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Walking Activity during Daily Living in Children with Myelomeningocele

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Abstract

Purpose—To quantify the walking activity of children with myelomeningocele during daily living.

Method—Walking activity was measured using a StepWatch activity monitor over one week in 47 children with myelomeningocele (27 males; 9y 11mo SD 2y 7mo; 18 sacral, 9 low lumbar, 20 mid-high lumbar) and 7 children with typical development (5 males; 11y 1mo SD 1y 11mo) in a prospective, cross-sectional study. Average total steps per day, number of steps and minutes spent at low, medium and high intensity stepping were evaluated. Groups were compared using t-tests and chi-squared tests with Bonferroni post-hoc adjustment.

Results—Children with sacral and low lumbar myelomeningocele exhibited no significant differences in demographic characteristics or walking performance compared to typically developing children. Children with mid-high lumbar myelomeningocele exhibited higher BMI percentile than the control group ($p=0.04$) and took fewer total steps per day than all other groups ($p=0.04$). Children with mid-high lumbar myelomeningocele also spent significantly less time taking steps at all intensity levels, particularly medium-intensity, than the sacral and low lumbar groups ($p=0.04$).

Conclusions—Children with sacral and low lumbar myelomeningocele had walking performance similar to typically developing children despite a common need for braces and assistive devices. Children with mid-high lumbar myelomeningocele were less active, which may lead to heightened risk for secondary health conditions in addition to those associated with myelomeningocele.

Keywords

walking activity; myelomeningocele; spina bifida; pedometer

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Declaration of Interest:

The authors report no conflicts of interest.

Myelomeningocele is the most severe and common form of spina bifida. Worldwide, spina bifida is observed in 2 to 8 out of 1000 live births [1]. Patients with this congenital defect may have difficulty with ambulation due to loss of sensation, muscular weakness or paralysis, and decreased efficiency of muscular function. Ability to ambulate may worsen with age despite stable neurologic function. This is due to increased body mass coupled with weak muscle strength as well as with the development of joint contractures, which are common in this population. About one third of patients who are initially community ambulators can be expected to have reduced walking ability by the third decade of life [2].

Although patients with L4 function are able to walk, it may be difficult for them to ambulate long distances. It has been shown that up to half of adult patients with myelomeningocele with sacral involvement are not community ambulators [3]. Previous studies have demonstrated that both adult and adolescent patients are more prone to obesity than the general population [4,5]. In addition, they may have abnormal skeletal growth and development due to decreased loading of bones during childhood and adolescence.

While qualitative information about a patient's activity can be obtained from history and compared to expected activity of typically developing controls, an objective comparison may aid in patient management and designing interventions to increase walking frequency and ability. As Bisaro et al. suggests, measures of walking performance in a usual environment is necessary in youth with spina bifida[6]. The purpose of this study was to quantify the daily walking activity and performance of children with myelomeningocele using a StepWatch activity monitor. We hypothesized that patients with myelomeningocele would have diminished walking activity based on all measured parameters of ambulation compared with typically developing peers.

Materials and Methods

This prospective, cross-sectional study analyzed data collected on walking activity in children with myelomeningocele and a typically developing comparison group using a StepWatch activity monitor (StepWatch, Orthocare Innovations, Mountlake Terrace, WA). The StepWatch is a small, self-contained device that is worn on the ankle to provide a quantitative record of physical activity [7]. Participants with myelomeningocele were classified using the International Myelodysplasia Study Group (IMSG) criteria [8]. The IMSG classifies the neurosegmental level of children with myelomeningocele based on manual muscle testing. 54 children participated, including 47 children with myelomeningocele (18 sacral, 9 low lumbar, 20 mid-high lumbar; 27 males) and 7 typically developing children (5 males) from December 2010 to December 2012. Participants gave written informed assent while their guardian provided written informed consent. All study procedures were approved by the hospital's institutional review board.

This study included ambulatory children with myelomeningocele between the ages of 6 and 13 years old. Potential participants were excluded from the study if they had chronic conditions other than myelomeningocele or hydrocephalus, bilateral tibial metal implants, or current glucocorticoid or seizure medication use. Participants were invited to join the study from local pediatric spina bifida clinics and medical therapy units. The comparison group in

this study was a convenience sample of typically developing youth who were also between the ages of 6 and 13 years old.

During an in-person interview, children and their parents were asked to report how many hours the child typically spent weekly in physical activity, watching television and playing video games or using a computer. After examination, participants were sent home with an individually calibrated StepWatch. They were instructed to wear the device on their stronger leg, as determined by manual muscle testing, for 8 consecutive days during waking hours and to ambulate as normal. In the event that both legs were equal in strength, the device was put on the child's right leg. They were directed to remove the device only while bathing, swimming, or sleeping. The participants were shown how to attach the device and were given a printed set of instructions to take home.

Activity Performance

The StepWatch recorded the step frequency of each participant throughout the day in 10-second increments. The activity data included the total step counts per day as well as the number of steps and minutes spent in low-, medium-, and high-intensity walking. Percentage of the day spent with no walking activity and walking activity of each intensity level was also determined. Low-intensity walking was defined as <30 steps/minute; medium-intensity walking was defined as 30-60 steps/minute; high-intensity walking was defined as >60 steps/minute. These criteria were selected based on past work in children with cerebral palsy [9].

Data Analysis

Eight consecutive days of data were collected. The data analyzed, however, included only days where the monitor was worn for the full day with the exception of bathing, swimming, and sleep hours. To ensure this, only days in which the step count was greater than or equal to 5% of the average total steps taken over the study period were used. The first and last days of data collection, which were partial days, were also excluded.

The comparisons of outcomes between children with myelomeningocele and typically developing children were done using independent t-tests for continuous variables and chi-square tests for categorical variables. Bonferroni adjustment was applied for multiple comparisons.

Results

Demographic information and baseline characteristics for the different groups are included in table 1. Average age was 9y 11mo $\pm$ 2y 7mo for all participants with myelomeningocele combined and 11y 1m $\pm$ 1y 10mos for the comparison group. There was no significant difference in sex, Hispanic ethnicity, Tanner stage, age, weekly television and video game activity, or height and weight percentile across the groups (sacral, low lumbar, mid-high lumbar, control). While the mid-high lumbar group had a higher BMI percentile than the control group ($p=0.04$), no significant difference was found in BMI percentile compared to the sacral or low lumbar groups. Although the difference was not statistically significant, the

children with low lumbar myelomeningocele were younger than the other participants and had lower height and weight percentiles for their ages.

The average number of steps taken daily was 9589 ± 3322 steps for the control group, 9166 ± 3305 steps for the sacral group, 9657 ± 5331 steps for the low lumbar group, and 4867 ± 3316 steps for the mid-high lumbar group (table 2). Children in the mid-high lumbar group took significantly fewer steps daily than those in the control ($p=0.02$), sacral ($p<0.01$), and low lumbar ($p=0.04$) groups. No significant differences were found in performance-based daily step total among the control, sacral, and low lumbar groups ($p>0.99$). Children in the mid-high lumbar group took significantly fewer daily steps at the low-intensity level than the sacral group ($p<0.01$), significantly fewer daily steps at the medium-intensity level than the sacral ($p<0.07$) and low lumbar ($p=0.04$) groups, and significantly fewer steps at the high-intensity level than the sacral group ($p=0.04$) (figure 1).

All groups spent at least 75% of the time with no walking activity (figure 2). The mid-high lumbar group had a significantly higher percentage of time with no walking activity compared to the sacral group ($p=0.03$) group; there was no significant difference in time without walking activity between the control group and the other groups ($p=0.99$).

With regard to intensity of steps, walking activity was mostly low-intensity in all groups. Low-intensity walking activity accounted for 19.9% of time during waking hours for the control group and 21.5%, 19.2% and 16% for the sacral, low lumbar, and mid-high lumbar groups, respectively. All groups spent much less time taking medium-intensity and high-intensity steps compared with low-intensity steps (table 3). The amount of time spent taking medium-intensity steps was significantly lower for the mid-high lumbar group compared to the control ($p=0.04$), sacral ($p<0.01$) and low lumbar ($p=0.03$) groups, and the amount of time taking high-intensity steps was significant lower for the mid-high lumbar group compared to the sacral group ($p=0.04$).

Discussion

In order to advance the treatment of patients with spina bifida, measurement of their performance in a usual environment is helpful to assess their functional status compared to typically developing counterparts. Previously recorded measurements have been based on subjective self-reported values given by the parents of the children [10]; however, these measurements may not accurately reflect actual performance over an extended period of time. The purpose of this study was to provide objective data on walking activity in patients with spina bifida compared with typically developing controls over the course of a week of typical daily living.

In this study, the StepWatch activity monitor was used to quantify the participants' activity. Measurements from the StepWatch in typically developing adolescents ages 6- to 20 years old have proven accurate when compared to manual counting with up to 99.87% accuracy and a maximum discrepancy of only 2.4% as reported by McDonald et al. [11]. Furthermore, when used on patients with disability, McDonald et al. found no difference between the counts recorded by the StepWatch and those recorded manually [12]. In an accuracy and

reproducibility test performed by Song et al., the StepWatch was found to be accurate within an average of 3% with reproducible results from each trial and child [7].

Previous studies have demonstrated that walking activity correlates with the level of spinal involvement of the afflicting condition. Bowman et al. demonstrated this in a study of patients with spina bifida where a manual motor test was conducted immediately after birth and annually thereafter [10]. In a 25-year follow-up, Bowman et al., had patients fill out a mailed questionnaire about their activity. Most patients were examined at a spina bifida clinic for more detail, whereas those who moved away self-reported their detailed activity during a phone interview. In the study, 93% of patients with sacral level involvement relied on ambulation as their only method of locomotion, 91% of patients with a L5 lesion relied on ambulation the majority of the time, and 57% of patients with a L4 lesion relied on ambulation the majority of the time. Patients with a thoracic, L1, L2, or L3 lesion did not ambulate as their main method of locomotion. The study also reported a decline in ambulatory frequency from 75% at 0-5 years of age to 46% by 20-25 years of age.

Similar to Bowman et al., Bjornson et al. found a relationship between walking activity and neuromuscular involvement comparing the walking activity of youth with cerebral palsy and typically developing youth [13]. They found that these patients were less active overall than the comparison group with an average of 4,222 and 6,739 steps each day, respectively. Youth with cerebral palsy were active for 40.2% of the day compared to 49.6% in the typically developing group. Moreover, youth with cerebral palsy spent 5.6% of activity time in high-intensity activity (>42 steps per minute) whereas typically developing youth spent 9.7% of active time at high-intensity levels. Though the present study found similar step counts, the percent of time spent at each activity level is different likely due to the 2007 study having lower cutoffs for each activity level. Bjornson et al. reported that activity time decreased as functional level worsened and that the highest functioning youth with cerebral palsy (Gross Motor Function Classification System I) spent a percentage of time in activity that was comparable to that in typically developing youth [13].

Furthermore, in a 2014 study comparing youth with cerebral palsy (Gross Motor Function Classification System I-III) and typically developing youth, Bjornson et al. found that the average number of strides spent in low (1-30 strides/min) and moderate (31-60 strides/min) activity levels decreased significantly with functional level ($p=0.02$ to <0.001) and were all significantly lower than the typically developing cohort ($p<0.001$). They also found that as functional level worsened, the children spent less time performing at each activity level [8].

These previously reported results comparing typically developing children and children with cerebral palsy are consistent with those in the present study in children with myelomeningocele. Children in the most involved group assessed, the mid-high lumbar group, took significantly fewer steps per day and spent less time walking at all intensity levels, particularly at the medium-intensity level, when compared to the control group and other myelomeningocele groups and high-intensity level when compared to the sacral group. However, there were no significant differences in walking activity between the sacral and low lumbar groups and the control group. This absence of a statistically significant difference may indicate that there is truly no difference in walking activity between children

with sacral and low lumbar lesions when compared with their typically developing counterparts. Alternatively, the failure to detect a significant difference may indicate that our study was not adequately powered to do so.

Patients with a low lumbar lesion took roughly the same average number of steps per day as those in the control and sacral groups and significantly more steps than those in the mid-high lumbar group children. It is possible that the slightly younger age, though not statistically significant, in the low lumbar group permitted this group to have similar step counts to that of the sacral and control groups. Perhaps for this very reason, along with the less frequent use of assistive devices, the low lumbar group exhibited a higher average step per day count compared to the mid-high lumbar group. The disparity between low lumbar children and mid-high lumbar children may further be explained by their neurologic level and the muscle groups affected that influence gait. Patients with low lumbar myelomeningocele have no ankle plantar flexor function and no hip extensor function. This leads to increased hip flexion in terminal stance and a propensity for hip flexion contracture. Increased hip flexion in terminal stance shortens step length and consequently results in more steps to cover the same distance as an individual without excessive hip flexion at terminal stance [14]. Furthermore the low lumbar patients were at least 1 year 8 months younger and at most 2 years 7 months younger than all other cohorts though no significant differences were statistically detected. Song et al. reported that younger able-bodied children took more average total steps daily compared to their older counterparts [7]. Moreover, the lower body weight corresponding to their younger age and possible decreased incidence of joint contractures at this age may account for increased walking activity in the low lumbar group compared with the older patients in both the mid-high lumbar and sacral groups [15]. It would be interesting to observe whether walking ability worsens in this younger group as they grow with age.

Past studies have shown that the ambulatory status of participants early in life may predict the ability to ambulate in adulthood and may affect their quality of life. Seitzberg et al. demonstrated that in 52 total participants five to eight years of age, 41 retained their ambulatory status at follow-up in adult life while those who lost their ambulatory function were primarily dependent on walking aids from a young age [16]. A similar study conducted by Mazur et al. showed that children with high-level spina bifida who walked earlier in life experienced pressure sores five times less than and fractures half as much as those who were reliant on wheelchairs at the same age, sex, level of lesion, and intelligence [17]. Mazur et al. also noted the greater independence of participants who engaged in walking at a young age as opposed to those who were bound to a wheelchair. They found that more of those who walked in early childhood were able to walk independently both inside and outside of their home and were better able to transfer themselves from a wheelchair to the ground, a chair, or a toilet compared to those who always used a wheelchair [17].

Study Limitations

There are several limitations to the present study. First, each cohort in our study had a relatively small number of participants, particularly the control and low lumbar groups, which had only 7 and 9 participants, respectively, and may therefore not be representative of

the population. This may have limited the power to detect statistically significant differences between cohorts, particularly after adjustment for multiple comparisons. Second, though the difference was not statistically significant, there was an age discrepancy amongst the cohorts. The younger average age in patients in the low lumbar group may have overestimated walking activity in this group. Additionally, although patients were directed on the use of the StepWatch at the initiation of the study, it is impossible to know for certain that participants were fully compliant with its use, and use of a self-reported activity log was not implemented.

Next, walking activity amongst the groups may have been affected by confounding factors not accounted for in this study. Children from lower socioeconomic classes may have decreased access to physical therapy and other resources compared with children from higher socioeconomic status and more reliable access to treatment. Bartonek et al. demonstrated that factors such as balance disturbances, spasticity, and number of shunt revisions may influence ambulatory function within a single cohort [18]. Further, the heart rate in children with myelomeningocele has been shown by Bartonek et al. to be elevated compared to their able-bodied counterparts. Ambulatory function may be reflective of a need to avoid a strenuous activity level [19]. We did not investigate the possible effect of these factors on walking activity.

Conclusion

In conclusion, this study provides insight on the walking activity of children with myelomeningocele in their usual environment. We found that the walking activity of children with sacral and low lumbar level function is similar to that of typically developing children despite the common need for braces and assistive devices. Children with a mid-high lumbar functional neurosegmental level, however, demonstrated decreased walking activity with fewer steps per day and lower-intensity activity than both typically developing children and children with lower level myelomeningocele. This decrease in activity puts children with mid-high lumbar level myelomeningocele at higher risk for secondary health issues like obesity and disuse osteoporosis.

Understanding walking activity and intensity in youth with myelomeningocele may aide in developing focused rehabilitation interventions. Moreover, because this type of data is objective and quantitative, StepWatch activity and intensity measures have the potential to help guide therapists and surgeons to more effective treatments. Through quantification of walking activity in children with myelomeningocele using the StepWatch monitor, we hope to provide an objective baseline to serve as the foundation for future studies in this population.

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Figure 1. Average steps taken daily compared by group. Children in the mid-high lumbar group took significantly fewer steps per day than children in the other groups.

Figure 2. Relative proportions of no activity and low/medium/high intensity walking activity across groups. Note the trend towards increased time with no activity and decreased time taking steps of higher intensity with higher neurosegmental level IMSG classification.

Table 1

Demographics and clinical characteristics for all study groups.

	Control (n = 7)	Sacral (n = 18)	Low Lumbar (n = 9)	Mid-High Lumbar (n = 20)
Age (years)	11y 1mo ± 1y 11mo [8y 1mo -13y 2mo]	10y 2mo ± 2y 8mo [6y -13y 11mo]	8y 6mo ± 2y 5mo [6y -13y 4mo]	10y 4mo ± 2y 6mo [6y-13y 6mo]
Sex, n (%) male	5 (71%)	9 (50%)	5 (56%)	13 (65%)
Ethnicity, n (%) Hispanic	4 (57%)	15 (83%)	8 (89%)	19 (95%)
Tanner, n (%)				
1	2 (29%)	9 (50%)	6 (67%)	10 (50%)
2	2 (29%)	1 (6%)	1 (11%)	1 (5%)
3	1 (14%)	2 (11%)	0 (0%)	3 (15%)
4	0 (0%)	1 (6%)	1 (11%)	4 (20%)
5	2 (29%)	5 (28%)	1 (11%)	2 (10%)
Television (hours per week)	9.4 ± 5.79 [3.0-17.5]	11.8 ± 8.66 [0.8-32]	11 ± 5.24 [2.0-15]	10.9 ± 6.49 [0.0-25]
Video Games (hours per week)	8.9 ± 9.75 [0.0-28]	5.8 ± 6.50 [0.0-21]	7.2 ± 7.66 [0.0-20]	5.4 ± 6.40 [0.0-21]
Height Percentile	60.1 ± 38.15 [13.6-97.7]	42.0 ± 32.47 [0.1-95.5]	27.1 ± 23.41 [0.0-53.98]	32.2 ± 30.81 [0.0-94.5]
Weight Percentile	60.9 ± 36.52 [8.1-98.2]	53.9 ± 37.28 [2.9-99.5]	41.1 ± 36.38 [0.1-93.3]	67.4 ± 33.73 [1.4-99.5]
BMI Percentile	53.1 ± 34.87 [15.9-97.1]	63.3 ± 32.57 [3.6-98.9]	63.2 ± 27.53 [9.7-97.1]	84.1 ± 19.97 [*] [38.2-99.4]
Lesion Level, n (%)	-	S1: 3 (17%) S1-S2: 11 (61%) S2: 2 (11%) S2-S3: 2 (11%)	L4: 1 (11%) L4-L5: 5 (56%) L5-S1: 3 (33%)	L1-L2: 1 (5%) L2: 1 (5%) L3-L4: 18 (90%)
Assistive Device, n (%)				
None	7 (100%)	18 (100%)	7 (78%)	7 (35%)
Crutches	0 (0%)	0 (0%)	1 (11%)	9 (45%)
Walker	0 (0%)	0 (0%)	1 (11%)	4 (20%)
Brace, n (%)				
None	7 (100%)	11 (61%)	1 (11%)	0 (0%)
AFO	0 (0%)	7 (39%)	7 (78%)	11 (55%)
KAFO	0 (0%)	0 (0%)	1 (11%)	6 (30%)
HKAFO	0 (0%)	0 (0%)	0 (0%)	3 (15%)

Continuous variables are presented as Mean ± standard deviation [Range]. Categorical variables are presented as n (%).

^{*}
p < 0.05 compared with control groups

Table 2

Intensity of Steps – average number of steps taken daily with low-, medium-, and high-intensity and total number of steps for the different groups. The mid-high lumbar group took significantly fewer steps of all intensity levels compared with the other groups.

	Control (n=7)	Sacral (n=18)	Low Lumbar (n=9)	Mid-High Lumbar (n=20)
Low-Intensity	5401 ± 1487 [3494-7942]	5546 ± 1911 [1856-8886]	5087 ± 1846 [1866-7130]	3396 ± 1868 [†] [362-6572]
Medium-Intensity	3853 ± 2759 [1542-8620]	3337 ± 1669 [1036-7066]	4207 ± 3555 [18-11850]	1438 ± 1648 ^{†‡} [0-6910]
High-Intensity	335 ± 496 [0-1260]	281 ± 374 [0-1422]	361 ± 569 [0-1678]	32 ± 82 [†] [0-358]
Total	9589 ± 3322 [5212-13858]	9166 ± 3305 [3014-16046]	9658 ± 5331 [1884-18960]	4867 ± 3316 ^{*†‡} [362-12934]

Average number of steps per day ± standard deviation [Range]

^{*}
^p=0.02 compared with control group

[†]
^p 0.04 compared with sacral group

[‡]
^p=0.04 compared with low lumbar group

Table 3

Intensity of Steps – percentage of time with no walking activity, low-intensity activity, medium-intensity activity, and high-intensity activity for the different groups.

	Control (n=7)	Sacral (n=18)	Low Lumbar (n=9)	Mid-High Lumbar (n=20)
No Activity	76.8 ± 6.04 [68.4-85.8]	75.6 ± 7.19 [64.0-89.6]	77.2 ± 6.48 [70.1-87.8]	82.8 ± 7.55 [†] [70.5-95.5]
Low-Intensity	19.9 ± 5.71 [12.8-28.2]	21.5 ± 6.46 [9.4-31.0]	19.2 ± 4.88 [11.2-26]	16 ± 6.75 [4.5-27.3]
Medium-Intensity	3.1 ± 2.02 [1.4-6.6]	2.8 ± 1.35 [1.0-5.7]	3.4 ± 2.75 [0.0-9.1]	1.2 ± 1.30 [*] ^{†‡} [0.0-5.3]
High-Intensity	0.2 ± 0.27 [0.0-.70]	0.1 ± 0.22 [0.0-0.8]	0.2 ± 0.31 [0.0-0.9]	0.01 ± 0.04 [*] [0.0-0.2]

Average percentage of steps per day ± standard deviation [Range]

^{*}
^p=0.04 compared with control group

[†]
^p 0.03 compared with sacral group

[‡]
^p=0.03 compared with low lumbar group