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ORIGINAL PAPER

Ambulation in adults with myelomeningocele. Is it possible to predict the level of ambulation in early life?

Aase Seitzberg · Marianne Lind · Fin Biering-Sørensen

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Abstract
Objective The objective of this study was to evaluate the prediction of ambulation in adults with myelomeningocele from muscle strength testing and ambulation in early life.
Materials and methods Fifty-two myelomeningocele (MMC) individuals at the age 18–37 years at follow-up were studied. Information on muscle strength and ambulatory function in early life was retrieved from medical records. The motor levels determined by the muscle strength were used to predict ambulatory function later in life. At follow-up, a clinical examination was performed.
Results Of 20 MMC individuals assessed with muscle strength within the first year of life, 7 achieved the predicted ambulatory function, 6 had a better, and 7 a poorer function. Of 32 individuals with known muscle strength at the age of 5–8 years, 10 had function as predicted, 5 a better ambulatory function, and 17 had a poorer ambulation in adult life than predicted. Good strength in quadriceps muscles gave significant better prospect for adult walking. Of the 52 participants, 41 retained their ambulation status from 5–8 years of age.
Conclusion For MMC individuals with motor levels L3–L5, adult ambulatory function cannot be determined from muscle strength in early life, while it to some extend can be predicted for motor levels at or above L2 and at or below S1. The majority of the participants who at the age 5–8 years were community walkers without walking aid kept that function.

Keywords Myelomeningocele · Spina bifida · Muscle strength · Contracture · Quadriceps · Ambulation · Prediction · FIM · Follow-up

A. Seitzberg · M. Lind (✉)
Physiotherapy Department, Clinic for Orthopedics and Rehabilitation Rigshospitalet T4114,
Copenhagen University Hospital,
Blegdamsvej 9,
DK-2100 Copenhagen, Denmark
e-mail: rh08790@rh.dk

F. Biering-Sørensen
Clinic for Spinal Cord Injuries, Rigshospitalet,
Copenhagen University Hospital,
Blegdamsvej 9,
DK-2100 Copenhagen, Denmark

Introduction

Having a newborn child with myelomeningocele (MMC) is of great concern to the parents, and one of the first questions is how will the child function in future life? In our center, it is a routine that a multidisciplinary team of doctors specialized in neonatology, pediatric surgery, neurosurgery, orthopedic surgery, and a physiotherapist evaluate the child born with MMC. It has been customary for many years to use the motor level to predict future ambulation [8, 9, 13, 20, 22].

Ambulation early in life has been suggested by Findley et al. [5] to be a better predictor for adult ambulation than neurological level determined by muscle strength. Schopler and Menelaus [21] and McDonald et al. [14] mentioned that quadriceps muscle strength is an important factor in walking ability. Furthermore, Asher and Olson [1] stated that knee flexors and quadriceps were necessary to be ambulatory.

The aim of this study was to investigate whether knowledge of muscle strength or ambulation early in the child's life could predict future ambulation to give the family and the child a realistic goal.

Materials and methods

Material

Inclusion criteria:

1. Individuals born with MMC in the period 1965–1984 and followed at Copenhagen Orthopedic Hospital/

Rigshospitalet, which has centralized care for persons with MMC in East Denmark, corresponding to a population of 2.5 million inhabitants.
2. At the time of the follow-up, the patient should be living in East-Denmark.

Exclusion criteria:

1. Individuals with diagnoses of lipoma, meningocele, sacral agenesia, traumatic spinal cord lesion, and encephalocele.
2. Information regarding muscle strength tests performed within the first year of life or between 5 to 8 years of age or information about ambulatory function in the age 5 to 8 years not available.

Archives from Copenhagen Orthopedic Hospital, the Pediatric Clinic, the Pediatric Surgical Clinic, the Pediatric and Adult Orthopedic Clinics, the Neurosurgical Clinic, and the Clinic for Spinal Cord Injuries were searched, together with the electronic patient administrative system for possible MMC patients.

In all individuals, 125 with potential MMC were identified. Of these, 53 were excluded according to the criteria above.

Therefore, 72 were left as potential candidates for the study. Of these, 12 did not want to participate and 8 did not respond. Thus, the participation rate is 72%.

Medical records

It has been a routine that children with MMC underwent muscle strength testing of the lower limbs at first visit and onward in the orthopedic clinic. Some of the children were seen within days of birth, others later in life. Experienced physiotherapists assessed the muscle strength by manual muscle testing according to a 0 to 5 graded scale [4]. Only five physiotherapists have been involved in all the muscle strength testing carried out in the MMC individuals in this study. The information about muscle strength was retrieved from the medical records together with information about ambulation function at the age around 7 years.

Information about hydrocephalus and shunting of this and operations that could influence muscle testing were recorded.

To predict the ambulatory function later in life, the motor levels were used. We refer to the motor level as the muscle corresponding to the lowest level of the spinal cord with strength not less than grade 3 within the available range of joint motion. If there was a difference in muscle strength between the two legs, the best one was used. This corresponds to the definition used previously [1, 20]. In newborn children in particular, it can be difficult to determine whether movements in the lower limbs are voluntary or reflex activity [23]. Reflex activity does not count.

A classification based on Sharrard's [22, 23] work for prediction of motor level was used (Table 1). We developed a description of expected ambulatory status corresponding to the muscle strength, comparable to the one described by Bartonek and Saraste [2].

Follow-up

Two experienced physiotherapists (first two authors) carried out an interview using a questionnaire including information on ambulation, the use of braces, walking aids, and wheelchair. In addition, functional status was assessed using the Functional Independence Measure (FIM™) [11]. In this study, we used the FIM™ cognitive score only. A physical examination with muscle strength testing of the lower extremities, assessment of hip, knee, and ankle contractures and foot alignment, and evaluation of walking status was performed. The two physiotherapists together with two medical doctors carried out this examination.

All participants signed informed content forms before participation in the study [Ethical Committee of Copenhagen (KF) 01–045/00].

Table 1 Evaluation of motor level according to muscle strength based on Sharrard [21, 22] and the corresponding expected ambulation status

Motor level	Muscle function	Description of expected ambulation status
At or above L2	No muscle activity in the lower limbs or hip flexors poor. No knee extension	Wheelchair use for mobility ambulation during therapy
L3	Good to normal hip flexion. Knee extension moderate	Household ambulation with long leg callipers. Mainly wheelchair user
L4	Hip flexors normal. Knee extension good to normal. Dorsi-flexion of foot good to normal	Community ambulation with need of ankle foot orthoses and need of walking aid
L5	Hip flexors and knee extension normal. Normal dorsi-flexors and good to normal evertors and invertors of the foot. Plantar-flexion <3	Community ambulation with ankle foot orthoses
S1	Good to normal plantar-flexion ≥3	Community ambulation, no orthoses

Statistics

Fishers' exact and Mann–Whitney tests have been used to test the non-parametric data, and 0.05 was chosen as level of significance.

VassarStats were used for direct data entry (http://faculty.vassar.edu/lowry/VassarStats.html).

Results

Participants and non-participants

The participants (n=52) consisted of 29 men and 23 women. The age at follow-up was 18–37 years. The non-participants (n=20) were 9 men and 11 women, 21–36 years, i.e., no significant differences in these respects between the two groups.

Prediction of adult ambulation from muscle strength within the first year of life

Twenty had a muscle strength test performed within the first year of life (range, 3 days to 7 months and 21 days; median, 18 days). Each child's ambulation was predicted according to lower extremity muscle function (Table 1). Only two participants could be classified to a higher motor level using the worst leg, and in both cases, the best leg was the best predictor. Of the 20 MMC individuals, 7 achieved the ambulatory function as predicted, while 6 had better and 7 poorer function than predicted, including 4 who were predicted to be walking, but ended up in a wheelchair (Table 2). Of those four, one lost muscle strength within the first year of life, one had severe balance problems and was only walking in training situations at the age of 5–8 years, and the last two never started walking after a period of immobilization of more than 6 months after the age of 12 years.

One had a motor level at or above L2 and became, as expected, a wheelchair user. Five participants had sacral motor levels. Four kept function as predicted, and the one who did not function as predicted lost muscle strength already within the first year of life. Those with motor levels of L3–L5 showed less uniformity.

In our material, the motor level L3–L5 according to muscle strength within the first year of life could not be used to predict adult ambulation (Table 2).

Table 2 Prediction of adult ambulation from motor level according to muscle strength within the first year of life (cf. Table 1) in 20 individuals with myelomeningocele

Motor level	Number	As expected	Better than expected	Worse than expected
At or above L2	1	1		
L3	2		1	1
L4	5		3	2
L5	7	2	2[a]	3
At or below S1	5	4		1

P=0.007 (two-tailed; Fisher's exact probability test 2×3: L3–L5 together, and As expected tested against Better or Worse than expected)

[a] Did not use foot ankle orthoses

Table 3 Prediction of adult ambulation from motor level according to muscle strength at the age of 5 to 8 years (cf. Table 1) in 32 individuals with myelomeningocele

Motor level	Number	As expected	Better than expected	Worse than expected
At or above L2	1	1		
L3	7	2	1	4
L4	8		1	7
L5	8	2	3[a]	3
At or below S1	8	5		3[b]

P=0.01 (two-tailed; Fisher's exact probability test 2×3: L3–L5 together, and As expected tested against Better or Worse than expected)

[a] Did not use foot ankle orthoses

[b] Did use foot ankle orthoses

Prediction of adult ambulation from muscle strength at the age of 5 to 8 years

McDonald et al. [13] stated that the accuracy of standard manual muscle examinations peaks at the age of 5 years and remains stable thereafter. Therefore, we looked at those 32 MMC participants, where we had a muscle strength test at the age 5 to 8 years (median 6 years and 3 months). Ambulation status in adult life was predicted according to lower extremity muscle function (Table 1). Ten had a function as predicted and five a better ambulation function, including three who had chosen not to use ankle foot orthoses even one could expect that, while 17 had a poorer ambulation in adult life than predicted, including three who were using ankle foot orthoses even one could expect they did not need to. Among the 17 with poorer ambulatory function, 12 became full-time wheelchair users. Of those, five had had periods of immobilization of at least 6 month (Table 3).

One individual had a level at or above L2. At follow-up, he was a full-time wheelchair user as predicted. Participants with a sacral motor level all became community walkers, although three used ankle foot orthoses. There is no clear indication for prediction for those with levels at L3 to L5.

Table 4 Quadriceps strength and strength of knee flexion at the age of 5–8 years compared with ambulation function (cf. Table 1) at follow-up (n=32)

	Actual ambulation status at adult life				
	Wheelchair use for mobility Ambulation during therapy	Household amb. Mainly wheelchair user	Community amb. Need ankle foot orthoses and walking aid	Community ambulation with ankle foot orthoses	Community ambulation, no orthoses
Quadriceps strength at the age 5–8 years[a]					
Quadriceps strength less than normal at both sides	9	1			
Quadriceps strength normal at both sides or normal on one side and close to normal (4+) on the other side	4	2	1	7	8
Strength of knee flexion 5–8 years[b]					
Strength of knee flexion less than grade 3 on both sides or 3 on one side and less than 3 on the other	9	2		1	
Strength of knee flexion grade 3 or more at both sides	4	1	1	6	8

[a] Mann–Whitney test: P=0.0006 (two-tailed)
[b] Mann–Whitney test: P=0.0015 (two-tailed)

Quadriceps strength/knee flexion strength and ambulation in adult life

Table 4 shows the quadriceps strength at the age of 5–8 years for 32 MMC individuals compared with the ambulatory function at follow-up. There was significant better chance for ambulation in adult life with better quadriceps strength in childhood (Mann–Whitney test: p=0.0006, two-tailed). Of the 22 persons with normal or close to normal (i.e., muscle strength 4) quadriceps strength, four persons were full time wheelchair users at follow-up, all had had an immobilization period longer than 6 months after the age of 12 years.

Asher and Olson [1] believe that grade 3 knee flexion is important for stabilization of the pelvis. Therefore, we looked at the participants with knee flexion strength at or above grade 3 vs below grade 3 (Table 4). We found overall a significant better chance for ambulation with knee flexors grade 3 or more (Mann–Whitney test: p=0.0015, two-tailed). But when looking at the knee flexion strength in the 22 participants with quadriceps strength normal at both sides or normal on one side and close to normal on the other side, we could not find that knee flexors had a predictive value for the ambulation later in life (Fisher exact probability test: p=0.16, two-tailed).

Ambulation at the age 5 to 8 years and ambulation in adult life

All 52 participants had a walking function at the age of 5 to 8 years, although some were walking during therapy only.

Altogether, 41 retained their ambulation status at the follow-up. Table 5 illustrate that those who used walking aid were those who primarily lost their ambulatory function. They all became mainly wheelchair users. Of the two who lost the ability of community walking, one became wheelchair user and the other became household walker.

Contractures

In Table 6 the individuals are distributed according to ambulation status at 5–8 years of age and at adult life, including information about the presence of hip, knee, and ankle contractures and foot alignment at the time of follow-

Table 5 Actual adult ambulation status compared with the ambulation status at the age of 5 to 8 years in 52 individuals with myelomeningocele

	Number	Kept function from 5 to 8 years to adult life	Lost function from 5 to 8 years to adult life
Mainly or constant wheelchair user	14	14	0
Community ambulation with walking aid	11	2	9
Community ambulation without walking aid	27	25	2

Fisher exact probability test p<0.0001 (two-tailed)

Table 6 Presence of hip flexion, knee flexion, and/or ankle contractures at time of the follow-up in relation to ambulation status at 5–8 years of age and at follow-up in adult life

	Kept function from 5 to 8 years to adult life	Lost function from 5 to 8 years to adult life
Contractures	7	4
No contractures	30	8

Contractures unknown for 3 of the 52 participants
Fisher exact probability test (p=0.43, two-tailed)

up. As with Bartonek and Saraste [2], we define ankle contracture as 15° or more fixed equinus position and hip and knee-flexion contractures as 20° or more.

At follow up, we found contractures in 11 participants (unknown for 3 of 52). Eight of the participants without contractures and four of the participants with contractures or problems with foot alignment lost, to some degree, walking function. There is no significant relation (Fisher exact probability test (p=0.43, two-tailed) between presence of contractures in the group who kept ambulation function and those who lost function.

Relation between shunted hydrocephalus and prediction of ambulation in adult life

Nine never developed hydrocephalus, 13 were unshunted, and 30 had shunted hydrocephalus. We found no correlation between shunted hydrocephalus and loss of function from age 5–8 years to follow-up (p=1).

Relation between FIM™ cognitive score and prediction of ambulation in adult life

FIM™ cognitive score in relation to the predicted ambulation status in adult life from muscle function in the first year of life and at the age of 5 to 8 years or from ambulation at the age of 5–8 years showed no statistically significant difference between the three groups of expected walking, i.e., better, worse or as expected.

Discussion

Murdoch and Young [15] found a poor correlation between the power of the muscles in the legs of newborn children with spina bifida and their subsequent mobility. We found the same for MMC individuals with motor levels L3 to L5, while we find better prediction for those with motor levels at or above L2 and at or below S1, although the limited number of individuals in the latter groups in our material must be taken into account.

McDonald et al. [13] stated that the accuracy of standard manual muscle examination peaks at the age of 5 to 6 years and afterwards remain stable. Again, we found no obvious prediction for those with motor levels from L3 to L5. All with motor level S1 and below were community walkers, three with foot ankle orthoses.

According to our classification (Table 1), persons with a sacral motor level using ankle foot orthoses will be classified as worse than expected. The use of ankle foot orthoses does not necessarily influence daily living that much, so for that reason, we may suggest that the need of ankle foot orthoses or not in the group of community walkers could not be distinguished. We believe functional test like 6 min walking test [6] will give a more realistic picture of the walking ability.

If we, in our material, took the consequence of this adjustment of the expected or not expected in Table 3, then all with sacral motor levels would be predicted as expected.

One reason for poor prediction of ambulatory function could be loss of muscle strength after the muscle test was performed due to tethered cord. According to Brezner and Kay [3], almost all children with MMC have tethered cord, but the clinical manifestations are only present in 3–32% [13, 17, 18, 24].

Another reason for difficult prediction could be that the level sometimes are assessed to be better in cases where there is no function of the medial hamstrings because the function of the gracilis muscle, which is innervated from a higher neurological level is misinterpreted as hamstings function [15].

Surgical procedures, e.g., tendon transfers or releases, may weaken the muscle strength and therefore could influence the determination of the motor level. In our study, there was no clear indication that lower extremity surgery had specific influence on the prediction, although it must be admitted that the operations vary very much in their possible influence on the muscle mechanics and strength. Hoffer et al. [8] state that it "is difficult to determine if any specific operative procedure improve the walking status of any group of patients. Many procedures were done in young patients, and seemed to be associated with improvement in walking, but obviously, in early childhood, natural developmental progress tends to confuse analysis of therapeutic gains." We only looked at surgical procedures that could influence muscle strength and the determined motor level. It could be a weakness that procedures done for correction of the structural bony deformities such as osteotomy and operations for foot deformities were not included. We did not measure the degree of rotation of the lower limbs, but it has always been the policy in our department to correct bony deformities and try to keep the foot plantigrade if necessary with corrective osteotomies in early stage.

Previously, the importance of quadriceps muscle strength for ambulation has been stressed [14, 21]. We did find a significant better chance for ambulation in adult life with better quadriceps strength in childhood. Still, 6 out of 22 persons with a normal or close to normal quadriceps strength were full time wheelchair users at follow-up.

Findley et al. [5] suggest that ambulation early in life is a better predictor for adult ambulation than the neurological level. All our participants had at the age of 5 to 8 years some sort of a walking function. It has been our aim to reach the highest possible level of ambulation and also to give every child the opportunity to experience a standing and walking function even if the motor level could indicate that walking function would be ceased later on. Mazur et al. [12] found that children with high-level spina bifida (at or above L2) who had participated in a walking program at early childhood had fewer fractures and pressure sores and were more independent than were children with same level who had used wheelchair from early in life. Other authors [8, 20] found patients with the thoracic level and the level L1/L2 to be non-ambulatory. For those with sacral levels, most were community walkers. Patients with lesions at other levels showed less uniformity in the ambulation they achieved. We found a similar pattern.

We found that the majority of the children who at the age of 5 to 8 years were walking freely kept that walking function as adult. Participants who were only walking in training situations at 5 to 8 years of age all became full-time wheelchair users as expected.

The majority of those performing community ambulation with need of walking aid ended up as mainly wheelchair users. In a previous study [7], it was found that bracing was discouraged by most adult individuals with spinal cord lesions due to troublesome donning and doffing, impracticality because hands are not free, fear of falling, and it can course too heavy load on arms. An additional reason for giving up walking for individuals in need of some kind of walking aid could be that the motivation for maintaining a walking function has diminished concurrently with better opportunities for getting around outdoors and in public buildings with wheelchairs and the development of more easygoing wheelchairs.

Comparison of studies can be difficult, as Samuelsson and Skoog [20] point out, because of different definitions of level of lesion and varying classifications of ambulation. Still, there seems to be a good agreement.

Contractures have been found as a factor influencing ambulation [8, 20]. In our investigation, those who ambulated worse than expected did not have significant more hip, knee, and ankle contractures than the rest (Table 5). Unfortunately, we only have the joint status at follow up; therefore, we cannot conclude if the contractures were the significant factor affecting the ability to maintain the ambulation or not. Maybe the contractures in certain instances occurred due to immobilization.

Furthermore, mental illness and depression, spasticity, obesity, balance problems, scoliosis, and impaired hand function could be reasons for cease walking [2, 8, 10, 16, 20].

Another issue of importance could be the possible presence and shunting of hydrocephalus. Murdoch and Young [15] claim that hydrocephalus and its complications influence the child's intelligence and his chance of realizing his full potential to become mobile. We found no correlation between shunted hydrocephalus and loss of function from age 5–8 years to follow-up.

Several authors [2, 5, 8, 16, 19] have found a correlation between IQ and lack of initiative and ambulation level, whereas Asher and Olson [1] found no relation between IQ or psychological independence and ambulatory status. Our FIM results could not support the majority of the literature on this issue.

Conclusion

The walking function the child with myelomeningocele had achieved around the age of 5 to 8 years could, for the majority, be used as a predictor.

Muscle test performed in the early life can to some extend be used for those with motor levels at or above L2 and sacral levels to predict future use of wheelchair respective ambulation. Children with levels between L3 and L5 showed less uniformity. The strength of the quadriceps muscle could similarly predict walking ability in adult life.

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