

Ambulation in patients with myelomeningocele: a study of 1500 patients

I Díaz Llopis MD, M Bea Muñoz MD, E Martínez Agulló MD, A López Martínez MD, V García Aymerich MD, JV Forner Valero MD

Department of Rehabilitation, La Fe Hospital, Valencia, Spain.

Data from 1500 patients affected by spina bifida have been collected in a multicentre study in Spain from 1986 to 1988. This paper is concerned with a part of the data, specifically regarding the walking of patients and certain factors that influence the prognosis for ambulation.

The neurological level of lesion most commonly present was lumbosacral (65.6%). Hydrocephalus was frequent (62% of the sample), and has significant implications regarding prognosis for walking.

Hip dislocation (32%) and scoliosis (22.9%) were orthopaedic problems noted in our sample. Pressure sores appeared in 31.7% of the patients.

The onset of walking ability has been studied; 15% of the sample started walking at an age older than 5 years.

Finally, different modalities of ambulation are described according to the use of ancillary devices, and in independence in activities of daily living.

Keywords: ambulation; myelomeningocele; spina bifida.

Introduction

A few years ago, patients with myelomeningocele were condemned to a short and distressing existence, but, nowadays, with medical advances in prophylaxis, and the treatment of neonatal meningitis and hydrocephalus, their life has been prolonged. In the next few years these patients, now almost exclusively children, will reach adulthood.

This new situation requires us to change their medical management, treating new and specific problems, and making every effort to improve their quality of life.

From the medical point of view, this quality of life depends to a certain extent on four features: locomotion; level of intelligence; urological problems (including sphincter incontinence); and genitosexual aspects. The problems concerning locomotion are the subject of our study.

It is our opinion that compared to other reports in the literature, the importance of this study relates to the large number of patients with myelomeningocele that we have been able to study. Determining factors for walking ability are: neurological level; hydrocephalus; orthopaedic problems;

pressure ulcers; and others (eg obesity, family conditions, etc). The management of these problems has allowed ambulation for a great number of patients.

Material and methods

The data of this work come from a multicentre study begun in 1986 and concluded in 1988, covering the whole of Spain, under the direction of Dr E Martínez Agulló and Dr V Alberola Cuñat.¹

Private and public associations' records (Table I), and hospitals' and doctors' files and records were used to obtain the cases: a total number of 1770 patients was obtained, a questionnaire was prepared, and 1500 patients were interviewed (Table II) by appropriately trained doctors, nurses, psychologists, and social workers.

The medical and psychosocial aspects of myelomeningocele were included in the questionnaire, only a part of which has been used in the preparation of this paper, to obtain relevant information about the level of injury, hydrocephalus, orthopaedic complications, pressure sores, and onset and type of ambulation achieved.

Table I Private and public associations used to obtain a list of patients with myelomeningocele

Hospital files

List from the Dirección Nacional del INSERSO

Directories from the Direcciones Generales de Bienestar de las Comunidades Autónomas

Spina Bífida Associations from Algeciras, Córdoba, Granada, Jaen, Málaga, Zaragoza, Asturias, Canarias, Cantabria, Castilla-León, Catalunya, Madrid, Murcia, Alava, Gipuzcoa, Vizcaya, Alicante, Valencia

Table II Number of patients identified and interviewed according to the community to which they belong. Number of patients identified = 1770, number of patients interviewed = 1500

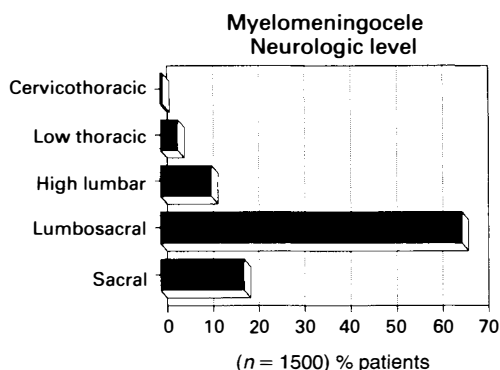
Community	Identified	Interviewed	Community population
Andalucía	149	136	6,558,542
Aragón	75	44	1,196,952
Asturias	25	22	1,129,556
Baleares	39	39	655,909
Canarias	49	48	1,367,646
Cantabria	23	22	513,115
Castilla-La Mancha	54	48	1,648,586
Catalunya	294	294	5,956,414
Extremadura	12	12	1,065,168
Galicia	84	51	2,811,922
La Rioja	11	3	254,349
Madrid	299	281	4,686,895
Murcia	93	93	955,487
Navarra	6	5	509,002
Pais Vasco	155	110	2,141,809
Pais Valenciano	402	292	3,646,778

Fifty-three percent of the sampled population were male, and 47% female. The population's age was distributed as follows: 8% were younger than 2 years of age; 14.2% were between 2–5 years; 24.9% between 6–10 years; 25.1% between 11–15 years; 13% between 16–20 years; 8.9% between 21–30 years; and 5% were older than 31 years. We received no answer concerning age in 0.9% of the patients.

Results

The lumbosacral level of lesion (L3–S2) was the most commonly found in 65.6% (984 patients) of the sample, followed by the sacral level (S3–S5) with 18.1% (271 patients) (Fig 1).

Hydrocephalus appeared in 930 patients (62% of the sample) and of those patients, 779 (83.8%) were operated on, having a shunt. In this group, the following complica-

**Figure 1** Neurological level in patients with myelomeningocele.

tions were found: infection of the shunt in 118 cases (15.2%), obstruction of the system in 242 patients (31.1%), and in 98 cases (12.6%) the derivative system became disconnected.

The main spinal orthopaedic abnormality

was scoliosis in 343 patients (22.9% of the sample), with only 4.5% patients suffering from kyphosis. Hip dislocation occurred in 32% of the sample (480 patients). Pressure sores were also a common problem, occurring in 475 patients (31.7%).

Walking ability was not achieved by 31.1% of the sample at the time of the study. Three hundred and four patients (20.3%) started walking before their second year of life, and 453 (30.2%) between the second and fourth year. Two point one percent of the sample were able to walk between their ninth and twelfth year (Fig 2).

Regarding assistive devices and aids for ambulation, 533 patients (35.5%) were able to walk without such devices; 255 patients walked using crutches and orthosis; 102 used crutches only, and 230 orthosis only. Wheelchair use was required in 330, (22%) of the patients who were studied, for some or all of personal mobility (Fig 3).

Discussion

Gender predominance had not been stated clearly in the literature. Laurence² found in a series of 407 patients a predominance of female (57%). Another series^{3,4} shows a predominance of male patients, like ours (52.9%).

Given our data, and comparing them with described predictors of ambulation, the following aspects require consideration:–

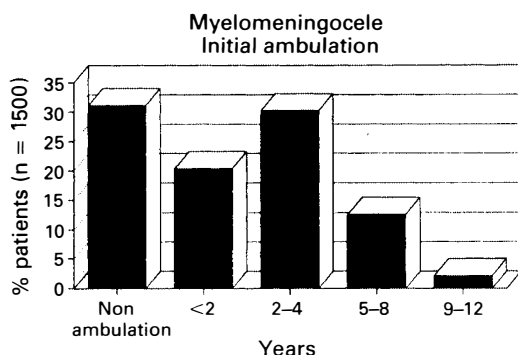
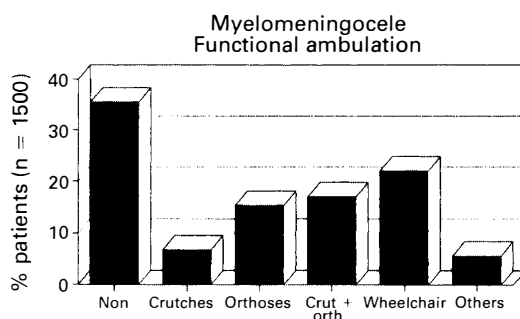


Figure 2 Age at which some kind of ambulation was achieved. In the first group figure those patients who were not able to walk when the sampling was made.



No answer: 5.2%

Figure 3 Functional types of ambulation according to the different kinds of support received. Included are those patients who transfer themselves on a wheelchair and those who cannot walk.

Level of lesion: according to other published work the level of the lesion is the main predictor of ambulation,³⁻⁹ there being a high degree of correlation between lesion level and ambulatory ability. Lumbosacral lesions are the commonest in most series^{3,4,9,10} and accounted for 65.6% of patients in our study. These patients have at least some ambulatory potential either using unparalysed muscles alone or with the help of assistive devices.

Hydrocephalus: this factor will affect the chances of survival and the future level of intelligence. Obstruction or infection of the shunt can suddenly impair the patient's quality of life. Comparing with previous series¹¹⁻¹³ a low percentage has been obtained (62% vs 70%–90%). Probably, patients severely affected by hydrocephalus have died during their first years of life, and have not been included in the sample, justifying this difference in percentage.

Patients with shunts (83.8%), or their parents have to be informed of the dangers of shunt dysfunction. This warning may prevent long periods in bed, avoiding musculoskeletal deformities and walking problems. Adequate management of hydrocephalus will also improve intelligence.

Orthopaedic problems: the most frequent spinal deformity, as previously reported, has been scoliosis.^{14,15} Shurtelf¹⁶ found kyphosis more frequent in young children

because it is a congenital deformity, and scoliosis in older ones (acquired deformity). The relatively high percentage of kyphosis in our study can be related to the large number of young children.

In agreement with other authors,^{14,16} the most frequent lower limb deformity, excluding the feet, has been hip dislocation.

The development of one of these orthopaedic problems, in those with lower lumbar and sacral lesions can threaten the ambulatory ability in some patients.³

Pressure sores: these can give rise to a delay or loss of walking ability. Previous works relating inability and pressure sores have not been found.

A high percentage of patients (35.5%) able to walk without help (community ambulators) has been obtained; 22% required to use a wheelchair. The remainder (39.5%) use crutches, orthoses or both. This last group would include community ambulators and household ambulators, according to Hoffer's classification.⁶

According to Cuxart⁵ the onset of ambulation takes place frequently between 24–36 months of age. However, patients in our

sample achieved this walking ability some time later. Two point one percent of patients started to walk at 9 years of age. For this reason, these patients have to be well taken care of in order to achieve any degree of ambulation. We should not forget that there are also ambulating patients who lose their ability to walk.

Conclusion

Neurological level is the most important predictive factor concerning ambulatory capacity. The common site of myelomeningoceles, in the lumbosacral region, is not a factor in impairing ambulatory prognosis. This puts much emphasis on preventing complications such as hydrocephalus, musculoskeletal problems, and pressure sores, to maintain ambulation and permit a good quality of life.

Patients who have myelomeningocele often have a delay in achieving ambulation, but through rehabilitation of their spared muscles we have to ensure that they obtain the most useful kind of ambulation possible.

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