

# Myelomeningocele at the Sacral Level

## LONG-TERM OUTCOMES IN ADULTS\*†‡

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**ABSTRACT:** We reviewed the long-term outcome of thirty-six patients who had a myelomeningocele at the sacral level and whose average age was twenty-nine years (range, nineteen to fifty-one years). The patients were followed at our institution for an average of ten years (range, one to thirty-three years); however, the medical records from birth on were available for all of the patients. Instead of the expected outcome that function had been maintained in this group of patients, we found a decline in the ability to walk of eleven of the thirty-five patients who had been community ambulators initially. At the time of the most recent follow-up examination, five had become household ambulators, two were non-functional ambulators, and four were non-ambulators. The one patient who initially had been a household ambulator was a non-ambulator at the time of the most recent follow-up examination.

A decrease in plantar flexion was found in fourteen patients and a decrease in plantar sensation, in fifteen. Breakdown of the skin and soft-tissue infections on the plantar surface of the metatarsal heads and of the heel were seen in twenty-seven and twenty-three patients, respectively, and were related to the absence of plantar sensation. Fifteen patients had osteomyelitis involving the lower extremity. Eleven patients had had a total of fourteen amputations: five involved one toe or more, four involved one ray or more, two were Syme amputations, and three were below-the-knee amputations.

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By the most recent follow-up examination, thirty-three patients had had a total of 371 orthopaedic procedures. The procedures included tendinous procedures; osteotomies; soft-tissue releases, transfers, and débridements; amputations; and arthrodeses of the lower extremities or spine.

Neurological lesions at the sacral level account for approximately one-fifth of all myelomeningoceles reported in the literature<sup>2,8-10,12,13,16,18-21</sup> (Table I). It is commonly accepted that patients who have such a lesion function at or near normal levels and have few complications, unlike patients who have a lesion of the lumbar or thoracic spine<sup>1,2,8-10,13,16,20</sup>. Health-care professionals at centers that manage a large number of children who have a myelomeningocele tend to focus their attention and energies on the patients who have a high-level lesion because reports have suggested that 95 per cent of patients who have a sacral lesion remain community ambulators<sup>2,8-10,13,16,20,21</sup>. Children who have a lesion at the sacral level are believed to integrate more easily into regular schools, since they often do not use braces or walking aids and the myelomeningocele commonly goes unnoticed by their peers. Long-term studies of this group of patients have been difficult because patients are generally discharged from a center and are lost to follow-up when they reach maturity, and few centers specialize in the care of adults who have a myelomeningocele.

At Rancho Los Amigos Medical Center, all patients who have a myelomeningocele are seen at least once a year from birth throughout their lives. This fact made it possible to investigate the long-term outcomes of patients who had a myelomeningocele at the sacral level.

### Materials and Methods

We reviewed the medical records of all adults who had a myelomeningocele and who had been followed at the Rancho Los Amigos Medical Center, Downey, California, since 1958. Thirty-six of forty-eight patients who had a neurological lesion at the sacral level were available for follow-up. The twelve patients who were lost to follow-up had moved out of the Los Angeles area during childhood or adolescence. Of the thirty-six patients