The Management of Spinal Deformity in the United Kingdom

Guide to Good Practice

This account of the management of spinal deformity has been prepared by the British Scoliosis Society Executive. Founded in 1976 and affiliated to the British Orthopaedic Association, the British Scoliosis Society is the professional group of surgeons, clinicians and scientists with a special interest in this clinical discipline.

17 November 2003

British Orthopaedic Association website: http://www.boa.ac.uk

1. Introduction

a. This document has been produced for information and guidance of NHS Trusts, Trust Chief Executives, NHS Strategic Health Authorities and Primary Care Trusts. Clinical effectiveness groups and the Medical Defence Societies will find important information about the range of practice in the management of spinal deformity in the United Kingdom.

b. Presently there are approximately 30 surgeons in the United Kingdom and the Republic of Ireland undertaking the management for spinal deformity. The total number of patients undergoing treatment is not known, but at least 1000 patients per year undergo surgery.

c. The most appropriate surgeon to undertake the management of spinal deformity would be an active member of the British Scoliosis Society (BSS) and involved in team working in surgical practice, as recommended by the Senate of Surgery of Great Britain and Ireland (Ref 1). The majority of spinal deformity surgeons will treat both children and adults and will have experience in spinal reconstruction for non-deformity conditions. BSS advises that units treating spinal deformity should in future have a minimum of two consultant surgeons.

d. The BSS is of the view that consultant surgeons should be involved in the care of at least 20 patients annually. There is a substantial range of practice, both in the absolute numbers per surgeon and the range of procedures. Some surgeons do fewer than 10 operative procedures per year, and others more than 100 procedures per year.

e. The largest single clinical grouping of patients with spinal deformity is children with adolescent idiopathic (late onset) scoliosis. Progressive adolescent idiopathic scoliosis has an incidence of about two per thousand children.

f. There is a very complex mixture of patients who suffer from spinal deformity. Many patients have associated congenital and developmental problems of childhood, including spinal dysraphism, neuro-muscular and connective tissue abnormalities. Children with cardiac, respiratory and renal problems present a particular problem with regard to resources and the infrastructure, to allow optimal practice.

g. Access to surgery is effectively 'rationed' at present. Many patients are never referred for specialist assessment, and thus denied any opportunity to benefit from surgical intervention. In addition all spinal deformity services are currently short of facilities, and all these factors combine to produce an under-provision of service.

h. Many patients attending clinics for the assessment of spinal deformity will not require surgery. A proportion will require treatment with orthotic devices and regular follow-up until at least the end of growth when progression of spinal deformity will generally have ceased.

i. The requirement for operative intervention in adults is poorly defined. There is evidence that this problem is increasing and represents an important area of clinical under-provision. Untreated spinal deformity in skeletally immature patients is known to progress in adulthood sometimes.

2. Organisation of Specialist Clinics

a. Clinics are currently centered at some university hospitals, a few specialist children's hospitals, some specialist orthopaedic hospitals, and some large district general hospitals. Children may be referred by their family practitioners or other primary care workers, but in the main are referred by paediatricians, other orthopaedic surgeons and neurosurgeons. Secondary tertiary referral is therefore common. School nurses and teachers continue to be important in the early recognition of children with spinal deformity.

b. The clinic attendances are characteristically spread over a period of many years, and it is normal practice to follow-up children until growth is complete. Most clinics will be in large population centres serving up to 2-4 million people.

c. Physiotherapists with special experience in the assessment and management of spinal deformity and care of respiratory problems, are frequently employed within spinal deformity clinics, and make an important contribution to the assessment of any associated disability. Nurse practitioners in the United Kingdom have not assumed the same role at this time as nurse practitioners in North America and many European countries. This failure represents both a training and a resource issue,

d. The association with neurosurgery is not formally defined. The management of deformity of the spine is exclusively an orthopaedic spinal matter but, in turn, many spinal deformities are associated with important intraspinal and congenital anomalies which are neurosurgical issues primarily. In addition, both children and adults may have developed spinal deformity as a manifestation of neurological disease, eg syringomyelia. The initial diagnosis of syringomyelia in children may be made frequently in orthopaedic spinal deformity clinics. Spinal tumours may present to spinal deformity surgeons from time to time.

3. Initial Patient Assessment and Counselling

a. The majority of patients will be children and appropriate facilities are essential (Ref 2). Adult patients with spinal deformity will usually be seen in separate facilities. In the private sector amenities must be at least equivalent to those available to National Health patients. Ideally patients listed for operation should attend an anaesthetic pre-assessment clinic.

b. The management of spinal deformity may often require prolonged outpatient attendance, at least until skeletal maturity in children, and parents and patients should be advised accordingly. The place of surgical management of spinal deformity in children with major handicap is always a delicate issue, and must be discussed frankly with the parents and carers.

c. Outpatient assessment requires the careful taking of medical history and a full examination with special emphasis on a comprehensive neurological examination. Many patients have already seen a consultant and a radiological investigation already undertaken may be inadequate or inappropriate. Further imaging is likely to be required.

d. Many parents and adolescents are anxious about the possibility of surgical treatment, and it is good practice to address this issue at an early stage. It is common for parents and patients to have severe misapprehensions about the indications and risks of surgical treatment.

e. The Scoliosis Association of the UK (Ref 3) provides valuable support for carers and parents. For children with unusual congenital and developmental conditions there are often specialist groups of parents who are able to provide helpful advise for children with spinal deformity.

4. Investigation of Patients

a. Investigation of patients with complex spinal disorders requires appropriate resources, especially access to MRI scan, CT scanning and neurophysiological investigations. Currently many spinal deformity services are unable to investigate patients comprehensively within the same facility, which in turn will require patients to be seen at several hospitals and on different occasions for primary investigation.

b. A clinical photography service may often best demonstrate the severity of the deformity. Topographical representation using light diffraction systems or videos are employed in some centres.

c. Measurement of height and weight is an essential clinical parameter and appropriate equipment with properly trained staff is mandatory.

d. Respiratory function studies may be made at initial consultation. This can be essential information to decide whether a particular patient may be suitable for operative treatment.

e. Xrays for measurement and demonstration of the extent of deformity are mandatory. Specialist xray cassettes and the employment of lateral bend xrays are essential.

f. Techniques such as the use of rare earth screens to minimise xray exposure to the immature skeleton and the developing breast bud are vital. Clinical observation may be made over several years, and the number of xray examinations should be minimised.

g. Xrays to estimate skeleton are especially important in immature patients.

h. CT scanning may be appropriate to determine vertebral body dimensions and to define the precise anatomy in congenital spinal deformity. The determination of the nature of the deformity in small children will often allow the establishment of prognosis for a particular deformity, and also any need for early surgery.

i. Isotope bone scanning will sometimes be indicated, especially in patients where spinal deformity is associated with pain. This investigation will frequently be required in immature patients.

j. MRI scanning may disclose important neurological problems (Ref 4). All early onset scoliosis should be scanned to exclude a syrinx in the cervical spinal cord. All atypical spinal deformity requires being MRI scanned, especially when there are vertebral bony anomalies present and if surgical intervention is anticipated. MRI scanning is mandatory in all patients with spinal deformity, showing evidence of spinal cord compromise.

k. Neurophysiological investigation may often be required to confirm any underlying neurological disease and sometimes as a pre-operative investigation when spinal cord monitoring is to be employed during corrective surgery.

l. Access to spinal cord angiography may occasionally be needed.

m. Dexascan may be required for patients whose deformity is associated with abnormal bone density.

n. All this information may be best recorded on special documentation, or alternatively on a computerised record.

5. Indications for Operative Treatment

a. Indications for surgery will differ according to the precise diagnosis, and tend to be case specific. In general, however, a deformity which is significant and progressive, or anticipated to become significant in an immature patient, especially with major trunk imbalance, is an indication for operation.

b. The outcome data that is available supports early intervention in some young children, to prevent the development of important compromise or respiratory function (Ref. 5).

c. Pain may be an important indication for surgery in adults. Occasionally pain is an important feature of spinal deformity in immature patients. Neurological compromise, or predicted neurological compromise, because of the deformity, is an important indication for advising operative treatment.

d. Outcome data in adult deformity indicates that disabling low back pain may be a reason to recommend operative intervention and in addition to prevent the progression of spinal deformity, even in mature patients. Degenerative change in the spine may severely exacerbate deformity and cause spinal stenosis.

6. Pre-operative Management and Consent

a. Spinal deformity surgery is major complex surgery inevitably associated with a degree of risk. It is important that consent is taken by the surgeon who performs the operation and who will explain what is involved to patients and relatives, the treatment alternatives and the potential risks (Appendix – Blue consent).

b. Patients will require recent radiographic investigation prior to operation, as deformity may have progressed from the time of listing for operation. The progression of the deformity may change the recommended operative treatment. Special radiological cassettes may be needed.

c. Pre-operative neurophysiological investigation may be advised where sensory evoked potentials or motor evoked potentials are to be employed intra-operatively. The significance of this will be explained during the consent for surgery.

d. The anaesthetist is a key member of the spinal deformity team. All patients must be assessed pre-operatively by an anaesthetist with experience in spinal deformity anaesthesia, who may recommend investigation which will vary according to the diagnosis, and include respiratory function assessment.

e. Spinal deformity surgery is associated with a time of great stress for the carers and parents of patients, and their needs with respect to accommodation within the hospital must be considered. Appropriate schooling may need to be provided if the length of stay in hospital is going to be exceptional. The input of play specialists, social care workers and teachers is therefore essential.

7. Surgical Procedures

a. Procedures are case specific and invariably complex. Operations involve anterior and/or posterior spinal fusion with or without instrumentation. In young children excision of the vertebral end growth plates may be performed. Thoracotomy is frequently required and it is sometimes recommended to perform a costoplasty. Decompressive surgery is sometimes appropriate.

b. Regular exposure to spinal deformity surgery by clinicians will produce optimum outcomes, and it is appropriate to perform operations in a specialised unit. There is no case for the occasional operator in this field of surgery.

c. All spinal deformity operations are accompanied by a risk of neurological injury, including paraplegia (Ref. 6). Electrophysiological spinal cord monitoring or the 'wake-up test' may reduce this risk and should be available at the discretion of the surgeon.

d. Some procedures are so complex that two consultant surgeons are required to complete the operation within a reasonable time frame, and prevent exhaustion of the surgeon, especially when anterior and posterior operation is required.

e. A thoracic surgical and/or neurosurgical colleague may occasionally be required, at the discretion of the deformity surgeon, and in special circumstances.

f. Spinal deformity surgery is often associated with high blood loss and the use of measures to minimize the use of homologous blood should be encouraged. These may include:

- Appropriate anaesthesia to produce a bloodless field
- Careful positioning of the patient
- The administration of drugs by epidural catheter intraoperatively
- Autologus pre-donation. This may be combined with pharmacological measures to enhance red cell formation.
- The use of devices such as a cell saver
- Normovolemic haemodilution

g. Spinal implants either in the form of rods, screws or plates, would generally be available in stainless steel. There are special indications for the use of titanium implants, especially where the continuing management of an individual patient will involve repeat MRI scanning in future years, eg. spinal cord tumours.

h. Implant costs are currently high because of the low volume and high specification requirements.

8. Post-operative Care

a. Surgical management should always be in an environment which is appropriate to the age and maturity of the patient. Post-operative management in a high dependency unit, with appropriate specialist nursing, together with protocols for guaranteed access to paediatric intensive care units to provide appropriate ventilatory support is a requirement when this surgery is undertaken in specialist hospitals.

b. Pain relief measures may include the use of PCA (patient controlled analgesia) and thoracic epidural catheters with an appropriate local anaesthetic and opiate. Additionally an intra-pleural catheter may be indicated following thoracotomy or costoplasty.

c. Experience outside the United Kingdom has indicated that a high dependency unit with ventilatory capacity is usually appropriate and intensive care unit access is rarely required.

d. Appropriately trained physiotherapy staff experienced in both the management of paediatric spinal deformity and respiratory care are essential, especially with the management of children who have undergone a thoracotomy.

e. Plaster or glass fibre casts as a post-operative external support may be needed, especially in some small children. In most adolescent patients there is a minimal requirement for post-operative casts and braces, especially when a patient has a normal quality bone. Casts require a trained technician to be available in the hospital.

9. Orthotic Treatment

a. The facility to use localiser plaster casts and braces, which may be made with the patient awake or anaesthetised, is required together with skilled and experienced orthotic support.

b. Direct access by parents and carers to the orthotic department is important for repairs, adjustment and advice.

c. A majority of spinal deformity units have no de facto recognition as a 'Regional Centres'. This unquestionably contributes to difficulties that parents and carers may experience with regard to the provision of appropriate orthotic devices and wheelchairs.

10. Training of Appropriate Surgeons and the Future

a. Surgical intervention in spinal deformity is certain to continue to be undertaken by orthopaedic spinal surgeons, as opposed to neurosurgical spinal surgeons. The training of these clinicians is currently being examined by the relevant specialist societies and specialist advisory committees. A major shortfall in trained surgeons is an immediate concern in the United Kingdom.

b. An absolute minimum of one year of specialist spinal training, either as a 'fellowship appointment' or an advanced training post, is essential. The concept of 'proleptic appointment' in the United Kingdom in spinal surgery has widespread support among established surgeons to ensure safe practice.

c. Operative techniques are radically different in the 21st century compared with even 10-15 years previously. Anterior interbody fusion done via a thoracotomy or thoraco-laparotomy may become the principal method of managing idiopathic deformities, especially in immature patients.

d. Research work into the aetiology of spinal deformity, especially idiopathic scoliosis, is currently concentrating on the genetic aspects of the condition. It is unlikely however that the demand for operative treatment will change. Indeed the experience of surgeons involved in this work suggests that the reverse will occur, namely that there will be an increasing demand for surgical intervention.

e. Previously patients who are now adults were either treated with inadequate intervention or were never offered appropriate surgery. These patients now present to orthopaedic surgeons with disabling symptoms, associated with deformity, and who are seriously handicapped. Problems of adult spinal deformities are being increasingly addressed in North America and Continental Europe, and there is no question that these patients will have to be treated in the United Kingdom.

f. These patients will represent the natural history of severe deformity which, in turn, is the consequence of spinal malalignment. It is hoped that more modern methods of surgical intervention will lessen the requirement for adult surgery as the deformity will have been addressed in the formative years.

11. Conclusions

a. The British Scoliosis Society, being the oldest of the professional specialist spinal societies in the United Kingdom, sees its role as promoting the highest standards of surgical practice, and identifying key issues in service provision, training and future planning for the treatment of these unfortunate patients.

b. Although the incidence of spinal deformity seems remarkably uniform through the world, at about two per thousand children, the condition is not reportable in any Western Country, and accurate figures are not available.

c. In the United Kingdom further information is being collected at the initiative of the BSS to provide a reliable statistical background for mortality and morbidity in spinal deformity practice. It is essential that accurate data becomes available.

A G Thompson FRCS

Contributions by:

Mr N R Boeree FRCS
Mr J Carvell FRCS
Mr J Dorgan FRCS
Mr J Dove FRCS
Mr M Edgar FRCS
Mr A Gardner FRCS
Dr Y Girgis FRCA
Mr D S Marks FRCS
Mr M McMaster FRCS
Mr I Nelson, FRCS
Mr A O Ransford FRCS
Mr J O'Dowd FRCS
Mr A G Thompson FRCS
Mr B Williamson FRCS
Mr J Webb FRCS

References:

1 Consultant Surgeons – Team Working in Surgical Practice
The Senate of Surgery of Great Britain and Ireland. Paper 7, May 2000

2 Children's Surgery – A First Class Service
Report of the Paediatric Forum of the Royal College of Surgeons, May 2000

3 The Scoliosis Association (UK)
2 Ivebury Court 323-327 Latimer Road London W10 6RA

4 Edgar M (2000)
Neural Mechanisms in Aetiology of Idiopathic Scoliosis in Aetiology of Adolescent Idiopathic Scoliosis
Page 459 Ed Burwell G. Hanley and Belfus Spine State of the Art Reviews Vol 14.2

5 Reid L (1969) Pathological changes in the lungs in scoliosis
Scoliosis P67 Ed Zorab PA Londong Heinemann