

ORIGINAL ARTICLE

Walking in adults with spina bifida with respect to muscle function

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ABSTRACT

The aim of this study was to gather information about walking function in adults with myelomeningocele and, in particular, to investigate walking function with respect to muscle function in adults with spina bifida. Based on muscle strength examination, 45 participants (median age 35 years) were classified according to severity of muscle function (MF groups 0–III). Functional walking ability, outdoor walking distance, and use of orthoses and walking aids were documented. Joint range of motion and lower limb muscle strength were examined. Timed Up and Go (TUG), 10-Meter Walk Test (10MWT) and 6-Minute Walk Test (6MWT) were performed. After the 6MWT, the participants estimated pain and perceived breathlessness. Compared to the other groups, MF III took a significantly longer time during TUG and 10MWT, and walked a significantly shorter distance in the 6MWT. Participants in MF III reported shorter walking distances outdoors and less active functional walking ability than those with more muscle function. Pain was equally distributed among the groups, whereas breathlessness was most reported in MF III. In conclusion, patients with severe muscle function loss walk more slowly, walk shorter distances and report breathlessness, indicating great impact on their everyday walking function, with very few walking farther than 100 m daily.

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Introduction

Neural tube defects are the second most common serious congenital defect and the most common of the central nervous system defects, ranging between spina bifida occulta and spina bifida aperta [myelomeningocele (MMC)], [1] the latter being the most severe form of neural tube defect. [2] The annual incidence of children born with neural tube defects has decreased in Sweden from approximately 80 children in 1973 to 20 children in 2005, which is mainly explained by improved diagnostic ultrasound during pregnancy with early detection of fetal malformation and early termination of pregnancy. [3] In most individuals there is a bladder and bowel dysfunction. [4] About 80% of the children have hydrocephalus due to poor drainage of the cerebral hemispheres, usually Arnold Chiari malformation and/or aqueductal stenosis. [4] In individuals with hydrocephalus, cognitive dysfunction is often present in areas of memory, attention and executive functioning. By contrast, in people with spina bifida without hydrocephalus, cognitive function is relatively spared. [5]

The malformation of the spinal cord, which is most frequently observed in the lumbosacral spine, [6] is mostly associated with some degree of muscle weakness and lack of sensation in the lower limbs. The degree of sensorimotor impairment depends on the level of spinal involvement. Most common is flaccid paralysis and loss of sensibility caudal to the cele, although paresis with elements of reflex activity caudal to the cele occur, as well as asymmetric levels with different sensorimotor function of the right and left side. [7] Impaired sensory function constitutes a risk of secondary

injury or pressure ulcers [7] and is considered to involve disturbed body image. [4] Secondary neurological and orthopedic deformities in the lower limbs are also common. [8]

In MMC, the extent of motor function in the legs is vital to standing and walking ability, and is directly affected by the level of the cele. [7] For children with motor disabilities, early stimulation to promote walking is a natural part of the physiotherapy interventions. Most children with MMC use orthoses, often in combination with other walking aids, for shorter or longer periods, with the intention of improving their activity levels. [9] Improperly loaded joints are known to lead to degenerative changes, contractures and deformities. [10] The medical benefits of walking are reported to be fewer fractures and pressure sores in children who have had early walking ability compared to those who always used a wheelchair. [11] It is common to combine walking with the use of a wheelchair, also for individuals with walking function. [12] In a Swedish population, parents of patients with no walking function reported that their children had a similar health-related quality of life to those with functional walking. [12]

The ability to walk often changes during adolescence. [13] People with MMC with sacral and low lumbar lesion levels maintain their walking ability into adulthood, whereas those with high lumbar and thoracic injury levels often cease to walk. [9,14–17] Children with MMC are given extensive orthopedic and physiotherapeutic treatment in Sweden during childhood, with the goal of promoting the development of walking ability. From the year when adolescents turn 18, all those with MMC living in the greater Stockholm area are

offered a yearly medical follow-up in an outpatient clinic in Stockholm.

Since the 1990s, there has been no documentation of ambulatory status in adults with MMC in Sweden, and physiotherapeutic guidelines for goal setting and intervention are lacking. The purpose of this study was, therefore, to gather information about walking function in adults with MMC today and, in particular, to investigate walking function with respect to muscle function.

Methods

Participants

All adults in the greater Stockholm area with spina bifida registered at the Spinalis clinic in Karolinska University Hospital (today Rehab Station Stockholm) who had been to a yearly medical follow-up and had a documented walking ability were offered participation in the study. 69 people were contacted, of whom 45 (23 women and 22 men) accepted participation in the study. Of the 24 people who did not participate, nine declined, nine did not respond despite several invitations, two could not participate because of mental retardation, two wore prostheses and two could not walk. The 45 participants were born between 1947 and 1989, with a median age of 35 years (range 18–65 years), of whom 42 had MMC and three had spina bifida occulta. 20 participants had shunted hydrocephalus. The study was approved by the Regional Human Ethics committee in Stockholm. Written consent was obtained from all participants.

All participants underwent a clinical examination by the same physiotherapist.

Patient characteristics are shown in Table 1.

Based on a muscle strength examination on a 0–5 graded scale,[18] the participants were classified according to muscle function (MF) group:[13] MF 0, with no loss of muscle strength; MF I, with weakness in foot intrinsic muscles and plantarflexors grade 4–5; MF II, with foot plantarflexion grade

≤3, knee flexion grade ≥3, hip extension and/or hip abduction grade ≤2–3; and MF III, with hip flexion and knee extension grade 4–5, knee flexion grade ≤3, and only traces of hip extension, hip abduction and below-knee muscles. Joint contractures of more than 20 degrees in the hip, knee or ankle joints were registered.[19,20]

A self-reported assessment of walking ability classified participants as community ambulators (Ca), walking both indoors and outdoors, of whom some never used a wheelchair and some used a wheelchair for longer transfers; household ambulators (Ha), walking indoors, using a wheelchair both indoors and outdoors; and non-functional ambulators (Nf), walking only for a limited time at home and always using a wheelchair for transfer. The self-reported regular walking distance was classified in groups of more than 1000 m, 100–1000 m, 10–100 m and 10 m or less. Self-reported use of various orthoses, walking aids and wheelchairs was also registered (see also Table 1).

Walk tests

Timed Up and Go

Walking, functional movement and balance were tested with the Timed Up and Go (TUG).[21] The time taken to complete the test is strongly correlated with the level of functional mobility.[22] The TUG is a test of balance that is commonly used to examine functional mobility in community-dwelling, frail older adults (aged 70–84 years),[22] including people with arthritis, stroke and vertigo.[23] Participants were instructed to stand up from sitting on a chair, walk 3 m, cross a line on the floor, turn around, walk back and sit down on the chair, while the time taken to perform the task was recorded.

10-Meter Walk Test

The participants' self-selected walking speed during the 10-Meter Walk Test (10MWT) [24] was recorded. The 10MWT

Table 1. Distribution of age, functional ambulation, joint contractures, regular walking distance, use of orthoses, walking aids and wheelchair with respect to muscle function (MF) group.

	MF 0 (n = 10)	MF I (n = 8)	MF II (n = 10)	MF III (n = 17)
Age (years), median (min.–max.)	32 (20–55)	40 (25–65)	35 (19–60)	35 (17–54)
Functional ambulation	Ca: 10	Ca: 8	Ca: 10	Ca: 4 Ha: 8 Nf: 5
Joint contractures				
Hip/knee			4	9
Knee				
Ankle	1	6	5	11
Walking distance (m)				
<10	–	–	–	5
<100	–	–	1	10
<1000	2	–	6	1
>1000	8	8	3	1
Orthoses	Insole: 2	Insole: 5	Insole: 1 AFO: 4	2: Insole 5: AFO 2: KAFO
Walking aids	–	–	1	12
Wheelchair	–	–	6	19
Manual	–	–	5	15
Powered	–	–	1	4

Ca: community ambulators; Ha: household ambulators; Nf, non-functional ambulators; AFO: ankle-foot orthoses; KAFO: free-articulated knee-ankle-foot orthoses.

assesses the short-duration walking speed. The test has been used in gait studies of patients with general neurological movement disorders,[25] as well as for patients with stroke [26] and Parkinson's disease.[27]

Six-Minute Walk Test

The Six-Minute Walk Test (6MWT) measures the distance in meters walked within 6 min. It is a valid and reliable method used to assess the functional training capacity.[24,28] In older adults, the 6MWT has been described as a measure of functional status,[29] and for healthy elderly people it represents a submaximal exercise test.[30] The participants were instructed to walk on a 30 m track back and forth during 6 min, with possibility of a break by briefly standing still if required. Immediately after completion of the 6MWT, the participants were requested to estimate pain and breathlessness using a visual analogue scale, where zero indicates no pain or shortness of breath and 10 indicates maximum pain or shortness of breath.[31]

Procedures

Study subjects visited the Spinalis clinic on one occasion that lasted between 60 and 90 min. Initially, the participants were asked about their functional walking ability, walking distance, and use of orthoses, walking aids and wheelchairs. Thereafter, the walk tests were performed, starting with the TUG test, followed by the 10MWT. Three trials of TUG and 10MWT were performed and averaged. Finally, the 6MWT was performed, during which small breaks are allowed. After completing the 6MWT, the participants were asked about pain and perceived breathlessness.

Before initiation of the walk tests, the participants were informed that short breaks were allowed between the three tests and during the 6MWT.

The clinical examination was performed after completion of the walk tests.

Statistical analyses

The chi-squared test was used to analyze age, joint contractures, use of orthoses, walking aids and wheelchairs among the MF groups. The Kruskal–Wallis test and *post hoc* Mann–Whitney *U* test were used to compare the results of walking tests between the MF groups. The statistical analyses were performed using commercially available software (SPSS version 21; IBM Corp., Armonk, NY, USA). Statistical significance was determined at $p \leq 0.05$.

Results

Distribution of age, functional ambulation, joint contractures, regular walking distance, and use of orthoses, walking aids and wheelchair with respect to MF group are presented in Table 1.

The presence of joint contractures in the knee and hip in the MF groups varied significantly, with the highest number

in MF III ($p = 0.005$), whereas there was no difference in ankle contractures.

21 participants reported a regular walking distance of more than 1000 m, nine of 1000 m, 10 of 100 m, and five participants reported that they walked 10 m or less. The distribution of use of orthoses, walking aids and wheelchairs varied significantly between the MF groups, with the highest number of users of all three categories in MF III. In MF II and MF III, both manual and powered wheelchairs were used.

Walk tests

The results of TUG, 10MWT and 6MWT with respect to MF group are presented in Table 2 and illustrated in Figure 1.

All participants completed the TUG. The median duration for the entire group was 10.5 s (range 7.2–40 s). As analyzed with the Mann–Whitney *post hoc* test, MF III took longer to perform the test than all the other groups.

All participants completed the 10MWT. The median duration for the entire group was 9.1 s (range 6.8–32.2 s). As analyzed with the Mann–Whitney *post hoc* test, the participants in MF III took longer to complete the 10MWT than all the other groups.

Two participants, one in MF 0 and one in MF III, did not agree to perform the 6MWT. The median distance for the entire group was 412 m (range 37–570 m). Nine MF III participants interrupted to take a short break during the test. As analyzed with the Mann–Whitney *post hoc* test, the participants in MF 0, MF I and MF II walked a longer distance than MF III, and MF 0 a longer distance than MF I and MF II.

Estimation of pain and breathlessness after the 6-Minute Walk Test

Of the 43 participants who took part in the 6MWT, 20 indicated that they perceived pain immediately after the test, most frequently reported in MF III, but not significantly different between the MF groups ($p = 0.082$). Of those perceiving pain, seven participants localized pain to the lumbar back, four to the hip and three to the knee, and one participant to the foot, and five participants reported load-related pain in the arms and shoulders, all of whom were using walking aids (Table 3).

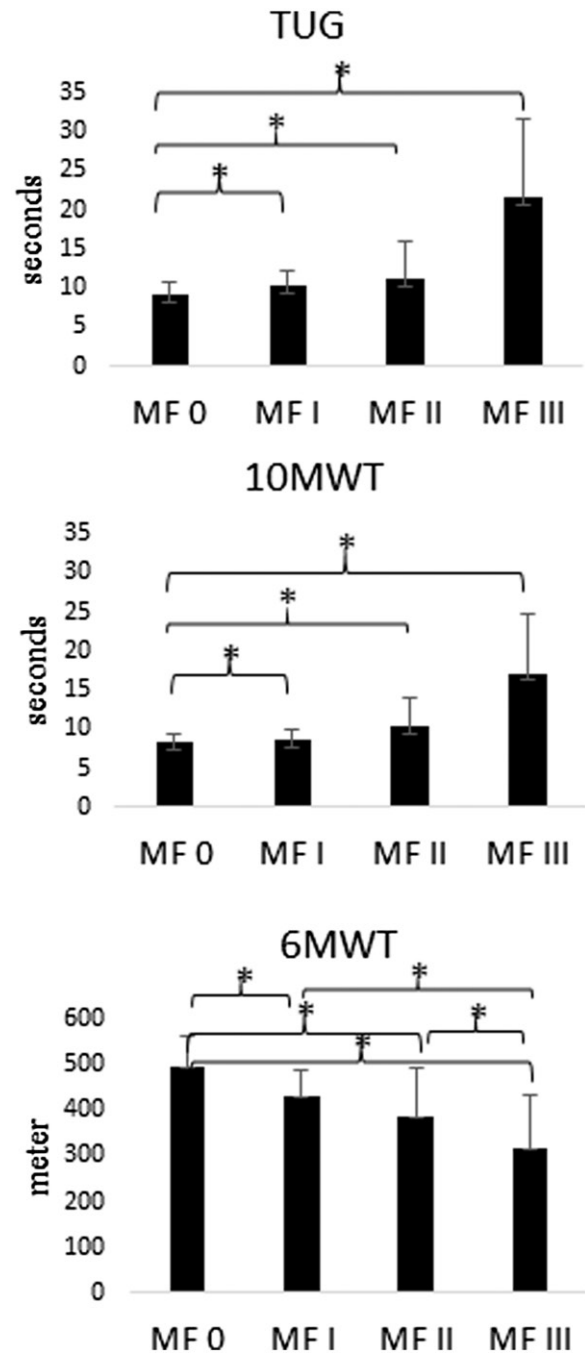
35 participants reported that they felt breathlessness after the test. All participants in MF II and MF III reported breathlessness, whereas four in MF 0 and five in MF I felt breathlessness ($p = 0.001$). Estimated breathlessness immediately after the 6MWT with respect to MF group is shown in Table 3.

Discussion

Three participants had spina bifida occulta with no or only minor loss of muscle strength, whereas the other 42 participants had MMC, the most severe form of neural tube defect. Those with spina bifida occulta were designated MF 0 and MF I, whereas those with MMC were distributed in all four MF groups, indicating that this study represents a patient group

Table 2. Timed Up and Go (TUG), 10-Meter Walk Test (10MWT) and Six-Minute Walk Test (6MWT) with respect to muscle function (MF) group in 45 participants.

	Muscle function group							
	MF 0 (n = 10)	MF I (n = 8)	MF II (n = 10)	MF III (n = 17)	p	MF 0-MF I	MF 0-MF II	MF 0-MF III
TUG (s) Median (min.-max.)	9.3 (7.2-11.2)	10.4 (7.9-12.9)	9.8 (8.1-25.1)	22.6 (9.4-40.0)	<0.001	0.203	0.529	<0.001
10MWT (s) Median (min.-max.)	8.6 (6.8-10.3)	8.5 (7.1-11.0)	9.2 (7.2-20.0)	16.3 (7.3-32.2)	<0.001	0.696	0.063	<0.001
6MWT ^a (m) Median (min.-max.)	505 (355-570)	449.5 (318-490)	412 (152-560)	195 (37.2-460)	<0.001	0.046	0.013	<0.001

^a43 participants in the 6MWT.**Figure 1.** Illustration of the Timed Up and Go (TUG), 10-Meter Walk Test (10MWT) and Six-Minute Walk Test (6MWT) with respect to muscle function (MF) group in 45 participants. *Indicates statistical significance between groups marked with braces.**Table 3.** Estimated pain and breathlessness immediately after the 6-Minute Walk Test (6MWT) with respect to muscle function (MF) group.

	MF 0	MF I	MF II	MF III
Pain	n = 2	n = 2	n = 5	n = 11
Median (min.-max.)	2.95 (0.9-5)	0.4 (0.4-0.4)	4 (2-6)	2.5 (1-4)
Breathlessness	n = 4	n = 5	n = 10	n = 16
Median (min.-max.)	2 (1.1-4)	1.3 (0.3-2)	1.8 (1.3-4.7)	5.6 (2-8)

with severe consequences on motor function due to a neural tube defect.

The main finding of this study is that the degree of muscle function impairment interferes with walking function. The time it took the participants to perform both the TUG and

the 10MWT was increasingly longer with less muscle function, but significantly longer in MF III than in the other groups.

Time to complete TUG is strongly correlated with the level of functional mobility.[22] Podsiadlo and Richardson [22] found that elderly volunteers performed the TUG in 10 s or less, which is in accordance with our findings where all participants in MF 0, I and II completed the TUG in less than 10 s. The participants in MF III required approximately twice as long to complete the TUG. This indicates a dependence in activities of daily living in this patient group and a requirement for assistive devices for ambulation, as reported in older adults.[22]

In a study by van Hedel et al.,[32] people with an incomplete spinal cord injury tested with the 10MWT walked more quickly than our participants in MF III. The people in MF 0 and I had similar walking speeds. However, they had a slower velocity compared to controls in the study by van Hedel et al., indicating deficiency even in these groups.

Walking distance on the 6MWT was shorter the lower the muscle function. Two participants did not agree to participate in this test, one in MF 0 and one in MF III, because of pain. There was a large variation in the walked distance after 6 min, with the shortest distance in MF III, in which nine participants took a short break during the test. The break was most likely due to pain, since perceived pain after the test was most frequently reported in MF III. In our study, more than half of the participants stated that they had pain after the 6MWT. Reported pain was most frequent in the lower back, hips and knees. Study results indicate that knee joint pain is relatively frequent.[10] However, all those who reported pain estimated low pain relative to what one would expect based on the observed walking pattern, with lateral flexion of the trunk to compensate for poor hip stability and valgus position of the knees and ankles during weight bearing. The low pain estimation may also be due to impaired sensory function in the legs. Breathlessness after the test was reported by all participants in MF II and MF III, as well as by four in MF 0 and five in MF I. However, MF 0 walked significantly longer than both MF I and MF II. It is likely that the walk tests were demanding to some of the participants. The investigator therefore continuously reminded the patients that they were allowed to take short breaks between the trials and between the tests, as well as during the 6MWT.

Joint contractures affect the ability to walk.[13,15,17] In this study, there were no contractures in the hips and knees in MF 0 and MF I, whereas we found joint contractures in the hips and knees of more than 20 degrees in both MF II and MF III. In most participants in MF II and MF III, a knee valgus position was observed visually during the walking tests. According to Williams et al., the overload caused by a walking pattern of weakness in hip abductors, hip extensors and calf muscles leads to anterior-medial rotational instability and possibly degenerative changes in both ligaments and joint surfaces.[10]

In our study, the participants in MF 0 were the only ones walking the same distance as a healthy control group in the 6MWT.[33] People in MF I and II walked a shorter distance, indicating that weakness in the lower limb muscles influence the walking function. Kirkegaard and Tollback [34] pointed

out that the distance walked by people with myotonic dystrophy was associated with their rating of muscular impairment. The subjects who had highest muscular impairment walked an average of 374 m and the subjects with the lowest muscular impairment walked an average of 692 m. In our study, we saw corresponding results where people with no loss of muscle strength, MF 0, walked the longest average distance (505 m) and those in MF III an average of 195 m. The large difference in walking distance between the study on people with myotonic dystrophy and those in our study indicates a greater impact on the walking function on individuals with spina bifida.

Corresponding results, with respect to the reported walking distance, were also found when the participants rated their everyday functional ambulation. Those with lower muscle function estimated that they walked shorter distances in their daily lives and that they had a less functional walking ability. Findings of previous studies [14,15,35] confirm that people with lower muscle function have a lower grade of functional ambulation. Only one participant in the MF III group reported a walking distance longer than 1000 m. This person did not have any knee and hip contractures, nor did he use any wheelchair or walking aid. He was highly motivated to walk despite abductor weakness with consequently increased lateral sway trunk movements. Solid ankle-foot orthoses in carbon fiber material with a flexible forefoot offered him sufficient support during both standing and walking. Similarly, the participants in MF 0, MF I and MF II all reported their functional walking ability as pedestrians both indoors and outdoors (community ambulators), of whom six people in MF II used a wheelchair for long outdoor distances. In contrast, among the participants in MF III, there were community, household and non-functional ambulators, as well as the highest rate of wheelchair users. This may indicate that the ambulation may also be influenced by the person's cognitive function. This, however, has not been investigated in our study.

Muscle strength in the quadriceps muscle has been emphasized as an important factor in achieving functional walking ability and maintaining the ability to walk into adulthood.[11,16,36] This is in accordance with our study, where all participants had knee extensor muscle strength, which enabled them to resist gravity in weight-bearing.

There was a sparse use of orthoses in the study group, with only a minority of the participants in MF II and MF III using ankle-foot orthoses or free-articulated knee-ankle-foot orthoses. The lack of orthoses led to insufficient stabilization of the ankle joint and a requirement for walking aids (used by a majority of those in MF III) to compensate for high demand on the knee extensors as well as for reduced hip stability in both the sagittal and frontal planes. In addition, those with contractures in the knees or hips had difficulties extending the joints during walking and needed to relieve their body weight. Several participants reported that they had had orthoses until adolescence and then stopped using them when they found them inconvenient and impractical in combination with wheelchair use. We had expected a higher number of orthosis users among MF II and MF III. However, only five of the participants grew up during the active

orthotic program for children with MMC from the early 1990s.[37] Today, several adolescents use orthoses constructed from carbon material aimed at replacing the loss of eccentric calf muscle work.[38] This orthosis type, however, has been studied in children and from a biomechanical perspective, and it remains to be studied in an adult population. To obtain information, not only from the gait pattern, instruments covering outcomes at the activities and participation level of the International Classification of Functioning, Disability and Health (ICF) should be included, as suggested in a review article.[39] During the present study, we recommended that 14 participants make use of orthoses to improve ankle and knee joint stabilization.

A Danish study [16] reported that it is difficult to predict the walking function/ability in adulthood in individuals with lesion level corresponding to motor level L3–L5. If the level of lesion was higher than L2 or lower than S1, one could more accurately predict walking function in adulthood. In our study, all participants who were included had lesion levels lower than L2 and all of those with a sacral lesion level walked both indoors and outdoors in adulthood.

Future studies will involve all adults with spina bifida in the greater Stockholm area, including those who have ceased walking and those who have never been ambulators. To cover outcomes at the body functions and structures, activities and participation levels of the ICF, physical factors, cognitive aspects and perceived quality of life will be included.

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Declaration of interest

The authors report no conflicts of interest.

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