Outcome in people with open spina bifida at age 35: prospective community based cohort study

Gillian M Hunt and Pippa Oakeshott

BMJ 2003;326:1365-1366
doi:10.1136/bmj.326.7403.1365

Updated information and services can be found at:
http://bmj.com/cgi/content/full/326/7403/1365

These include:

References
This article cites 5 articles, 1 of which can be accessed free at:
http://bmj.com/cgi/content/full/326/7403/1365#BIBL

3 online articles that cite this article can be accessed at:
http://bmj.com/cgi/content/full/326/7403/1365#otherarticles

Rapid responses
One rapid response has been posted to this article, which you can access for free at:
http://bmj.com/cgi/content/full/326/7403/1365#responses

You can respond to this article at:
http://bmj.com/cgi/eleletter-submit/326/7403/1365

Email alerting service
Receive free email alerts when new articles cite this article - sign up in the box at the top left of the article

Topic collections
Articles on similar topics can be found in the following collections

Other Neurology (3663 articles)
Genetics (3956 articles)
Disability (47 articles)
Other Pediatrics (1849 articles)

Notes

To order reprints follow the "Request Permissions" link in the navigation box
To subscribe to BMJ go to:
http://resources.bmj.com/bmj/subscribers
ses and interpretation of findings. Patient led research typically presents numerical results and illustrates these with quotations to show what the data mean in terms of patients’ lives, whereas clinical researchers tend to undertake further statistical analysis of the data, sometimes ignoring the original data. The findings relate to the experience of persistent memory loss. Routine neuropsychological tests have been used in studies of electroconvulsive therapy to establish objective measures of memory loss and concluded that there was no evidence of persistent memory loss. It would seem that these are the studies on which the Royal College of Psychiatrists based its findings. The studies, however, typically measure the ability to form new memories after treatment (anterograde memory). Reports by patients of memory loss are of the erasing of autobiographical memories or retrograde amnesia. Thus the risks reported by patients do not appear in clinical assessments. The levels of perceived benefit differed between patient led and clinician led studies because different methods were used and because in many cases these methods did not allow an adequate description of the complexity of subjective experience. Even where findings, such as persistent memory loss, did not differ between patient led and clinician led studies, the interpretations may have differed radically. It is therefore not surprising that disputes can arise and that organisations should emerge that provide support for those who feel their treatment has not been beneficial.

Conclusion

Although clinical trials concluded that electroconvulsive therapy is an effective treatment, measures of efficacy did not take into account all the factors that may lead patients to perceive it as beneficial or otherwise. Studies of treatment are needed that are able to investigate a range of outcomes valued by patients, including factors that impact on effectiveness and satisfaction. Also important is loss of autobiographical memory, which is widely described but insufficiently systematically investigated.

Contributors: See bmj.com

Competing interests: This paper is based on a report funded by a grant from the Department of Health, England. The Department of Health has given permission for publication but does not necessarily endorse the views contained in the paper.

(Accepted 15 May 2003)

Outcome in people with open spina bifida at age 35: prospective community based cohort study

Gillian M Hunt, Pippa Oakeshott

The introduction of the cerebrospinal fluid shunt led to a fourfold increase in survival of babies with open spina bifida in the United Kingdom.1 In 1963 a prospective independent review was set up to record the results and implications of the new treatment.2 Such data are crucial to the dilemmas associated with termination of affected pregnancies or treatment at birth.1 We investigated survival, disability, health, and lifestyles in a complete cohort of adults with spina bifida.

Participants, methods, and results

Between 1963 and 1971, 117 babies had their backs closed at Addenbrooke’s Hospital, Cambridge, without any attempt at selection. Before closure of the back each baby had a full neurological examination. When necessary, hydrocephalus was controlled by the insertion of a ventriculostom at birth. In spring 2002 we reviewed the cohort by confidential postal questionnaire backed by a telephone call to the patient or carer. The Office for National Statistics provided information on deaths.

Ascertainment was 100%. Sixty three (54%) had died, mainly the most affected. Causes of death were cardiorespiratory (19) or renal (18) failure, hydrocephalus (10), central nervous system infection (10), convulsions (2), inhaled vomit (2), sudden infant death (1), and thrombocytopenic purpura (1). The mean age of the survivors was 35 years (range 32-38). The male:female ratio was 1:1.3, the same as at birth.

(Accepted 15 May 2003)

What is already known on this topic

Around 11 000 people receive electroconvulsive therapy in England annually

Controversy exists as to whether treatment is beneficial and whether patients are satisfied with it

Patients’ views have never been systematically reviewed

What this study adds

At least one third of patients report significant memory loss after treatment

Routine neuropsychological tests to assess memory do not address the types of memory loss reported by patients

Reported patient satisfaction with electroconvulsive therapy depends on the methods used to elicit a response

Outcome in people with open spina bifida at age 35: prospective community based cohort study

Gillian M Hunt, Pippa Oakeshott

The introduction of the cerebrospinal fluid shunt led to a fourfold increase in survival of babies with open spina bifida in the United Kingdom.1 In 1963 a prospective independent review was set up to record the results and implications of the new treatment.2 Such data are crucial to the dilemmas associated with termination of affected pregnancies or treatment at birth.1 We investigated survival, disability, health, and lifestyles in a complete cohort of adults with spina bifida.

Participants, methods, and results

Between 1963 and 1971, 117 babies had their backs closed at Addenbrooke’s Hospital, Cambridge, without any attempt at selection. Before closure of the back each baby had a full neurological examination. When necessary, hydrocephalus was controlled by the insertion of a ventriculostom at birth. In spring 2002 we reviewed the cohort by confidential postal questionnaire backed by a telephone call to the patient or carer. The Office for National Statistics provided information on deaths.

Ascertainment was 100%. Sixty three (54%) had died, mainly the most affected. Causes of death were cardiorespiratory (19) or renal (18) failure, hydrocephalus (10), central nervous system infection (10), convulsions (2), inhaled vomit (2), sudden infant death (1), and thrombocytopenic purpura (1). The mean age of the survivors was 35 years (range 32-38). The male:female ratio was 1:1.3, the same as at birth. Of the
Neurological deficit in infancy in 117 consecutive cases of open spina bifida and outcome in 54 people who survived to mean age 35 years

<table>
<thead>
<tr>
<th>Sensory level in infancy</th>
<th>Below L3</th>
<th>L3-T11</th>
<th>Above T11</th>
<th>Asymmetrical</th>
</tr>
</thead>
<tbody>
<tr>
<td>Whole cohort</td>
<td>38</td>
<td>32</td>
<td>42</td>
<td>5</td>
</tr>
<tr>
<td>Those who died (n=63)</td>
<td>14</td>
<td>17</td>
<td>30</td>
<td>2</td>
</tr>
<tr>
<td>Survivors (mean age 35)</td>
<td>24</td>
<td>15</td>
<td>12</td>
<td>3</td>
</tr>
<tr>
<td>No CSF shunt (n=8)</td>
<td>7</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>IQ ≥ 80 (n=39)†</td>
<td>21</td>
<td>11</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Community walker (n=16)†</td>
<td>16</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Continent (n=11)‡</td>
<td>8</td>
<td>2</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Live independently (n=22)¶</td>
<td>14</td>
<td>5</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Drive cars (n=20)</td>
<td>14</td>
<td>4</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Open employment (n=13)</td>
<td>9</td>
<td>2</td>
<td>2</td>
<td>0</td>
</tr>
</tbody>
</table>

*P value for trend*<sup>a</sup>
† IQ recorded at age 5-15 years.
‡ Able to walk ≥50 metres with aids if required.
§ Continent without catheters or appliances.
¶ Living in community without help or supervision.

One hundred years ago

The wife of Major-General Chambers, of I.I. Trinity Gardens, Folkestone, recently paid the public vaccinator of Folkestone one vaccination compliment in the surgery where he sees his official patients, she apparently regards vaccination as too important an operation to be entrusted to an ordinary medical man, so, when she felt that she and her two daughters were in need of it, she selected one who may be regarded as a vaccination specialist. Many quite ordinary people, with whom we would not for a moment class the wife of a major-general, think and do the same, and the supreme delicacy of Mrs. Chambers’s conduct lies in the fact that, instead of being content to pay the public vaccinator a compliment in the surgery where he sees his official patients, she made it a direct and personal one by seeking him out with her two daughters in his private consulting room. Unfortunately, however, after this she rather spoiled the thing by refusing to pay his fees, and the intervention of another of H. M. officers, in the shape of the county court judge, had to be invoked before she rounded off her compliment by the noble fee of half a crown a shape of the county court judge, had to be invoked before she rounded off her compliment by the noble fee of half a crown a shape of the county court judge, had to be invoked before she rounded off her compliment by the noble fee of half a crown.