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Complications with shunts in adults with spina bifida

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Abstract

***Objective*—To assess the incidence of malfunction of shunts in adults with spina bifida who have shunts to control hydrocephalus.**

***Design*—A retrospective review of the medical notes and contact by questionnaire of adults with spina bifida to assess symptoms, function of shunts, frequency of operative procedures, and follow up.**

***Subjects*—110 patients with shunts who attended Lord Mayor Treloar College for the physically disabled between 1978 and 1993.**

***Results*—The average (range) number of revisions of shunts per person was 3·6 (0-28). Although 37 patients underwent an emergency operation for revision in their first year of life, there was a continuing low incidence, increasing in the early teenage years, which persisted into the third decade. Intervals between emergency revisions varied: 202/320 occurred within one year of the last shunt operation, 56 occurred after five years, 24 after 10 years, and 15 after 15 or more years. Fifteen patients had chronic intermittent headaches, of whom four died and three suffered severe morbidity. Thirteen died; three had raised intracranial pressure, and four died suddenly; these deaths were presumed to be related to their shunts. Up to the age of 16 there was 100% hospital follow up, but after that only 40% of young adults underwent review, including review of their shunt function.**

***Conclusion*—Shunts to control hydrocephalus may fail after many years without symptoms. This is difficult to diagnose and if missed may lead to chronic morbidity and death. As hospital follow up of this group is falling, both general practitioners and hospital doctors must be aware that a shunt may malfunction after prolonged quiescent periods.**

Time since last emergency operation for revision of shunt in group of subjects with spina bifida and hydrocephalus

Time since operation (years)	No of subjects
≤1	202
1	24
2	11
3	9
4	18
5*	11
6	6
7	7
8	5
9	3
10†	3
11	5
12	3
13	1
14	1
15‡	6
16	0
17	3
18	0
19	1
20	1
Total	320

*For 5 years onwards 56/320 (17·5%).
†For 10 years onwards 24/320 (7·5%).
‡For 15 years onwards 11/320 (3·5%).

Introduction

In a school population with many children with spina bifida and hydrocephalus a persisting incidence of malfunction of shunts, especially in the early teenage years, was observed. Two of these patients were stated to have arrested hydrocephalus and non-functioning shunts, hence causing delay and increased difficulty in making the diagnosis. Four patients died from shunt malfunction, two proved and two suspected. We therefore carried out a review of the whole group including all the school leavers to assess the importance of long term shunts in adults and whether complications with shunts continued to occur.

Method

We reviewed pupils who had attended Lord Mayor Treloar College for the physically disabled between 1978 and 1993. Of the 215 pupils with spina bifida, 179 (83%) had shunts. A questionnaire was sent to these 179 students or their families for completion and permission to review their medical notes. Contact was attempted initially via the Association for Spina Bifida and Hydrocephalus, and to those who did not respond a further attempt was made directly to their last known address at the time they left the college.

Results

Eighteen people refused to participate or allow examination of their medical notes; 39 did not respond to either attempt at contact; and 12 could not be traced as questionnaires were returned by the post office. The remaining 110 who were reviewed reflected the general age and sex distribution of the group (mean (range) age 21·5 (14-31) years, male:female ratio 1:1·3 in reviewed group; 24·3 (14-32) years, 1:1·3 in non-reviewed group).

As shunts have been replaced the ratio of ventriculo-atrial to ventriculo-peritoneal shunts has fallen from about 25:1 to 2:1. The mean (range) number of operations per person for revision of shunts was 3·6 (0 to 28), but the mode was only one. Of these revisions, 72 were prophylactic and 320 were emergency operations. Thirty seven subjects required emergency revision operations in their first year, the incidence falling to 4% (4/110) at 10 years, only to rise in the early teenage years to 13%, returning to a 4% incidence persisting into the third decade. The table shows the distribution in years of the time lag between emergency revisions and their last shunt operation and the total percentage occurring after intervals of 5, 10, and 15 years.

Headaches—Fifteen patients had complained of chronic intermittent headaches; 10 of these were alive and well but two continued to have headaches despite invasive investigations. One young woman diagnosed as having migraine gradually developed paraesthesia and weakness in her arms then became quadriplegic and collapsed. A blocked shunt was found at operation. Of the two other patients found to have blocked shunts and high intracranial pressures, one died at operation, the other died postoperatively. One 19 year old girl, having been told that if she had further symptoms she should have an operation to revise her shunt, died suddenly; raised intracranial pressure was reported at postmortem examination. A young man diagnosed as having chronic sinusitis deteriorated and died while waiting for a sinus operation. There was no post-mortem examination.

Deaths—There were 13 deaths in the series. Three died from proved shunt complications. Four died suddenly, shunt malfunction being suspected but not proved; two as described above, and two teenagers who were well and free of symptoms died in bed at night, but no cause of death was found at postmortem examinations. Six deaths were not related to shunts.

Hospital follow up—We found that up to the age of 16 years there was a 100% review of the shunt function as part of the care of the whole patient. After they left

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Key messages

- Young people with hydrocephalus are dying of complications with their shunts that are not diagnosed
- Shunts may fail after many years without symptoms
- Malfunction of a shunt should be considered with any unexplained symptoms or signs
- Descriptions like "arrested hydrocephalus" or "shunt independent" can be misleading and delay diagnosis
- All patients with spina bifida who have shunts need continuing comprehensive care

the paediatric departments, 13 had their shunt function reviewed by neurosurgeons, 31 in rehabilitation clinics, and 66 had no review of their shunt at all.

Discussion

Hemmer and Bohn stated that few patients with spina bifida who had a shunt inserted for hydrocephalus could at a later stage survive without it and coined the phrase "once a shunt always a shunt."[1] In 1982 there was much discussion about the needs of long term shunting and the possibility of arrested hydrocephalus. Either the removal of a non-functioning shunt or leaving one in situ in patients with "arrested" hydrocephalus became a definite treatment regimen.[2-4] Our findings support Hemmer and Bohn's original thinking. We have shown that although shunt malfunction occurred most commonly in the first year after insertion, shunts may fail up to 20 years later (table). During this time it may have been assumed that the shunt was not functioning.

As the response rate was 61%, the results may not be fully representative of the whole group. Although 10% refused to participate and 7% were untraced, another 22% did not respond to the letters. This is not too suprising from young people who characteristically have difficulty organising themselves because of their hydrocephalus. Some disabled school leavers become resentful of their condition and need for continuing medical care and are unwilling to complete associated questionnaires.

Functioning shunts cannot be expected to last indefinitely.[5,6] If blockage of a shunt is acute there are usually the typical symptoms and signs of raised intracranial pressure, and hospital admission is relatively straightforward. Chronic or intermittent malfunction, however, may present with only insidious symptoms, such as changes in behaviour or performance often associated with headaches. Irrespective of the length of time since the last shunt operation if no other cause can be found a referral for further investigation should be made. In hospital if all basic test results are inconclusive then shunt investigation should be considered. There are many new developments in non-invasive investigation of shunt function,[7-10] but invasive monitoring (despite the risks this entails)[11,12] may be the only way to make a definite diagnosis.

We found that all children with spina bifida and hydrocephalus were reviewed routinely by paediatric surgeons and neurosurgeons, who acquire great experience of this unusual group. In adult departments, hospital follow up becomes divided between different specialties, and only 40% of our subjects had regular review which included assessment of shunt function, often with no one taking responsibility for overall care. Therefore the initial decision as to whether symptoms may be related to the shunt may be left to the general practitioner or junior hospital doctor. It is difficult for those with little experience of this condition to make an accurate diagnosis with sufficient confidence to insist on admission to a neurosurgical unit.

Young adult patients with hydrocephalus may die or suffer severe morbidity because malfunction of their shunts is missed. Despite long periods since the last operation, malfunction must be considered seriously as the cause of any unexplained neurological symptoms. It is important for all people with a shunt to control hydrocephalus and chronic neurological problems to have continuing comprehensive care.

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Emergency psychiatric services in England and Wales

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Although few policies guide the local planning of emergency psychiatric services in Britain, service users and their carers frequently express a preference for local teams that can respond quickly to crises.[1] Acute psychiatric services are now usually provided by sector teams for defined geographical catchment areas.[2] The provision of emergency response as part of an integrated range of local services has substantial advantages in terms of continuity of care and service accessibility,[3] but such care may be difficult to sustain at night and at weekends for a small sector.[4] We describe how emergency services in England and Wales are currently organised and staffed, comparing patterns of provision outside office hours with those during the day.

Methods and results

We sent questionnaires to the general health manager of the mental health unit in every district in England and Wales (n=199). Reminders and, if necessary, follow up calls were used. We distributed