussion

The value of outcome assessment scales

There are a number of outcome assessment scales in use, including the Karnofsky Glasgow Outcome Score[1] and SF-36.[2] Most publications focus quite understandably on surgical complications and mortality.[4–13] While 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 the expected results of management.

Outcome assessment scales in general do not take into account the reliance the disabled patient may have to place on a carer, usually a close relative, in order to achieve the expected or the actual outcome status. Similarly, and equally importantly, less attention has been paid to the effect that the patient's disability has upon the carer's life and career, including employment. These observations apply equally to the GOS and the SF-36.[1,2]

The GOS is widely used and has much to commend it.[1] Nevertheless, there are significant deficiencies and difficulties in its use, such as the failure to address activities of daily living and the ability to cope with family, home, employment and a social activity. In addition, the effect of cognitive ability and its impact on domestic activity, including family responsibilities, complex social interactions, leisure pursuits and employment is not included.

The SF-36 is a more complex assessment and covers important features, which in general the GOS does not.[2] Notably, it does compare the patient's situation to normative data.

Although it is possible that subjective quality of life indices are not influenced by patients' characteristics, that are outside the domain of disease and health, one criticism is that these measurements of quality of life can, in fact, be influenced by personality factors, marital status, education, income, race and geography.[14,15] There is also a view that some patients give the answer that they believe to be socially acceptable, or which reflects favourably upon themselves.[16]

The Karnofsky scale was introduced primarily to assess response to chemotherapy and malignant disease.[3] It has been widely used, though its specificity and reliability in diseases other than malignant disease has to be questioned.

Valuable as these different scales may be as methods of assessing and recording disability, they are deficient in assessing and recording the effect upon carers, and also in indicating the extent to which the outcome for the patient is dependent upon a carer. It is not sufficient to assess the need for care without specifying whether such care can be given only in hospital, or, perhaps preferably, by a carer in the patient's own home.

Outcome as recorded in previous neurosurgical publications

Our surgical results differ little from those recorded in other reported series.[7,10–12,17,18] However, no other study, looking at outcome with this particular pathology, has used the SF-36 outcome measure, as most papers focus on technical success, morbidity and mortality. Unfortunately, the need for a carer, and the carer's predicament, has not been stressed sufficiently in the neurosurgical literature. Any assessment in comparison of the efficacy of different surgical approaches and methods should certainly include details of the long-term postoperative care required, and the care that is actually available.

Zentner *et al.*[12] reported early postoperative dysfunction in 56% of 19 patients with petro-clival meningiomas, with major permanent operative morbidity in two patients. The lesser degrees of disability and dependence upon carers were not important considerations in this paper. Kawase *et al.*[11] had no surgical mortality, and at an average follow-up of 4.5 years, 34 patients (81%) were independent. Presumably, this implies that they did not require carers, and that there had not been any effect upon the life-style or employment of close relatives. Three patients were disabled. The effect upon carers is not clarified. Couldwell *et al.*,[10] in a large series of 109 consecutive patients, reported perioperative death in 4 patients, and 56 significant complications in 35 patients. It is difficult to assess the true effect of these complications in the long-term. Sekhar *et al.*,[17] in a series of 41 patients, reported one operative death, and three patients who suffered permanent major neurological changes. The effect of lesser degrees of disability upon the patient and upon the carers are not clarified.

The effect upon carers

Our findings give some indication of the serious effect of the patient's disability upon the life-style and even employment of the carers. A favourable situation is when the spouse either works from home, or is retired, although age and infirmity of the carer may become relevant. The carer 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 carer's occupation and employment is essential for maintaining the home for both carer and patient. This situation was seriously disruptive for a number of carers and, therefore, for the patients.

Examples of the way in which the patient's disability has affected the life of carers are:

1. A husband had to give up his work to look after the patient and her disabled mother.
2. The patient's mother had to restrict her activities in order to help the patient at home.
3. The patient required outside help and her husband's help to cope with housework.
4. The patient's husband wished to give up work to care for his wife at home, but could not do this for financial reasons. Therefore, the pressures were to move the patient to a nursing home.
5. The patient's mother has to help her at all times at home.

Informed consent and carers

In elective complex skull base surgery for benign tumours, the major elements in the process of informed consent include: (i) the pre-operative degree of neurological disability and its progression; (ii) the probable natural history; (iii) the mortality and particularly the morbidity of surgery; and (iv) the prospects of surgical cure, or at least of preventing or delaying further progression. Our findings indicate that an additional factor should be the availability of a carer in the home and the probable effects of increased neurological disability upon that carer. In neurosurgical practice, and certainly in publications of neurosurgical results, this factor has received little attention.

The process of obtaining informed consent for surgery has been the subject of a number of publications. The General Medical Council booklet entitled *Good Medical Practice* (July 1998)[19] states that doctors must 'give patients the information they ask for or need about their condition, its treatment and prognosis. The doctor should provide this information to those with parental responsibility where patients are under 16 year's old and lack the maturity to understand what their condition or its treatment may involve, provided the doctor judges it to be in the child's best interest to do so'. It is notable that there is no reference to any duty to provide information to potential carers upon whom the adult patient may need to depend, and the carer whose life may be very significantly affected by the results of surgery.

In the Medical Defence Union booklet *Consent to Treatment* (1996),[20] there is no reference to the need or desirability of involving relatives in discussion during the process of obtaining consent to treatment from competent adults, other than for restricted consent for additional procedures, for maternity patients, and sterilisation.

Prior to our review of these cases, our normal practice was to explain everything fully to the patient, usually on more than one occasion. We did not describe the potential effect upon a carer, nor did we stress the way in which the outcome could depend upon the efforts of that carer. Our practice has changed. The spouse or close relative is involved; the potential effects upon the carer, and the patient's dependence on the carer, are discussed pre-operatively. Although it is solely the patient who can consent to operation, we now consider that a spouse or close relative has a 'right' (but not in a legal sense) to be fully informed and involved in the process.

It may be that in the future carers or potential carers will have more formalised 'rights' in relation to support from the social services, and from employers.

This would be a commendable response to some very pertinent comments by the Archbishop of Canterbury, who recently drew attention to the plight of carers who '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'.[21]

References

1. Jennett B, Bond M. Assessment of outcome after severe brain damage. *Lancet* 1975; **i**: 80–4.
2. Ware JE, Sherbourne CD. The MOS 36-item Short-Form Health Survey (SF-36). *Med Care* 1992; **30**: 473–83.
3. Karnofsky DA, Abelman WH, Carver LF, Burchenal JH. The use of nitrogen mustards in palliative treatment of carcinoma. *Cancer* 1948; **1**: 634–56.
4. Al-Mefty O, Fox JL, Smith RR. Petrosal approach for petroclival meningiomas. *Neurosurgery* 1988; **22**: 510–7.
5. Hakuba A, Nashimura S, Jang BJ. A combined retro-auricular and pre-auricular transpetrosal-transtentorial approach to clivus meningiomas. *Surg Neurol* 1988; **30**: 108–16.
6. Mayberg M, Symon L. Meningiomas of the clivus and the apical petrous bone. Report of 35 cases. *J Neurosurg* 1986; **65**: 160–7.
7. Samii M, Ammirati M, Mahran A, Bini W, Sepehrnia A. Surgery of petroclival meningiomas. Report of 24 cases. *Neurosurgery* 1989; **24**: 12–7.
8. Sekhar LN, Janetta PJ. Petroclival and medial tentorial meningiomas. In: Sekhar LN, Schramm Jr VJ. (eds) *Tumors of the Cranial Base: Diagnosis and Treatment*. New York: Futura, 1987; 623–40.
9. Yasargil MG, Mortara RW, Curcic M. Meningiomas of basal posterior cranial fossa. In: Krayenbuhl H. (ed) *Advances and Technical Standards in Neurosurgery*, vol. 7. Wien: Springer, 1980; 3–115.
10. Couldwell WT, Fukushima T, Giannotta SL, Weiss MH. Petroclival meningiomas: surgical experience in 109 cases. *J Neurosurg* 1996, **84**: 20–8.
11. Kawase T, Shiobara R, Toya S. Middle fossa transpetrosal-transtentorial approaches for petroclival meningiomas: selective pyramidal resection and radicality. *Acta Neurochir* 1994; **129**: 113–20.
12. Zentner J, Meyer B, Vieweg U, Herbethold C, Schramm J. Petroclival meningiomas: is radical resection always the best answer? *J Neurol Neurosurg Psychiatry* 1997; **62**: 341–5.
13. Megarian CA, Chiocca EA, McKenna MJ, Harsh 4th GF, Ojemann RJ. The subtemporal-transpetrosal approach for excision of petroclival tumours. *Am J Otol* 1996; **17**: 773–9.
14. Centres for Disease Control. Quality of life as a new public health measure–behavioral risk factor surveillance system. *MMWR* 1994; **43**: 375–80.
15. Van der Zee KI, Sandeman R, Heyink JW, de Haes H. Pshychometric qualities of the RAND 36-item health survey 1.0: a multi-dimensional measure of general health status. *Int J Behav Med* 1996; **3**: 104–22.
16. Brookes WB, Jordan JS, Devine GW, Smith KS, Neelon FA. The impact of psychological factors on measurement of functional status. *Med Care* 1990; **28**: 793–804.
17. Sekhar LN, Janetta PJ, Burkhart LE, Janosky JE. Meningiomas involving the clivus: a six year experience with 41 patients. *Neurosurgery* 1990; **27**: 764–81.
18. Bricolo AP, Turazzi S, Talacchi A, Cirstofori L. Microsurgical removal of petroclival meningioma. A report of 33 patients. *Neurosurgery* 1992; **31**: 813–28.
19. General Medical Council. *Good Medical Practice*. London: General Medical Council, 1998,
20. The Medical Defence Union. *Consent to Treatment*. London: The Medical Defence Union, 1996.
21. *The Times*, London 26th November 1998, page 2.