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Factors Affecting the Course of Ambulation in Lumbar Myelomeningocele

Jennifer L. Fell

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FACTORS AFFECTING THE COURSE OF AMBULATION IN
LUMBAR MYELOMENINGOCELE

by

Jennifer L. Fell
Bachelor of Science in Physical Therapy
University of North Dakota, 1992

An Independent Study
Submitted to the Graduate Faculty of the
Department of Physical Therapy
School of Medicine
University of North Dakota
in partial fulfillment of the requirements
for the degree of
Master of Physical Therapy

Grand Forks, North Dakota
May
1993
This Independent Study, submitted by Jennifer L. Fell in partial fulfillment of the requirements for the Degree of Master of Physical Therapy from the University of North Dakota, has been ready by the Faculty Preceptor, Advisor, and Chairperson of Physical Therapy under whom the work has been done and is hereby approved.

Erin E. Simonds
(Faculty Preceptor)

Thomas More
(Graduate School Advisor)

Thomas More
(Chairperson, Physical Therapy)
PERMISSION

Title Factors Affecting the Course of Ambulation in Lumbar Myelomeningocele

Department Physical Therapy

Degree Master of Physical Therapy

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Date 5-7-93
# TABLE OF CONTENTS

LIST OF TABLES .................................................. v

ACKNOWLEDGMENTS ................................................ vi

ABSTRACT ........................................................... viii

CHAPTER

I. INTRODUCTION ................................................... 1

II. LITERATURE REVIEW ........................................... 7

III. METHOD ......................................................... 12

Subjects ........................................................... 12

Procedure ........................................................ 13

Analysis .......................................................... 14

IV. RESULTS ........................................................ 16

V. DISCUSSION ..................................................... 20

VI. CONCLUSIONS .................................................. 29

APPENDIX A ........................................................ 31

APPENDIX B ........................................................ 41

REFERENCES ...................................................... 46
# LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Variable Associated with a Decline in Ambulatory Status Using the Mann-Whitney U-Test</td>
<td>18</td>
</tr>
<tr>
<td>2.</td>
<td>Course of Ambulation by Lesion Level</td>
<td>21</td>
</tr>
</tbody>
</table>
ACKNOWLEDGMENTS

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To My Family and Tom
ABSTRACT

Depending on the area of the spinal cord affected and the resultant degree of muscle paralysis, frequently ambulation is affected in the individual with myelodysplasia. While the ambulatory outcome of individuals with thoracic region myelomeningocele is unfavorable, those with sacral myelomeningocele hold excellent prognosis for functional ambulation. The walking potential of individuals with lumbar myelomeningocele, however, is less clear. Experts agree that, in addition to neurosegmental lesion level, several other factors can influence the ambulatory status of lumbar myelodysplastics. However, experts disagree on the relative significance of the individual factors. The purpose of this study was to analyze various factors cited by experts to be significant in affecting walking ability in individuals with lumbar myelodysplasia. Methodology entailed a retrospective chart review of 19 cases over the age of 18 years. The cases were reviewed at various age intervals representing childhood, adolescence, and adulthood. The results of this study revealed that the region of the myelomeningocele, extent of bracing, and knee contractures at all three age intervals were significantly associated with a decline in ambulatory status by the time the individual reached adulthood. The type of assistive device at age four to five years and scoliosis at 12 years were also significant predictors
of course of ambulation into adulthood. The methodology and results of this study indicated a need for further longitudinal studies of interval and ratio data based on standardized clinical evaluations to increase the accuracy of walking prognosis in lumbar myelodysplasia.
CHAPTER I
INTRODUCTION

Myelomeningocele occurs in roughly two out of every 1000 births and accounts for the most handicapping condition in children, second to cerebral palsy. While the etiology is unknown, pathophysiologically, myelomeningocele is thought to be a neural tube defect. The spinal defect results from a failure of the caudal portion of the neural tube to close early in embryonic development at approximately four weeks gestation. The result is abnormal formation of some or all of the developing spinal tissues. The location of the myelomeningocele, or myelodysplasia, grossly dictates cord or nerve root involvement and the severity of the paralysis. To varying degrees, ambulation is affected in the child with myelomeningocele.

Generally, experts recognize three to four levels of ambulatory status in myelomeningocele. Essentially, each ambulatory status is classified according to the frequency and distance of ambulation, and the type of equipment used by the child during ambulation. The four status categories as described by Hoffer are frequently cited by experts. Community ambulators are those patients who ambulate with or without crutches and braces for most of their indoor and outdoor activities. A wheelchair may or may not be used for
long trips out of the community. **Household ambulators** use walking with assistive equipment as their main means of mobility indoors and utilize a wheelchair for all activities in the community. Occasionally, the household ambulator may use his/her wheelchair during some activities at home or school. **Nonfunctional ambulators** are walking only during therapy sessions in the hospital, home, or school. Outside of therapy, nonfunctional ambulators rely on their wheelchair as their main means of mobility indoors, outdoors, and in the community. Those children who do not attempt functional ambulation and who are generally confined to a wheelchair for all mobility needs comprise the **nonambulators**. These children, however, are able to independently carry out basic wheelchair transfers.

Several factors influence which level of ambulation the child with myelodysplasia will achieve. Most consistently, authors recognize the neurosegmental lesion level to be the most significant factor in predicting ambulatory outcome. Other studies have shown that patterns of lower extremity muscle strength have significant prognostic value in predetermining locomotion. Moreover, strength patterns, it has been contended, may be more reliable than lesion level, since clinically determined patterns of muscle strength may differ somewhat from the classic neurosegmental level. Many studies cite the significance of the iliopsoas and quadriceps as valuable determinants. Achievement of early motor milestones has been shown to be a reliable and significant predictor of locomotor outcome; specifically,
wheelchair usage and the age at which the child is able to sit without support and walk outdoors are each noted. In addition, ambulatory outcome can be influenced by the presence of neurological factors (e.g., hydrocephalus, Arnold-Chiari malformation, tethered cord, syringohydromyelia) and orthopedic deformities (e.g., scoliosis, pelvic obliquity, hip deformity, contractures, fractures). Obesity, intelligence quotient, upper extremity function, therapy rigor, child motivation, and parental devotion are additional factors which have been recognized by experts as significant in influencing locomotor outcome.

As stated previously, ambulatory outcome can be grossly predicted according to the region of the spinal cord affected. Because the neural tube is most likely not to fuse toward the caudal end, cervical myelomeningoceles are extremely rare. When the myelomeningocele develops at the thoracic level of the spinal cord, the research has indicated that community ambulation as an adult is not predicted. For example, Hoffer et al found that out of ten patients with thoracic lesions, none were able to walk, maintaining a nonambulator status; four of the cases did achieve nonfunctional ambulation as inpatients, but none maintained the status six months beyond discharge despite outpatient therapy and frequent follow-ups. Studies have shown that, while many children with thoracic level myelomeningocele may achieve functional ambulation (i.e., household or community ambulation) and a minority will maintain it over the years, the trend is usually toward deterioration in ambulatory status. Experts concur that children with sacral
myelomeningocele hold excellent promise for ambulation, with the majority achieving and maintaining a community ambulator status.\textsuperscript{2,9,12,13,14} In the same study by Hoffer et al,\textsuperscript{2} all patients with sacral lesions achieved and maintained a community ambulatory status; roughly 80\% of these cases required the assistance of below the knee orthoses and orthopedic footwear because of the associated ankle weakness.

There is considerable inconsistency in the literature, however, regarding the ambulatory potential in children with lumbar level myelomeningocele. Furthermore, much controversy exists regarding the association, if any, of many factors with ambulation status.

Lumbar lesions are generally classified by most sources as low and high level, with the latter usually denoting L\textsubscript{3} and above. While some authors contend there is, in general, a poor prognosis for functional ambulation into adulthood with high lumbar lesions,\textsuperscript{5,10,12,14} other studies claim that there is really no significant difference between the two subgroups' potential.\textsuperscript{2,11} Several studies have analyzed factors influencing the walking potential of children with myelomeningocele based on individual segmental levels. The majority of studies indicate that independent ambulation decreases as neurosegmental lesion level increases.

Experts agree that, in addition to neurosegmental lesion level, there are several additional factors which significantly influence, and thus may be predictive of, ambulatory potential in the lumbar neurosegmental group. As
stated earlier, patterns of lower extremity muscle strength have been shown to hold great prognostic value for future ambulatory outcome. This is of significant relevance to the lumbar level population, as lumbar nerve rootlets innervate the vast majority of muscles necessary for proficient ambulation—those muscles crossing the hip, knee, and ankle. The presence and degree of scoliosis and pelvic obliquity, hip flexion contractures, knee flexion contractures, and number of fractures are orthopedic deformities that have been recognized as having a negative impact on ambulation for patients with lumbar myelodysplasia. Neurologic impairments, such as symptomatic Arnold-Chiari malformation, tethered cord, hydrocephalus, or syringohydromyelia, can also compromise ambulation, not exclusively in the lumbar myelomeningocele population. Additionally, obesity has been noted to adversely affect ambulatory skills in those individuals with high level paralysis. Experts disagree on the relative significance or correlation of these many factors when evaluating a child's ambulatory potential and predicting outcome.

Dispute also exists as to the importance, if any, of individual variables. Most notably, the consequence of hip deformity for ambulators has been debated by several authors. Some authors contend subluxated or dislocated hips are of no consequence for ambulation in patients with lumbar lesions; others argue that the hip deformity does impair mobility at specific lumbar levels.
The purpose of this study is to examine those individuals with lumbar region myelomeningocele who experienced a decline in ambulatory status when they reached adulthood and to identify factors that may have played a significant role in that decline.
CHAPTER II

LITERATURE REVIEW

Several authors have examined the ambulation potential in lumbar myelomeningocele as one group or in comparison with thoracic and sacral level lesion groups. In articles studying all neurosegmental groups, the results and discussion pertaining only to the lumbar neurosegmental level were cited for the purposes of this study. Traditionally, neurosegmental lesion level has been established as the most significant predictor of a child’s walking potential. Researchers agree that several additional variables influence ambulatory status, although specific factors have been the subject of much debate.

Hoffer et al. identified and defined four functional levels of ambulation: community ambulators, household ambulators, nonfunctional ambulators, and nonambulators. The authors investigated forty subjects with lumbar myelomeningocele, 19 upper lumbar (hip flexion and adduction, knee extension) and 21 lower lumbar (knee flexors, ankle dorsiflexors). Ages ranged from 5 to 42, and subjects were grouped according to level of lesion. Methodology entailed chart review, call-back examinations, and review of school performance. In this study, Hoffer et al noted that mental retardation, spinal
deformity, and residual contractures increased as ambulatory status decreased in lumbar lesions. Brain and kidney anomalies and home environment influenced the ambulatory status of all lesion levels. Hoffer et al found no discrepancy between high and low lumbar groups' ambulatory status.²

The results of Gaff et al were similar to the conclusions of Hoffer et al. The subjects in the study by Gaff et al were grouped according to lesion level; there were 12 subjects classified as 'high lumbar without quadriceps' and 23 subjects classified as 'lumbar with quadriceps.' The subjects' ages ranged from 14 to 17 years. Information for each subject was gathered by review of case notes and interview of the patient and family. The authors cited the importance of antigravity quadriceps for maintaining 'useful' walking ('lumbar lesions with quadriceps'). When compared to all lesion level groups, the greatest percentage decrease in 'useful' walking occurred in the 'high-lumbar without quadriceps' group.³

Asher and Olson conducted a cross sectional study of children with myelomeningocele ages five years or older (mean age of 14 years 4 months). There were 12 subjects with L₁, L₂ lesions, 20 subjects with L₃ lesions, 17 subjects with L₄ lesions, and 9 subjects with a lesion level of L₅. In this study, those with fifth-lumbar myelomeningocele were all community ambulators. Subjects with fourth-lumbar lesions were found to have excellent potential to be functional ambulators; their status was most significantly influenced by the presence of spine, pelvis, hip, or lower extremity deformity. The authors found
that patients with third-level lesions and above usually became nonambulatory. Hip deformity was the sole factor influencing the third-lumbar group, while obesity was the only significant factor affecting ambulation in first and second lumbar groups. The authors concluded that neurosegmental level was the most important variable affecting walking ability in myelomeningocele. 

Samuelsson and Skoog analyzed several factors affecting walking potential of 73 patients with lumbar myelomeningocele, whose ages ranged from 2 to 40 years (a mean age of 14 years 10 months). Using a multivariate statistical analysis, ambulation was correlated with neurological and radiological level of the lesion, scoliosis, age, pelvic obliquity, hip dislocation, and flexion contracture at the hip and knee. There were no ambulators at the first and second lumbar levels, 54 percent at the third lumbar level, 67 percent at the fourth, and 80 percent at the fifth. According to these authors, syringohydromyelia, Chiari malformations, scoliosis, age, and hip flexion contracture related to the inability to walk.

Charney et al examined ambulation and lower extremity muscle strength in patients with upper and midlumbar myelomeningocele. Data were retrospectively collected on 87 children with high lumbar lesions with an age range of 6 to 28 years (mean of 16 years). Charney et al defined high-level paralysis to be voluntary hip flexion and loss of motor power below lumbar level 2. The authors found that lesion level and distinct hip and knee muscle strength patterns determine if the child is upper lumbar and wheelchair
dependent or midlumbar with highly variable functional ambulation. The authors concluded that while myelomeningocele children with high level paralysis (42% of their population maintained community walking into the adult years), they noted that the trend is to decline in walking ability.\(^1\)

Most recent studies investigating ambulation in myelomeningocele contend that lower extremity muscle strength patterns hold the greatest prognostic value in terms of future ambulatory status. McDonald et al found that patterns of strength rather than individual muscle groups were more reliable due to the intercorrelation of muscle strengths in children with myelomeningocele. Methodology entailed standard manual muscle testing of 17 right and left muscles of 291 subjects over five years of age. Criteria for patient selection was not provided. Subjects with iliopsoas strength of less than grade 4-5 iliopsoas did not solely rely on a wheelchair. Strong iliopsoas and quadriceps (grade 4-5) were positive indicators for community ambulation but also represented the group most likely to decrease in status. Those individuals with strong quadriceps, iliopsoas, and antigravity glutei muscles were almost all community ambulators; 68 percent of those with less than grade three glutei muscles were community ambulators.\(^4\) The muscles of significance were those innervated by lumbar rootlets, although McDonald et al do not formally acknowledge a correspondence of muscular innervation to a lesion level in the article.
Numerous studies have examined the association of various factors with the ability to walk in children who have myelodysplasia. There is much disparity in the literature regarding the ambulation potential of the lumbar neurosegmental level, however. Researchers agree that several factors are associated with a change in ambulatory status, but disagree on the relative significance and, in some instances, mere relevance of the varying factors.
CHAPTER III

METHODS

Subjects

One-hundred-nine charts from a myelodysplasia clinic at a children's hospital in St. Paul, Minnesota were randomly obtained. Out of 109 charts reviewed, 56 (51.4%) were diagnosed with lumbar level myelomeningocele. Of the 56, only 19 met the criteria for this study. There were five males (26.3%) and 14 females (73.7%), with ages ranging from 18 to 30 years (mean = 22.2, SD = 3.8). Of the remaining 37, 91.9% of the charts were rejected because of insufficient data for collection. The remaining 8.1% were rejected due to the presence of differential or additional unrelated diagnoses, severe mental retardation, or lower extremity amputations.

Of the 19 cases with lumbar myelodysplasia, four (21.0%) cases were diagnosed with high (L₁, L₂) lumbar lesions, five (26.3%) with midlumbar (L₃) lesions, and ten (52.6%) with low (L₄, L₅) lesions.

Charts were acquired and reviewed in accordance with stipulations outlined by the Minneapolis Children's Medical Center and University of North Dakota Institutional Review Boards (Appendix A).
Procedure

Methodology entailed a chart review of 19 adult (born prior to 1974) cases with lumbar myelomeningocele either previously or currently enrolled in a myelodysplasia clinic at a children's hospital in St. Paul, Minnesota. The cases were divided into two groups: 1) those individuals who experienced a decline in ambulatory status as adults or 2) those who improved or experienced no change in ambulatory status in adulthood.

A data sheet was used to gather clinical information on the subject at four to five years old, at twelve years old, and at the oldest age (over 18 years) in which a thorough evaluation was completed. Age intervals were used to allow retrospective analysis of variable which may be significantly associated with a decline in ambulatory status over time. The four- to five-year interval was chosen since this is the age when the reliability of manual muscle strength testing has been found to have peaked. Furthermore, ability to ambulate out-of-doors at this age has been associated with independent ambulation as an adolescent. Age twelve years is a median age of 10-15 years, the range in which a decline in ambulatory status is most likely to occur. One group of researchers found that during the mid-teenage (age 12 or older) years their patients tended to prefer a wheelchair to braces. Data were collected at the oldest age (over 18 years) in which a complete evaluation was performed; for the remainder of the text, this will be referred to as "current age." An age of 18 years or older signifies adulthood, when mobility habits are likely to have
plateaued. Analysis of functional mobility status as an adult seems to be of greatest relevance since the majority of an individual's life is spent as an adult.

The data sheet was designed to collect information related to functional mobility according to various factors that have been identified by experts as significant in predetermining ambulatory outcome (see Appendix B). Obesity was defined as greater than 95% of weight for height in four to five years and a body mass index \((weight/height)^2\) of greater than 30 at 12 years and current age.²¹,²² By virtue of the methods procedure in which all data were obtained from chart review, the data sheet was modified after several pilot trials of data collection. The charts infrequently contained information related to school performance (I.Q.), therapy services received, child motivation, and family involvement. Therefore, these variable were omitted from the data sheet. All data were collected in codified form to insure confidentiality.

Analysis

All data were classified as ordinal or nominal and, therefore, nonparametric statistical tests were used for data analysis. All ordinal variables were assigned a numerical value, with the lower values corresponding to the higher ranking variables. Nominal variables were designated a 1 if the variable was male or yes and 2 if the variable was female or no. Refer to Appendix B for specifics. The Mann Whitney U test was used to analyze the significant ordinal variable associated with a decline in ambulatory status. Fisher's Exact test was used to determine significant nominal variables associated with
declined status. The Kruskal Wallis technique analyzed scoliosis with lesion level to further examine the significance of this variable. All variables were accepted as significant at the .05 level.
CHAPTER IV
RESULTS

Significant ordinal variables associated with a decline in ambulatory status are listed in Table 1. When comparing the group who experienced a decline in ambulation in adulthood with the group who improved or did not change, there was no significant difference between the two groups' hip status, presence of hip contracture, or status of hydrocephalus at any of the three age intervals at which data were collected. Additionally, there was no significant difference between the two groups by assistive device at 12 years and current age, or scoliosis at four to five years and current age.

Fisher's Exact test found that only the use of a wheelchair at all age intervals was significant when analyzed with ambulatory status. Neurological impairments, such as symptomatic Arnold-Chiari, tethered cord, and symptomatic syringohydromyelia, were not found to be significantly associated with a decline in ambulatory status. However, the frequency of occurrence of these variables in this study's sample was very low. The ability to ambulate at one and one-half years and to walk outdoors at four years was not significantly associated with the ability to maintain or improve one’s ambulatory status into
adulthood. In contrast to several other studies, there was no significant difference in the prevalence of obesity between the two status subgroups.

The Kruskal-Wallis test found no significant difference in severity of scoliosis between the three lumbar lesion subgroups.
TABLE 1.--Variables Significantly Associated with Decline in Ambulation Status using the Mann Whitney U Test

<table>
<thead>
<tr>
<th>Variable</th>
<th>Significance</th>
<th>Z Score</th>
<th>Mean Description of variable (group1/group2)</th>
</tr>
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<tr>
<td>Lesion Level</td>
<td>.01</td>
<td>-2.45</td>
<td>1.75/2.73</td>
</tr>
<tr>
<td>Bracing</td>
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<td></td>
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<td>age 4-5 years</td>
<td>.01</td>
<td>-2.51</td>
<td>3.50/2.00</td>
</tr>
<tr>
<td>age 12 years</td>
<td>.004</td>
<td>-2.92</td>
<td>3.25/1.82</td>
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<tr>
<td>age current</td>
<td>NS</td>
<td>-.93</td>
<td>1.63/1.82</td>
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<tr>
<td>Assistive Device</td>
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<td></td>
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<td>age 4-5 years</td>
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<td>-2.20</td>
<td>2.38/1.55</td>
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<td>age 12 years</td>
<td>NS</td>
<td>-1.38</td>
<td>2.00/1.55</td>
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<td>age current</td>
<td>NS</td>
<td>-.72</td>
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<td>NS</td>
<td>-.16</td>
<td>1.38/1.45</td>
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<td>age 12 years</td>
<td>NS</td>
<td>-.56</td>
<td>1.75/1.55</td>
</tr>
<tr>
<td>age current</td>
<td>NS</td>
<td>-.67</td>
<td>1.88/1.64</td>
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<tr>
<td>(L) Hip Status</td>
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<td></td>
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<td>NS</td>
<td>-.46</td>
<td>1.38/1.18</td>
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<tr>
<td>age 12 years</td>
<td>NS</td>
<td>-1.12</td>
<td>1.63/1.27</td>
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<tr>
<td>age current</td>
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<td>-1.26</td>
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<td>Scoliosis</td>
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<td>age 4-5 years</td>
<td>NS</td>
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<td>1.63/1.09</td>
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<tr>
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<td>.05</td>
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<td>NS</td>
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<td>2.13/1.81</td>
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</tr>
<tr>
<td>(R) Hip Flexion Contractures</td>
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<td>1.50/1.36</td>
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<tr>
<td>age 12 years</td>
<td>NS</td>
<td>-.16</td>
<td>1.63/1.36</td>
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<tr>
<td>age current</td>
<td>NS</td>
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<td>(L) Hip Flexion Contractures</td>
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<td>1.75/1.36</td>
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<td>NS</td>
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<td>1.88/1.09</td>
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<tr>
<td>(R) Knee Flexion Contractures</td>
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</tr>
<tr>
<td>age 4-5 years</td>
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<td>-2.15</td>
<td>1.38/1.00</td>
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<tr>
<td>age 12 years</td>
<td>&lt;.001</td>
<td>-3.32</td>
<td>2.13/1.00</td>
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<tr>
<td>age current</td>
<td>.003</td>
<td>-2.95</td>
<td>1.75/1.00</td>
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<td>age current</td>
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<td>-2.57</td>
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<td>Hydrocephalus</td>
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<td>NS</td>
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<tr>
<td>age current</td>
<td>NS</td>
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<td>2.50/2.27</td>
</tr>
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NS = nonsignificant
CHAPTER V

DISCUSSION

In the literature, experts almost exclusively found lesion level to have significance or a high correlation with ambulation in the myelomeningocele population.\textsuperscript{2,3,5,8-14} The results of this study agree with other reports asserting the significance of lesion level with ambulatory status in adulthood. As noted in Table 1, lesion level was found to be significantly related to ambulatory status as an adult, a finding which agrees with previous studies. Cases with L\textsubscript{1} and L\textsubscript{2} lesions were assigned an ordinal value of 1, L\textsubscript{3} assigned 2, and L\textsubscript{4} and L\textsubscript{5} assigned 3. In examining the mean description of the lesion level variable by status (Table 1), it is noted that those individuals who declined in status by the time they reached adulthood had a mean value of 1.75, which indicates that the majority of this group was between a high lumbar and midlumbar lesion level. Those who maintained or increased their ambulatory status had a greater average ($\overline{X} = 2.73$), and thus lower lesion level mean, with a greater frequency of cases having L\textsubscript{3} and L\textsubscript{4}-L\textsubscript{5} lesion levels. This suggests that those cases whose ambulatory skills declined as they reach adulthood tend to represent the high to midlumbar lesion level groups. Table 2 displays the status of
ambulation by high, mid, and low lesion groups, with more apparent variability noted at the midlumbar region.

Table 2.—Course of Ambulation by Lesion Level

<table>
<thead>
<tr>
<th>Region</th>
<th>Decline in Amb. Status n = 8</th>
<th>NoΔ/Improved Amb. Status n = 11</th>
</tr>
</thead>
<tbody>
<tr>
<td>High Lumbar</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>n = 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Midlumbar</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>n = 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low Lumbar</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>n = 10</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Key: Δ change

The extent and need for bracing as children and adolescents was found to be significantly associated with the course of ambulation into adulthood. When an individual required, on the average, extensive knee or hip bracing (\( \bar{X} = 3.50 \)), a significant association with decline in ambulation was noted. Those who improved, or at least maintained the ambulatory status they had as children or adolescents, required significantly less bracing; the bracing needs of this group averaged between no orthotic equipment and AFOs (ankle-foot orthoses). Bracing requirements as adults would expectedly be relevant to current ambulation status, although not valuably predictive. However, several individuals using wheelchairs as adults continued to utilize orthoses as well, perhaps for preventing or retarding progressive deformity; therefore, a
significance between the two groups was not observed. It is anticipated that bracing requirements for ambulation are strongly associated with lower extremity muscle strength and energy expenditure. The degree of trunk or lower extremity bracing indicates unstable joints and is reflective of existing muscle strength and agonist/antagonist imbalance. While extensive bracing in childhood may be feasible for ambulation, as the child grows, proficient, functional mobility is likely compromised by the discrepancy in lower body mass and upper body mass. As a child, the lower body is more proportional to the upper body. Perhaps, as the child with myelodysplasia grows, there is decreased bone and muscle growth and muscular atrophy (due to limited activities stimulating bone/muscle growth and denervation) in the lower body resulting in disproportional development of the lower half of the body. Conceivably, the limited development of the lower half of the body may be inadequate to endure its share of the demands imposed by the increased growth in the upper body (trunk and upper extremities) and atrophied lower extremities.

The type of assistive device at four to five years was found to be significant, and thus possibly predictive of the course of ambulation into adulthood. Those children who, on an average, used crutches or a walker ($\bar{X} = 2.38$) were more likely to decline in their ambulation skills than those children who used no device or crutches ($\bar{X} = 1.55$) when they were four to five. As noted in Table 1, there was no significance between the two groups' course
of ambulation by assistive device needs at 12 years or as adults, with both
groups typically using nothing or crutches. It is possible that by 12 years, and
indeed by adulthood, individuals with myelomeningocele prefer to use the least
cumbersome assistive device for functional ambulation. This may limit
ambulation distances and possibly confine them more to a wheelchair,
accounting for a decline in status, but, as one matures, proficient mobility
becomes more of a functional, as well as a social, issue. Furthermore, the type
of assistive device needed reflects the individual’s level of strength and
endurance which again may relate to the discrepancy between upper and lower
body mass. There was a significant difference between the two groups by the
use of a wheelchair at four to five years (p = .005), 12 years (p < .001), and, as
would be expected, current age (p < .001). None of the individuals in the group
who improved or maintained their ambulation status used a wheelchair at four
to five or 12 years of age. The majority of those who experienced a decline
used a wheelchair at four to five years (63%) and at 12 years of age (88%).

Scoliosis is a common clinical sequelae of myelomeningocele and a
general relationship with loss of ambulation has been established. At the
12-year-old age interval, scoliosis was found to be significantly associated with
a decline in ambulatory status in adulthood. The average degree of curvature
in the decline group was between mild to moderate (less than 40 degrees).
The 12-year-old age interval is likely associated with growth; the resultant
changes in muscle imbalance increase scoliosis, which, in turn, may impair the
child's ability to stand erect to varying degrees. In examining the mean scoliotic curve of the decline group in adults, it is noted that the average again is greater than a mild curve ($\bar{X} = 2.13$); although not statistically significant, the mean curve of the second group is less than mild ($\bar{X} = 1.81$). These results may suggest an association of moderate curvature with loss of ambulation skills. At four to five years of age, both groups were found to have averaged below a 20 degree scoliotic curve; therefore, no significant difference was distinguished.

The incidence of scoliosis has been shown to be related to the degree of neurological deficit with higher frequency and greater severity noted at higher levels. In this study, no significant differences were noted in severity of scoliosis in the three lumbar subgroups; however, the average severity of scoliosis per subgroup consistently increased with an increase in region of lumbar paralysis at each age interval.

The presence of knee contractures, bilaterally, was found to be significantly associated with the first group's decline in ambulatory status at all three age intervals. On the other hand, there was no significant difference in the presence or severity of hip contracture between group one and group two. As noted in Table 1, the majority of those cases who declined in ambulation had a mean value between 1 and 2 for both knees at most age intervals. This corresponds to presenting with knee flexion contractures of up to 15 degrees. The development of knee contractures of greater than 15-20 degrees has been found to significantly impair ambulation in the lumbar myelomeningocele.
population. Significant knee flexion contractures can preclude brace fitting. Furthermore, Perry et al points out that in those individuals without gluteus maximus and gastrocsoleus are unable to utilize postural forces to counteract the knee instability caused by a knee flexion contracture. In this study, those who experienced no change or improved in ambulation as they reached adulthood had no flexion contractures about the knee. The lack of significance in hip contractures between the two groups may suggest that ambulation is compromised by a greater average severity of hip contracture than was found in this study.

The impact of hip status on ambulation in individuals with myelomeningocele has been a subject of much discordance among experts. The results of this study found no significant association between hip status (located, subluxated, or dislocated; unilateral or bilateral) and declined walking ability into adulthood. Several studies are in agreement with the findings of this study. However, other researchers contend that ambulation at specific lumbar neurosegmental levels is adversely affected by hip deformity. Asher and Olson found that ambulation in the L₃ and L₄ lesion groups was significantly affected by hip status and advocated the necessary measures for maintaining a located hip status. Lindseth also found hip dislocation to impair ambulation at the L₄ level. Less specifically, Lee and Carroll contend that ambulation in children with myelodysplasia was enhanced by hip stability.
Because of the low incidence of symptomatic Arnold-Chiari, tethered cord, and symptomatic syringohydromyelia in this study's population, the significance of these variables could not be analyzed. Only two of the nineteen cases in this study had a history of tethered cord, both of which were subsequently detethered. In reviewing the data sheets, both cases experienced a decline in ambulatory status following the development and subsequent surgical detethering of the cord. One of the two cases went from being a community ambulator to a household ambulator (transitioning only one level). However, she had an L₃ lesion level with reportedly no muscle strength below the knee; the effect of these factors on endurance must be considered when analyzing her change in status. The second case was a community ambulator with an L₅ level with fair to good strength at the ankle reported in occasional evaluations. Following development of tethered cord and subsequent surgical detethering, the individual transitioned to a nonambulator. Secondary tethering reportedly occurs in 10 to 15 percent of initial detethering operations.²³ In the situation of the second case, it is suspected that the individual's total loss of ambulatory skills resulted from secondary tethering or unsuccessful surgical intervention.

There were several drawbacks to this study. Typically, the literature has examined the impact of various deformities, associated physiologic sequelae, and social factors on ambulation in the myelodysplasia population. However, in part due to the methodology of this study, frequently such data could not be obtained. Perhaps the relevance of social factors could have been analyzed
with a questionnaire or interview of the patient and family. Additionally, annual standardized clinic evaluations were not completed at the facility where data for this study were obtained; typically, clinic evaluations addressed problems acute in nature. Therefore, collection of information pertaining to, for example, annual extremity strength assessment could not be gathered; this made it impossible to examine the significance or impact of this variable upon ambulation.

Considerable inconsistency was noted in the assignment of lesion level per given subject. Therefore, this author collected the most commonly dictated lesion level and whenever possible, the dictated lesion level was verified by manual muscle strength grades. Researchers have noted that assignment of lesion level is often inconsistent and arbitrary. Experts usually designate lesion level according to corresponding myotome and dermatome levels. Assignment of lesion level according to dysraphism noted with radiologic evaluation may be inaccurate; Sharrard noted that in only 80% of spinal cords is there a direct correspondence between spinal neurological segments and the issuing motor rootlets. In the present study, it was noted that assignment of lesion level was most variable around the midlumbar and low lumbar areas. Several experts have found that medial hamstrings are usually stronger than the anterior tibialis and, therefore, contend that presence of medial hamstrings (rather than ankle dorsiflexion) should signify L₄ lesion level. Most recently, McDonald et al found discrepancies in the traditional neurosegmental innervation of lower extremity musculature proposed by Sharrard. For example, McDonald et al
found a closer correlation of medial hamstrings strength with quadriceps/iliopsoas strength rather than with the gluteus medius strength. Additionally, the glutei musculature was more frequently correlated with anterior tibialis rather than gastrocnemius strength. These authors suggest that children with myelodysplasia be grouped according to patterns of lower extremity muscle strength rather than by neurosegmental lesion level.
In individuals with lumbar myelodysplasia, the level of lesion, extent of bracing, wheelchair usage, and the presence of knee flexion contractures were found to be significantly associated with a decline in ambulatory skills by the time they reached adulthood. In addition, scoliosis at 12 years of age and the type of assistive device the individual uses at four to five years of age were also found to be related to the general course of ambulation from childhood to adulthood.

Myelodysplasia clinics incorporating routine standardized clinical evaluations measuring interval and ratio data would provide for the most complete means of data collection to increase the accuracy of retrospective, longitudinal studies. Moreover, as for any ailment, prevention is the best treatment; routine physical and musculoskeletal examinations may reveal early signs of potential problems in the easiest, cost efficient stage of their management.

Prospective studies using interval ratio data to analyze various factors with ambulation potential should be done to improve the accuracy of walking prognosis. Analysis of interval ratio data using parametric tests provides a
correlation of variables with the most objective prediction of future ambulatory status.

The results of such studies would be beneficial to new parents anticipating an uncertain future for their child. In addition, such studies could serve as more reliable guidelines for therapists setting goals related to functional mobility. In an era experiencing radical health care system reforms, the efficacy of health care treatment must be substantiated, further underscoring the need for such objective methods of research.
APPENDIX A
To:       Jennifer Fell  
Department of Physical Therapy  
501 North Columbia Road  
Grand Forks, North Dakota 58203

From:    Sandy Titus, PhD  
IRB Administrator

Date:    December 18, 1992

Subject: Ambulation in Lumbar Myelomeningocele: Relative Significance of factors in Predicting Ambulation Outcome

The above referenced protocol has undergone Expedited Review. It has been APPROVED. Please inform the IRB when your project is ended and plan to give Dr. Koop some form of a report. You need to give a report to us in 12 months.

Please be reminded that you are required to inform this office of any changes, additional risks, unanticipated problems, or termination of this research protocol in the interim.

We wish you success with your research.
To: Shirley Griffin  
Institutional Review Board  
c/o Office of Research and Program Development  
Room 101, Twamley Hall

From: Jennifer Fell, PT  
Department of Physical Therapy  
School of Medicine  
University of North Dakota

Date: December 16, 1992

Subject: Ambulation in Lumbar Myelomeningocele: Relative Significance of Factors in Predicting Ambulation Outcome

The above referenced project, entailing a chart review, was approved by the University of North Dakota's Institutional Review Board 10-22-92 under exempt category No. 4. I was granted permission from Medical Center Rehabilitation Hospital in Grand Forks to access a selected number of patients enrolled in their Myelodysplasia Clinic; however, there was an insufficient number of charts which met my selection criteria. I am, therefore, unable to conduct my research with the assistance of the University of North Dakota.

Currently, the protocol is undergoing the IRB process with Gillette Children's Hospital in Minneapolis, Minnesota.

If any of the above is unclear or you require further information, please contact my advisor, Erin Simmunds, at 777-2831, in my absence. Thank you.
DATE: December 18, 1992

NAME: Jennifer Fell

DEPARTMENT/COLLEGE: Physical Therapy

PROJECT TITLE: Ambulation in Lumbar Myelomeningocele: Relative Significance of Factors in Predicting Ambulation Outcome (Protocol Change)

The above referenced project was reviewed by a designated member for the University's Institutional Review Board on December 24, 1992 and the following action was taken:

☐ Project approved. EXPEDITED REVIEW NO. _______.
Next scheduled review is on _________________.

☒ Project approved. EXEMPT CATEGORY NO. 4. No periodic review scheduled unless so stated in REMARKS SECTION.

☐ Project approval deferred. (See REMARKS SECTION for further information.)

☐ Project denied. (See REMARKS SECTION for further information.)

REMARKS: Any changes in protocol or adverse occurrences in the course of the research project must be reported immediately to the IRB Chairman or ORPD.

Protocol change approved 12/24/92.

Approved.

E. Simunds, Adviser
Dean, Graduate School

Signature of Chairperson or designated IRB Member 12/24/92

UND's Institutional Review Board

If the proposed project (clinical medical) is to be part of a research activity funded by a Federal Agency, a special assurance statement or a completed 596 Form may be required. Contact ORPD to obtain the required documents. (9/87)
DATE: October 21, 1992

NAME: Jennifer Fell

DEPARTMENT/COLLEGE: Physical Therapy

PROJECT TITLE: Ambulation in Lumbar Myelomeningocele: Relative Significance of Factors in Predicting Ambulation Outcome

The above referenced project was reviewed by a designated member for the University's Institutional Review Board on 10/22/92 and the following action was taken:

☐ Project approved. EXPEDITED REVIEW NO. ______. Next scheduled review is on ________________.

☐ Project approved. EXEMPT CATEGORY NO. ______. No periodic review scheduled unless so stated in REMARKS SECTION.

☐ Project approval deferred. (See REMARKS SECTION for further information.)

☐ Project denied. (See REMARKS SECTION for further information.)

REMARKS: Any changes in protocol or adverse occurrences in the course of the research project must be reported immediately to the IRB Chairman or ORPD.

E. Simunds, Adviser

Signature of Chairperson or designated IRB Member

UND's Institutional Review Board

Date: 10/22/92

If the proposed project (clinical medical) is to be part of a research activity funded by a Federal Agency, a special assurance statement or a completed 596 Form may be required. Contact ORPD to obtain the required documents. (9/87)
Ambulation potential in children with myelomeningocele is highly variable and the prediction of functional mobility is difficult. Research suggests that it is easier to predict locomotor skills for children with a neurosegmental lesion in the thoracic (upper back) or sacral (hip region) spine.\(^1\) Prediction of ambulatory potential in children with lumbar (low back) spinal lesions, however, is less reliable.\(^1\)\(^-\)\(^5\) There are many factors clinicians consider when assessing ambulation potential. However, experts disagree on the relative prognostic value of each of the varying factors affecting ambulation potential in children with lumbar myelomeningocele.\(^1\)\(^-\)\(^5\) The purpose of this study is to identify the important factors affecting ambulation potential in lumbar myelomeningocele and determine their relative prognostic value. Because of the exclusive occurrence of myelomeningocele in humans, use of human subjects in this study is necessary.
PLEASE NOTE: Only information pertinent to your request to utilize human subjects in your project or activity should be included on this form. Where appropriate attach sections from your proposal (if seeking outside funding).

2. PROTOCOL: (Describe procedures to which humans will be subjected. Use additional pages if necessary.)

METHODS:

Methodology will entail reviewing 20-40 charts of subjects with lumbar myelomeningocele over 18 years of age currently or previously enrolled in the Myelodysplasia Clinic at Medical Center Rehabilitation Hospital and Clinics in Grand Forks, North Dakota. A data sheet will be used to record various factors (e.g., musculoskeletal, neurological) having potential to affect ambulation status in lumbar myelomeningocele. Data will be collected in a codified form to ensure confidentiality. Factors will be analyzed using multivariate statistical analysis to reflect a hierarchy for prognostic value.

* see attached Data Sheet sample (Appendix A)
3. BENEFITS: (Describe the benefits to the individual or society.)

It is hoped that by identifying a hierarchy of significant factors affecting ambulation in children with lumbar myelomeningocele, ambulatory outcome can be more accurately predicted. In turn, individual goal setting and treatment choice related to functional mobility will be enhanced.

RISKS: (Describe the risks to the subject and precautions that will be taken to minimize them. The concept of risk goes beyond physical risk and includes risks to the subject's dignity and self-respect, as well as psychological, emotional or behavioral risk. If data are collected which could prove harmful or embarrassing to the subject if associated with him or her, then describe the methods to be used to insure the confidentiality of data obtained, including plans for final disposition or destruction, debriefing procedures, etc.)

With a chart review process, there is a risk of an accidental breach of confidentiality. In this study, all data will be collected in a codified form to insure confidentiality of each subject using the subjects medical record number for identification.
5. CONSENT FORM: A copy of the CONSENT FORM to be signed by the subject (if applicable) and/or any statement to be read to the subject should be attached to this form. If no CONSENT FORM is to be used, document the procedures to be used to assure that infringement upon the subject's rights will not occur.

Describe where signed consent forms will be kept and for what period of time.

No consent form will be used. Each subject will be identified by his/her medical record number. Names of participating subjects will not be disclosed.

---

For FULL IRB REVIEW forward a signed original and twelve (12) copies of this completed form, and where applicable, twelve (12) copies of the proposed consent form, questionnaires, etc. and any supporting documentation to:

Office of Research & Program Development
University of North Dakota
Box 8138, University Station
Grand Forks, North Dakota 58202

On campus, mail to: Office of Research & Program Development, Box 134, or drop it off at Room 101 Twamley Hall.

For EXEMPT or EXPEDITED REVIEW forward a signed original and a copy of the consent form, questionnaires, etc. and any supporting documentation to one of the addresses above.

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The policies and procedures on Use of Human Subjects of the University of North Dakota apply to all activities involving use of Human Subjects performed by personnel conducting such activities under the auspices of the University. No activities are to be initiated without prior review and approval as prescribed by the University's policies and procedures governing the use of human subjects.

SIGNATURES:

Jennifer Isell
Principal Investigator
DATE: 10-14-92

Eric Simmonds
Project Director or Student Adviser
DATE: 10-14-92

Sining or Center Grant Director
DATE: ____________________

(Revised 7/1990)
REFERENCES


APPENDIX B
### DATA SHEET

<table>
<thead>
<tr>
<th>Case #</th>
<th>Date</th>
</tr>
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<tbody>
<tr>
<td>Sex:</td>
<td></td>
</tr>
<tr>
<td>DOB:</td>
<td></td>
</tr>
<tr>
<td>Chronological Age:</td>
<td></td>
</tr>
<tr>
<td>Neurosegmental Lesion Level:</td>
<td></td>
</tr>
</tbody>
</table>

#### A. AMBULATION

1. **ambulatory status:**
   - (1) community
   - (2) household
   - (3) non-functional
   - (4) non-ambulator

2. **bracing:**
   - (1) none
   - (2) AFOs
   - (3) KAFOs
   - (4) HKAFOs
   - (5) RGOs
   - (6) Parapodium/CSO
   - (7) Other

<table>
<thead>
<tr>
<th>4-5 years</th>
<th>12 years</th>
<th>Most Current Eval. (&gt;18 yo)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
3. assistive device:
   (1) none
   (2) crutches
   (3) walker

4. wheelchair (Y/N)
   Comments:

B. MUSCULOSKELETAL

1. hip status (indicate U/B):
   (1) located
   (2) subluxed
   (3) dislocated
   Comments:

2. scoliosis
   (1) none
   (2) mild (<20)
   (3) moderate (20-40)
   (4) severe (>40)
   Comments:

3. contracture (indicate R/L):
   hip flexion
   (1) none
   (2) mild (<15)
   (3) moderate (15-25)
   (4) severe (>25)
   Comments:

   knee flexion
   (1) none
   (2) mild (<15)
C. NEUROLOGICAL

1. hydrocephalus
   (1) none
   (2) arrested
   (3) shunted
   (4) malfunc. shunt

2. symptomatic Arnold-Chiari
   decompressed (Y/N)

3. tethered cord
   detethered (Y/N)

4. symptomatic syringohydromyelia
   shunted (Y/N)

Comments:

D. GROSS MOTOR SKILL ACQUISITION

1. sitting at 1.5 years of age (Y/N)
2. ambulates out-of-doors at 4.0 years (Y/N)
E. OTHER

1. obesity (>95th %ile weight for height)
   age 12: (Y/N)
   most current evaluation (>18 yo) (Y/N)
REFERENCES


