

The lack of comprehensive care causing complications in patients with myelodysplasia

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In recent years those working in German SCI centres have realised that a growing number of young adults with myelodysplasia are seeking special treatment because of the lack of comprehensive and lifelong care. Statistical investigations, collected over a period of nine years, demonstrate that only severe complications in soft tissues, urology and equipment have led to an admission. The capacity of the centres is limited, and more facilities are necessary. There is a political demand.

Keywords: myelodysplasia; comprehensive care; complications.

Introduction

The initial treatment for children with myelodysplasia is done by paediatric surgeons and after this by medical paediatricians. After childhood, comprehensive and lifelong care according to that necessary for patients with SCI is not arranged, though these patients have quite similar kinds of paralysis and complications. Therefore the German SCI centres need to realise that a growing number of young adults are asking for special treatment. The centres are not prepared to take care of this, as they are mainly organised and responsible for the treatment of spinal cord injuries of traumatic origin (70%) or caused by disease (30%). Bed capacity is limited. Therefore only those with myelodysplasia and severe complications or deficits in independence and the supply of aids are considered for admission. The purpose of this paper is to highlight these problems and illustrate them by statistical investigations collected in a period of 9 years in the spinal cord unit of the Workmen's Compensation Hospital in Hamburg, Germany.

Statistical results

During the years 1981 to 1990 5538 patients were treated in our hospital because of a spinal cord injury. Only 35 patients with myelodysplasia were admitted with compli-

cations, that is 0.63% of all admissions. Twenty patients were male and 15 female. The average age was about 20 years (Fig 1). The greatest number of patients were in the second and third decades of life (77%).

The level of paralysis was mainly from L1 to L3 (62.9%). Nineteen patients had a complete and 16 an incomplete lesion (Fig 2). According to the level of the lesion we found different degrees of mobility. Twenty-four patients (69%) were wheelchair bound; 11 walked, 8 with aids and 3 without any orthosis.

There were 64 admissions and readmissions in our 35 patients. Sixty percent were admitted once and 25% twice. One patient had to be readmitted 7 times because of various complications. The main reason for admission was soft tissue damage, that is, 27 patients had a pressure sore. In 24 cases we found a combination of sores and severe lack of mobility and aids. Nineteen required urological treatment in addition to surgery for pressure sores. Four patients had urological therapy and a supply of aids and 3 of these also required urological surgery. These results show very clearly the lack of comprehensive medical supervision outside hospital, because of the different reasons for admission present in nearly all of our patients (Fig 3).

Seventy-seven percent of our patients were admitted with a pressure sore, being

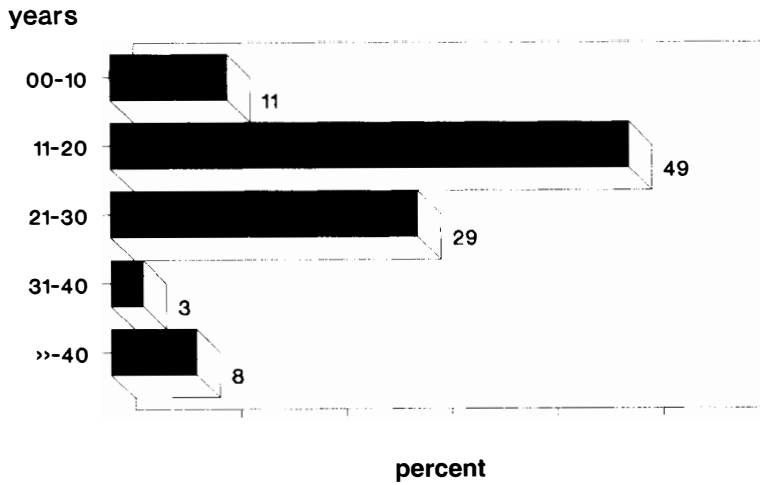


Figure 1 Age (n = 35).

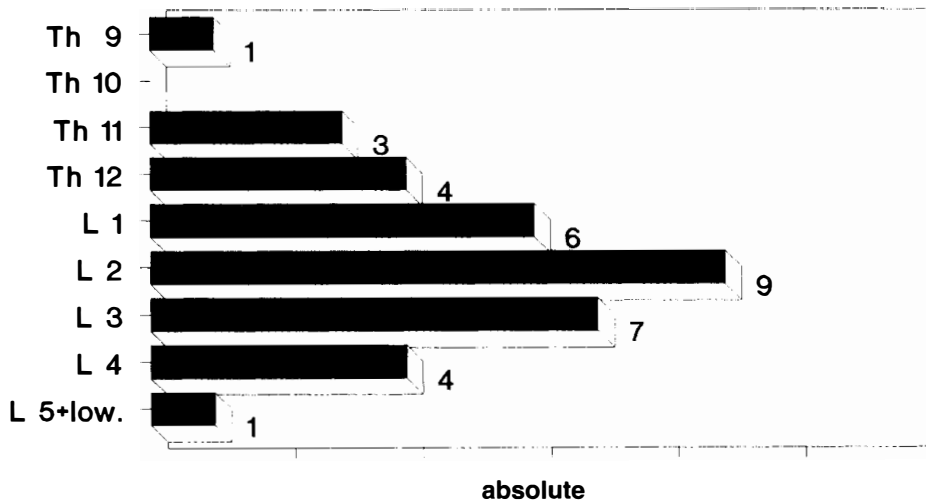


Figure 2 Level of paralysis (n = 35; complete = 19; incomplete = 16).

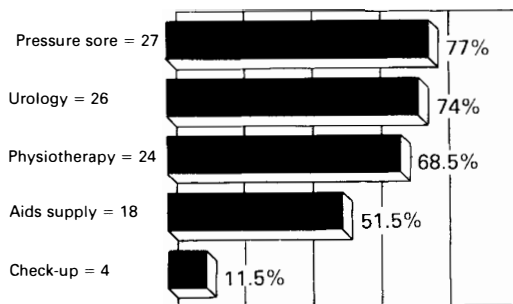


Figure 3 Treatment (n = 35).

multiple in 8. The commonest site was the ischial area (19), followed by the heels (4), the sacrum (2) and trochanteric (2) area. Eleven patients had sores in other regions: back, knee, ankle and scrotum. Surgery was necessary in 25 cases. Six patients developed new sores after discharge and had to be readmitted.

Urodynamic investigations were performed in 26 patients, followed by drug therapy to treat bladder function. Twenty-two patients had a urinary tract infection. In

6 patients 16 transurethral operations were performed (sphincterotomy, bladder-neck incision, TUR prostata, urethrotomy, etc). Four patients required other urological surgery such as vasectomy and meatotomy.

Special aids were needed for 18 patients; 6 got a new, well equipped wheelchair, 8 were supplied with an orthosis, 2 with a brace, 4 with orthopaedic shoes and 2 with crutches. As a result, they became more mobile and had better independence.

Conclusions

Expert medical supervision and treatment for myelodysplastic patients are demanded

by many authors.^{1,2,3} Even in 1976 the term 'comprehensive care' was used by Bull.⁴ Thus the demand is not new but has not been properly realised for the lifelong care of patients with a myelodysplasia. As we found in our investigation there is a severe lack of comprehensive care. Therefore an increasing number of patients with spina bifida are arriving for treatment, and the specialist SCI centres in Germany are faced with the request to treat this growing group of people. It has to be stressed that the centres are not prepared. Therefore an increase in the capacity of beds and treatment facilities should be arranged; there is a political demand.

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