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Relationship Between Motor Level and Wheelchair Transfer Ability in Spina Bifida: A Study From the National Spina Bifida Patient Registry

Gina McKernan, PhD[a,b], **Sara Izzo**[a], **Theresa M. Crytzer, DPT, ATP**[b,c], **Amy J. Houtrow, MD, PhD**[a], **Brad E. Dicianno, MD, MS**[a,b,c]

[a]Department of Physical Medicine and Rehabilitation, University of Pittsburgh School of Medicine, Pittsburgh, Pennsylvania;

[b]Veterans Affairs Pittsburgh Healthcare System, Human Engineering Research Laboratories, Pittsburgh, Pennsylvania;

[c]Department of Rehabilitation Science and Technology, School of Health and Rehabilitation Sciences, University of Pittsburgh, Pennsylvania.

Abstract

Objective: To identify the specific features that contribute to the variability in baseline wheelchair transfer and the changes in transfer ability (gain or loss) over time for a large cohort of patients with spina bifida (SB) in the National Spina Bifida Patient Registry.

Design: Longitudinal cohort study.

Setting: A total of 35 United States outpatient SB clinic sites.

Participants: Individuals (N=1687) with SB ages 5–73 (median, 13.33) years who were therapeutic ambulators or nonambulators.

Intervention: Not applicable.

Main Outcome Measure: Ability to transfer from a wheelchair to another level surface.

Results: Bayesian Network Analysis was used to reduce the initial variable set to the following predictors: SB subphenotype, motor level, age, insurance, sex, race, ethnicity, surgical procedures, and number of visits. We used a multinomial logistic model with Wald Chi-square analysis of effects to examine the relationships between transfer ability and predictors. A total of 295 of 1687 eligible patients (17.56%) with myelomeningocele (MMC) and 6 of 58 eligible patients (10.32%) with non-MMC experienced changes in transfer ability during the period of the study. For those with MMC and non-MMC, the highest number of individuals exhibiting changes in motor level had changes from thoracic to high-lumbar, high-lumbar to thoracic, high-lumbar to midlumbar, and midlumbar to high-lumbar lesion levels. Results of the Bayesian Network Analysis revealed that motor level was the predominant factor associated with baseline transfer ability followed by age. The combination of SB sub phenotype, motor level, age, insurance status, number and type

Corresponding author: Brad E. Dicianno, MD, MS, 6425 Penn Ave, Suite 400, Pittsburgh, PA 15206. dicianno@pitt.edu.

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of surgical procedures, and time point accurately classified the loss, gain, or no change in transfer ability 82.7% of the time.

Conclusions: Motor level was the predominant factor associated with baseline transfer ability, and the change in transfer ability was directly related to a corresponding change in motor level that might be explained by changes in muscle strength of the iliopsoas and quadriceps.

Keywords

Machine learning; Myelomeningocele; Registries; Rehabilitation; Spinal dysraphism; Walking; Wheelchairs

Spina bifida (SB) is the most common neural tube defect that is compatible with life and results in permanent disability with a prevalence of approximately 166,000 patients in the United States.[1] Myelomeningocele (MMC) is the most severe and the most common subphenotype of SB involving failed vertebral closure and exposed meninges, leading to dysplasia of the nerve roots and sensory and motor loss at and below the level of lesion.[2,3] Patients with MMC also have ventriculomegaly, hydrocephalus, and Chiari II malformation that often require surgery (ie, shunting, and posterior fossa decompression, respectively).[4–6] Those with MMC and other non-MMC subphenotypes may have other neurologic (eg, tethered cord, syringomyelia) and orthopedic conditions (eg, club foot, tibial torsion) requiring multiple operations, bracing, or assistive technology to correct, maintain, adapt to, or prevent mobility declination over the life span.[7] The resultant range of functional abilities in SB is a wide spectrum, from having normal lower limb motor function to complete paraplegia.[8–10]

People with MMC identify mobility, including the ability to transfer and ambulate, as essential to independence, employment, and quality of life.[11–15] Based on Hoffer classification,[16] the National Spina Bifida Patient Registry (NSBPR) reported that 28% (1895 patients, total registry N=6823) of those with SB age 5 years and older are nonambulatory, 5% (339) ambulate therapeutically (ie, with a therapist at school or in a hospital), 8% (544) ambulate within the home environment and 57% (3883) are community ambulators. Prior research has shown that ambulation ability is related to age, motor or lesion level, shunt status (or history of hydrocephalus), hip and knee contractures, and spasticity.[12–14,17–19] Up to 60% of patients with SB use wheelchairs, depending on severity of their condition.[14,20]

Three studies on wheelchair transfers in small populations of individuals with SB indicate that motor level (spinal level of lesion designated by muscle strength),[21] history of hydrocephalus, recent surgery,[22] transfer style, and assistance available[23] can predict independence with transfer ability. Kirby et al reported that having a diagnosis of SB and transferring sideways without a transfer board are associated with an increased risk of wheelchair-related accidents and injuries.[21] Verhoef et al showed that young adults with SB without hydrocephalus or lesions below L2 were generally independent with transfers, while 38% of those with hydrocephalus and a lesion at L2 or above required assistance with transfers.[22] Schoenmakers et al showed a temporary decrease in transfer ability of 10 children with SB within the first 6 months after spinal fusion surgery likely because of the

need to wear a hip spica cast for 3 months and a body jacket for an additional 3 months.[23] However, the literature on transfer ability in SB is otherwise sparse.

Understanding which factors contribute to transfer ability over time may help guide rehabilitation interventions. For example, if transfer ability decreases over time because of changes in motor level from deconditioning, rehabilitation interventions to strengthen muscle groups involved in transfer ability could potentially improve transfers. The goal of this project, therefore, was to understand the predictors of wheelchair transfer ability of patients in the NSBPR[24] and to identify which factors are associated with the loss or gain of transfer ability. We hypothesized that a combination of SB subphenotype, motor level, age, number and type of past surgical procedures, and number of annual visits would accurately classify transfer ability of at least 80% of the cases, where the predicted transfer ability is the same as the observed transfer ability. In addition, we hypothesized that changes in patients' motor level over time would be associated with changes in transfer ability.

Methods

This study was a retrospective analysis using longitudinal data from the NSBPR database.[24] The data set included 26,715 records representing 6823 unique patients from visits at 35 United States clinic sites occurring during the study period (between 2009 and 2017). All data were collected under each participating institution's approved institutional review board protocol, and informed consent, childhood assent, or proxy consent as appropriate was signed for all patients. Data collection occurred at initial enrollment and at subsequent visits, with the goal of obtaining annual participant follow-up. A prior publication and data codebook describe methods of data collection in detail[24,25]; the process involves standardized data collection forms and procedures, as well as data quality control processes.

Input variables

The variables from the NSBPR data set and their definitions used in the present analysis were

- Sociodemographic factors (age, sex, race, ethnicity)
- SB subphenotype (MMC, meningocele, fatty filum with tethered cord, lipomyelomeningocele, split cord malformation, or terminal myelocystocele)
- Number of orthopedic surgical procedures
- Number of neurosurgical procedures: any surgical interventions involving cerebral shunts were classified as shunt neurosurgical procedures. All neurosurgical procedures not involving cerebral shunts were categorized as nonshunt neurosurgical procedures.
- Functional motor level: functional motor level is reported in the NSBPR for both left and right as thoracic (flaccid lower extremities), high-lumbar (hip flexion present), midlumbar (knee extension present), low-lumbar (foot dorsiflexion present), or sacral (foot plantar flexion present). If left and right motor levels differed, the more severe (high motor level) side was used.

- Insurance status: insurance status was defined as private (any commercial health maintenance organization, preferred provider organization, and TRICARE military coverage), public only (Medicaid or Medicare and associated state programs), and "other," which included those who do not fall into the private or public categories with supplementary insurance, as well as the uninsured.

Outcome variable

The ability to transfer from a wheelchair to another level surface was classified as (1) able to transfer without assistance, (2) able to transfer with some assistance, or (3) not able to transfer unless fully assisted.

Patients were included based on the following characteristics:

Inclusion criteria

1. Primary diagnosis of SB with a subphenotype of MMC, meningocele, fatty filum with tethered cord, lipomyelomeningocele, split cord malformation, or terminal myelocystocele (these are the only subphenotypes eligible for the registry).
2. Therapeutic ambulator or nonambulator based on the Hoffer scale.[16]

Exclusion criterion—Children younger than 5 years were excluded because manual muscle testing is relatively unreliable until age 5.[23]

Data reduction

Patients were divided into 2 groups: MMC and non-MMC (meningocele, fatty filum with tethered cord, lipomyelomeningocele, split cord malformation, or terminal myelocystocele). Because transfer ability is collected only for those who use a wheelchair for all activities (ie, nonambulators, N=1493) or those can walk for therapeutic reasons but only if assisted by another person (ie, therapeutic ambulators, N=252), the sample size for this analysis was established at 1745 patients ages 5 years and older (25.6% of the original sample, N= 1745 patients). Motor levels were assigned numeric values: thoracic (5), high-lumbar (4), midlumbar (3), low-lumbar (2), and sacral (1). Accordingly, shifts in motor level over time ranged from −4 to 4, with negative numbers representing an increase in motor function (moving down the spine from thoracic to sacral) and positive numbers representing a decrease in motor function (moving up the spine from sacral to thoracic). Each value of motor level change corresponded to the number of levels of change in motor level compared with the previous visit. For example, if the participant had a motor level of high lumbar during the baseline visit and had a thoracic level at the second visit, the change in motor level was +1.

Statistical analyses

All analyses were performed using SAS version 9.4[a] (data editing, descriptive statistics, general linear model); IBM SPSS Modeler 18.1[b] (Bayesian Network), and SPSS Statistics 26[b] (data visualizations). Descriptive analyses were provided using frequency statistics for nominal variables and measures of central tendency for scale variables. Bayesian Network

analysis was used to examine the classification accuracy of the following predictors on transfer ability: SB subphenotype, motor level, age, insurance status, sex, race, ethnicity, number and type of surgical procedures, and time since initial assessment (y). Patients with 2 visits or more were included in subsequent modeling on changes in motor level and transfers. A Bayesian Network provides a graphical probabilistic framework for modeling complex data in which the model structure represents a set of random variables as nodes and the relationships between them as arrows, pointing from a parent node to a child node. If 2 unconnected parents share the same child, then they become conditionally dependent when information about the child node becomes available, whereas the absence of an arrow represents independent random variables.[26] The underlying probabilistic model accounts for variability by determining probabilities of the outcome (change in transfer ability). Individual predictors were assessed for their contribution of variance reduction in the model. In addition, we used a multinomial logistic model with Wald Chi-square analysis of effects to examine the relationships between transfer (loss/gain/no change) and the input variables: age, operations, time point, and motor level changes. All transfer changes for participants with multiple time points were considered because change in transfer is an unconditional, populated-averaged value. We used data visualizations, such as scatter plots, to examine the relationship between baseline right and left motor level and changes in transfer ability.

Finally, we reported the changes in motor level using proportions. Analyses were performed on the MMC and non-MMC populations separately.

Results

Demographics and baseline characteristics

Figure 1 shows the results of participant selection criteria. A total of 1745 patients and 19,677 annual visits were included (median, 4 visits; range, 1–10 visits). Visits occurred approximately annually, as intended (average 1.3±0.6y). The most common motor level at baseline was thoracic, N=818 (48.5%) in the MMC population and N=22 (38.5%) in the non-MMC population. Nearly equal percentages of MMC had high-lumbar (24.2%) and midlumbar functional levels (23.6%) at baseline, while there was a greater proportion of high-lumbar (35.9%) and midlumbar levels (17.9%) at baseline in the non-MMC population (fig 2). Baseline transfer ability was consistent between populations, with 62.4% (MMC) and 65.5% (non-MMC) of patients exhibiting the ability to transfer without assistance, while 27.5% (MMC) and. 27.6% (non-MMC) were not able to transfer unless fully assisted. Only a small proportion had the ability to transfer with some assistance. In addition, the MMC and non-MMC groups were similar in terms of their demographics, with non-MMC representing slightly older patients (median age, 13.7y) compared with MMC (median age, 11.8y) as demonstrated in table 1.

Change in motor level

A total of 295 of 1687 patients (17.5%) with MMC and 6 of 58 patients (10.2%) with non-MMC experienced changes in motor level during the period of the study. The highest proportion of changes occurred in the following: thoracic to high-lumbar, high-lumbar to thoracic, high-lumbar to midlumbar, and midlumbar to high-lumbar level for both groups.

Figures 3 and 4 show the number and frequencies (percentages) of patients in the MMC and non-MMC sample populations who exhibited changes to and from all motor levels.

Left and right motor level

While we identified a linear, positive relationship between baseline right and left side motor levels, the changes in the 2 were not necessarily equivalent. There was slight variability between baseline motor level, with 81 patients (4.8%) with MMC and 5 patients (7.8%) with non-MMC displaying asymmetry in motor levels.

Change in transfer ability

Because of the small proportion of the sample that could transfer with some assistance, we were not able to statistically model this group. Modeling was therefore limited to those who could transfer independently vs those who were not able to transfer unless fully assisted. In the MMC population, 82.4% of patients had no change in transfer ability over time compared with 89.7% in the non-MMC population. Specifically, 8.2% of those with MMC and 5.1% of those with non-MMC experienced a loss in the ability to transfer, while 9.4% of those with MMC and 5.1% of those with non-MMC had a gain in transfer ability over the course of the study. A multinomial logistic model with Wald Chi-square analysis of effects revealed that the change in transfer ability was associated with a corresponding change in motor level in the MMC population. Specifically, changes to a higher motor level (indicating a reduction in motor ability) were associated with a decreased odds for the ability to transfer, Wald χ^2=6.3 (P=.012).

Alternatively, changes to a lower motor level (indicating an increase in motor ability) were associated with an increased odds for ability to transfer Wald χ^2=7.3 (P=.007).

When there was no change in motor function over time, there also was no change in transfer ability. Correspondingly, similar findings were also noted in the non-MMC population, but the number of patients experiencing changes in transfer ability was smaller.

Results of the Bayesian Network analysis revealed that motor level was the predominant predictor of baseline transfer ability (predictor importance=0.88), followed by age (predictor importance=0.04). Predictor importance indicates the relative importance of each predictor in estimating the model. Because the values are relative, the sum of the values for all predictors is 1.0. The combination of SB subphenotype, motor level, age, insurance status, number and type of surgical procedures, and time point accurately classified the loss/gain/or no change in transfer ability 82.7% of the time (fig 5).

Examining the predictive probabilities related to the change in transfer over time, a 1–2 level change in motor level (decrease) was associated with an increased odds of transfer gain in the MMC population. For example, for each 1 level decrease in motor level (eg, moving from thoracic to high-lumbar level), the log-odds of independent transfer increased by 3.9. Similarly, a 2-level decrease in motor level resulted in a 3.2-times increase in the odds of gaining transfer ability. Although baseline motor level was the predominant predictor of transfer ability at baseline, it was not a significant predictor of change in transfer ability.

In addition, we examined the effects of age on the change in transfer ability (gain/loss of transfer ability) in the MMC population. Age had a positive, predictive relationship with transfer ability. For every 1-unit (y) increase in age, the log-odds of independent transfer increase by 0.023. Figure 6 shows the curvilinear, positive relationship between the likelihood of transfer and age. Specifically, the likelihood of transfer ability increases with age for the patients in the NSBPR. While surgery (count and type) and insurance status were included in the complete Bayesian model designed to explain variation in transfer ability, neither surgery nor insurance status were predictive of change in transfer ability alone. The modes for total number of surgical procedures (mode=3), number of neurosurgical procedures (mode=1), number of orthopedic surgical procedures (mode=0), and number of shunt surgical procedures (mode=2) remained consistent across those who experienced a gain, loss, or no change in transfer ability.

Discussion

This study contributes to the literature by identifying factors associated with transfer ability in the largest cohort of patients with SB in the United States. The first important finding was that those with higher functional (motor) levels (more lower body weakness) at baseline were less likely to be able to transfer independently at baseline. We were able to classify transfer ability over 80% of the time when including motor level, SB subphenotype, age, insurance status, number and type of surgical procedures, and number of visits in the model. These findings support the work of smaller cross-sectional studies that demonstrated motor level, history of hydrocephalus, and recent surgery are independent predictors of transfer ability[22,23] and also reveal new variables associated with transfer ability (SB subphenotype, age, insurance status, and number of visits) that were not previously reported.

The second important finding was that baseline motor level was associated with baseline transfer ability but not with the loss or gain of transfer ability over time. Transfer ability changed (as represented by a loss or gain in transfer ability) over time in only in a small subset of patients, and when it did, this change was associated with a change in motor level, regardless of the baseline motor level. Loss of transfer ability was related to loss of strength (motor level that moved higher) and gain of transfer ability was related to gain in strength (motor level that moved lower). Of those whose motor level changed, the most common reasons for that change were loss or gain of strength in hip flexion (iliopsoas muscle), as indicated by a change between high-lumbar and thoracic groups (33% of patients), and knee extension (quadriceps muscle), as indicated by a change from high-lumbar to midlumbar groups (35% of patients). Strength of these muscle groups is known to be a significant predictor of ambulatory ability in children with MMC[27] and is essential in various phases of sit-to-stand and stand-to-sit transfers.[28] The gain in motor ability (and subsequent improvement in transfer ability) in some patients may suggest that the iliopsoas and quadriceps muscle groups could be potential targets for rehabilitation interventions when they are still innervated but weak from effects such as deconditioning. Some muscle groups below the anatomic level of the spinal lesion may still be innervated because the level of a MMC lesion does not always perfectly correlate with motor level.[29] Conversely, permanent weakness may occur from the accumulation of neurologic or orthopedic conditions that then impede transfer ability. More research is needed to understand the patterns of weakness

that develop over time and the effects of rehabilitation interventions on motor level and functional outcomes.

A third finding was the identification of a curvilinear, positive relationship between the likelihood of independent transfer ability and age, indicating that as age increases, the likelihood of independent transfer also increases. This finding is likely because of a survival bias in older adults, many of whom were born before the availability of cerebral shunts. Those who survived to older ages may have less severe neurologic sequelae and therefore may have a higher level of function. As our present cohort ages, we expect that individuals who cannot transfer without assistance to become more prevalent in older age groups.

Taken together, these findings are clinically important. They support findings from smaller, cross-sectional studies that demonstrate that motor level has the strongest association with transfer ability at baseline. New findings from this study demonstrate that changes in motor level have the strongest association with changes in transfer ability over time and that other variables are important contributors to the model Additionally, this study adds to the literature by pointing to the possibility for future rehabilitation interventions to strengthen muscle groups that are innervated but have become deconditioned as a way to preserve or improve transfer ability.

Study limitations

Several limitations deserve discussion. First, the patients in the NSBPR attend multidisciplinary clinics primarily located at academic centers and may not be representative of the SB population as a whole. Those who are eligible to enroll but do not enroll in the NSBPR tend to be younger, be non-Hispanic, and have non-MMC subtypes. Motor level tends to be represented similarly in enrollees compared with nonenrollees. Little is known about those who receive care in nonacademic centers; one survey study revealed 53% of adults received care in states without SB clinics that do not participate in NSBPR. The majority of the respondents were white and female.[30] Second, the inter- and intrarater reliability of the motor level and transfer variables within the NSBPR is unknown. Reliability may account for some within-person variation in and correlation between these variables. However, the Centers for Disease Control and Prevention has clear guidelines for how variables are collected and defined and has implemented quality control processes to mitigate data collection bias. Third, limited longitudinal data for individual patients may have underestimated the number of patients with change in transfer ability. Fourth, the NSBPR does not collect additional variables that could potentially affect transfer ability, such as whether the person had physical therapy or variations in neuropsychological profiles. Future research should include such additional measures. Fifth, the association of number and type of surgical procedures with baseline transfer ability does not imply causation. The goal of surgery is often to improve or preserve long term mobility. While some operations may have a negative effect on transfer ability, loss of transfer ability may in some cases be a temporary effect of surgery or related to use of a postsurgical brace. The temporal relationship between transfer ability and operations needs to be further investigated.

Conclusions

Motor level was the predominant predictor of baseline transfer ability, and the majority of patients with MMC and non-MMC experienced no changes in transfer ability over time. However, in a subset of patients with MMC, a change in transfer ability was directly related to a corresponding change in motor level. Changes in muscle strength in the iliopsoas and quadriceps muscle groups were most commonly observed in those whose transfer ability changed.

Suppliers

a. SAS version 9.4; SAS Institute.

b. IBM.

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List of abbreviations:

MMC	myelomeningocele
NSBPR	National Spina Bifida Patient Registry
SB	spina bifida

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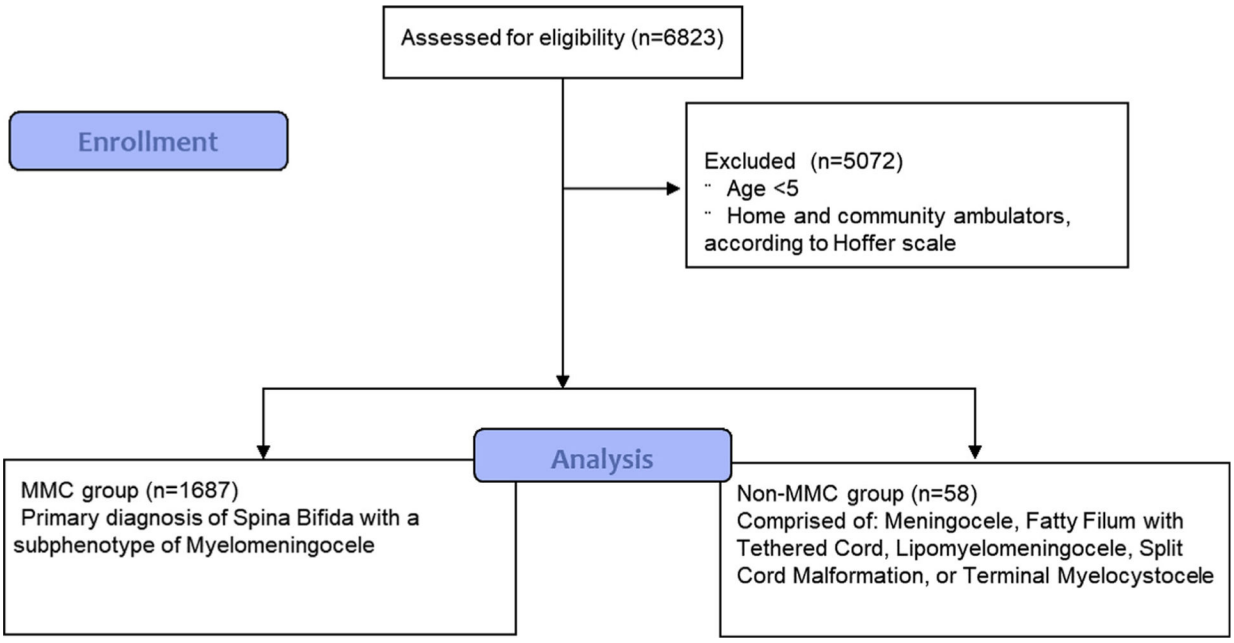

Fig 1.

Participant selection CONSORT diagram. Abbreviation: CONSORT, Consolidated Standards of Reporting Trials.

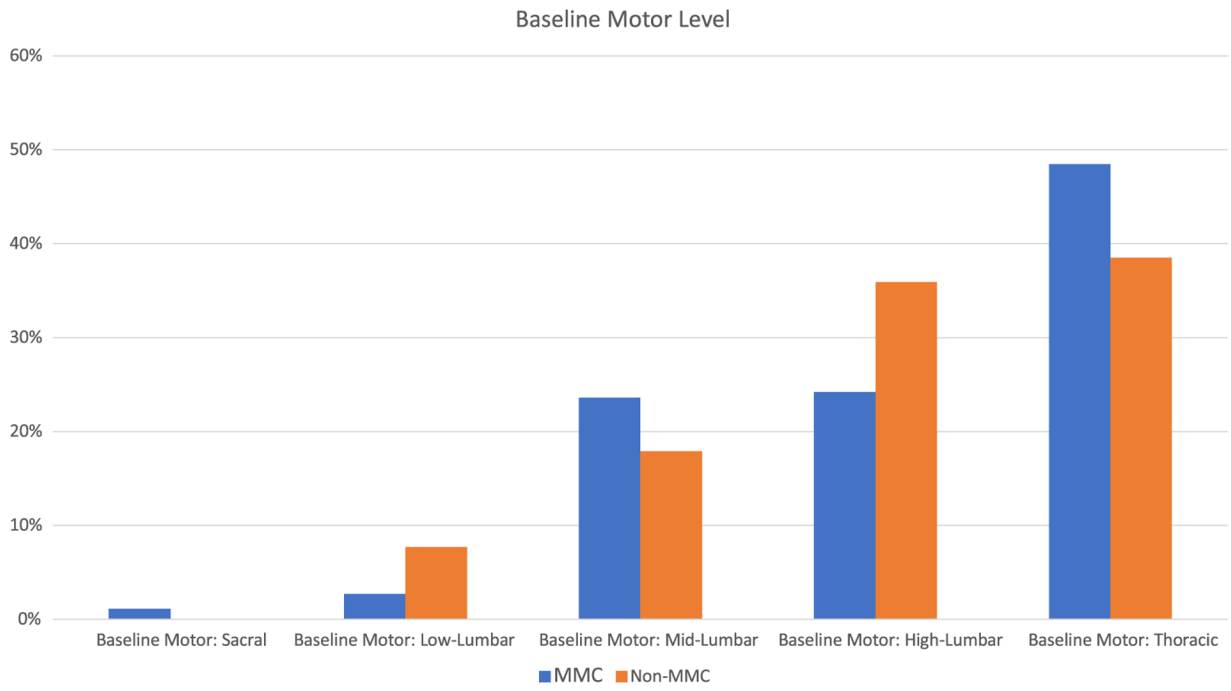

Fig 2.
Baseline motor level.

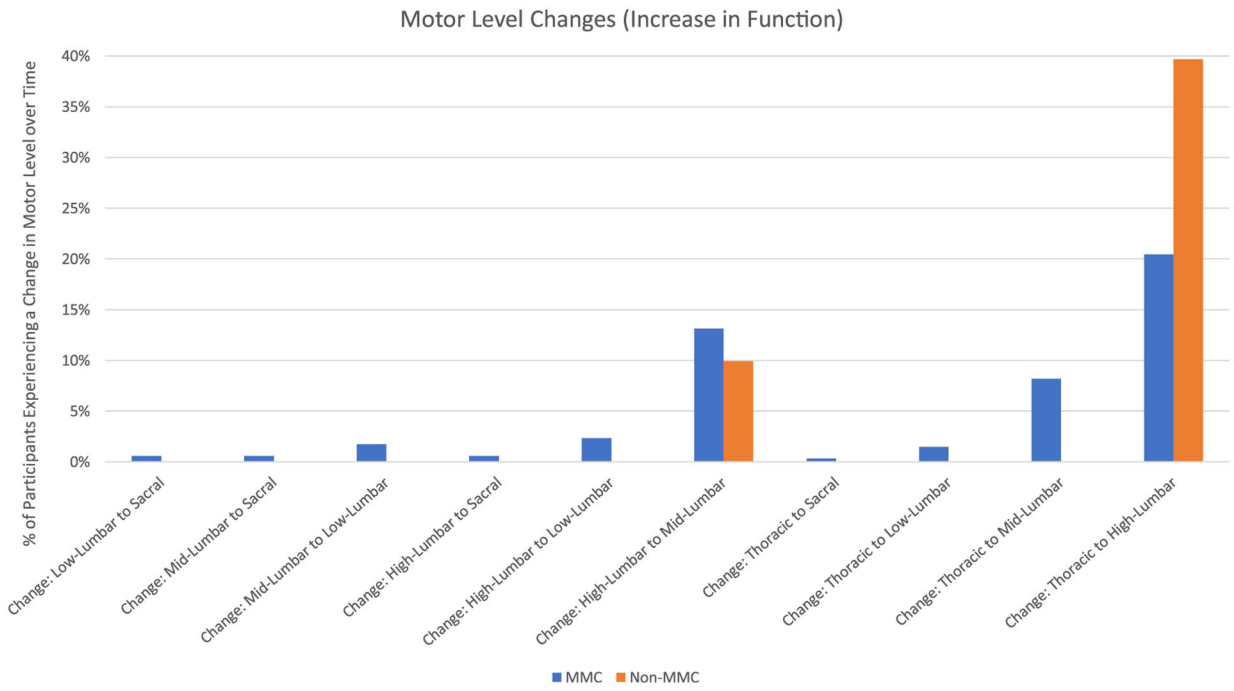

Fig 3.
Change in motor level (increase in function).

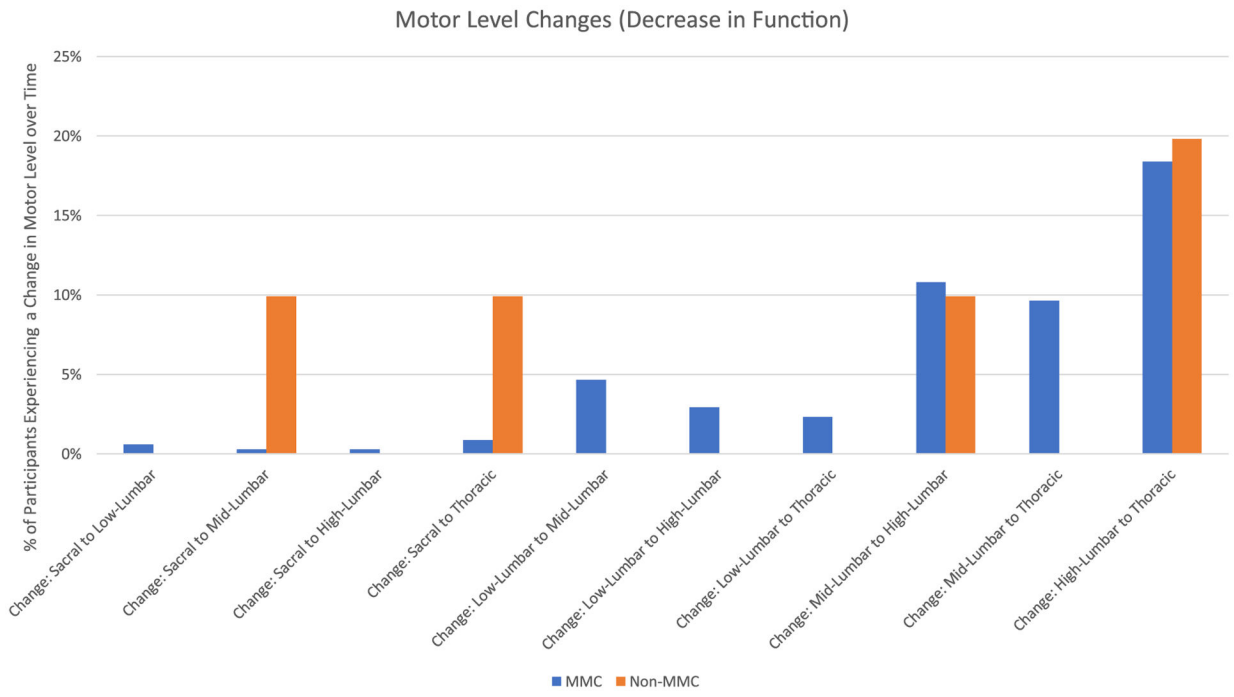

Fig 4.
Change in motor level (decrease in function).

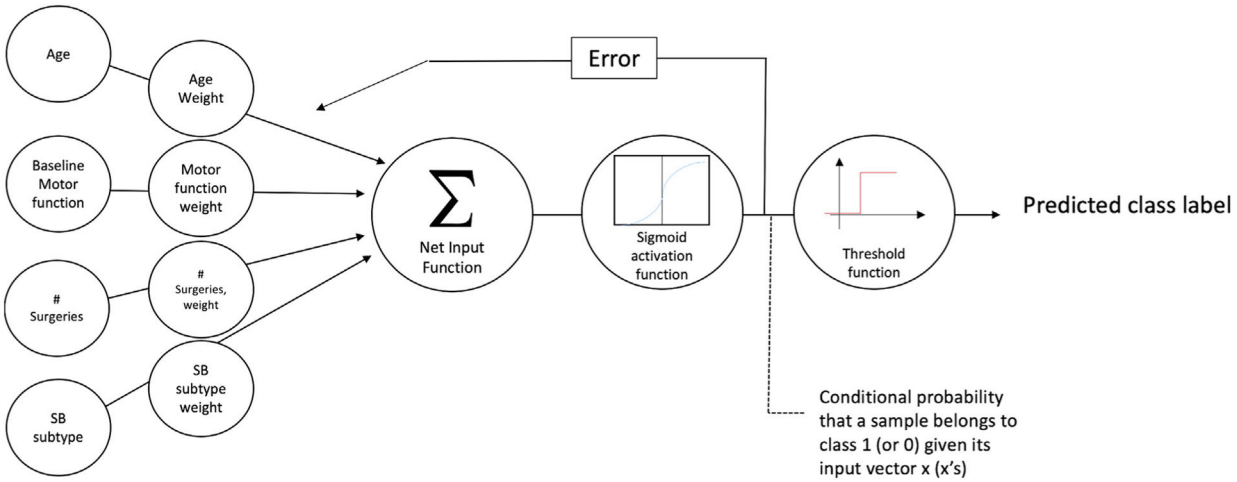

Fig 5.

Prediction of transfer ability by subphenotype, baseline motor level, age, surgical procedures, and number of visits.

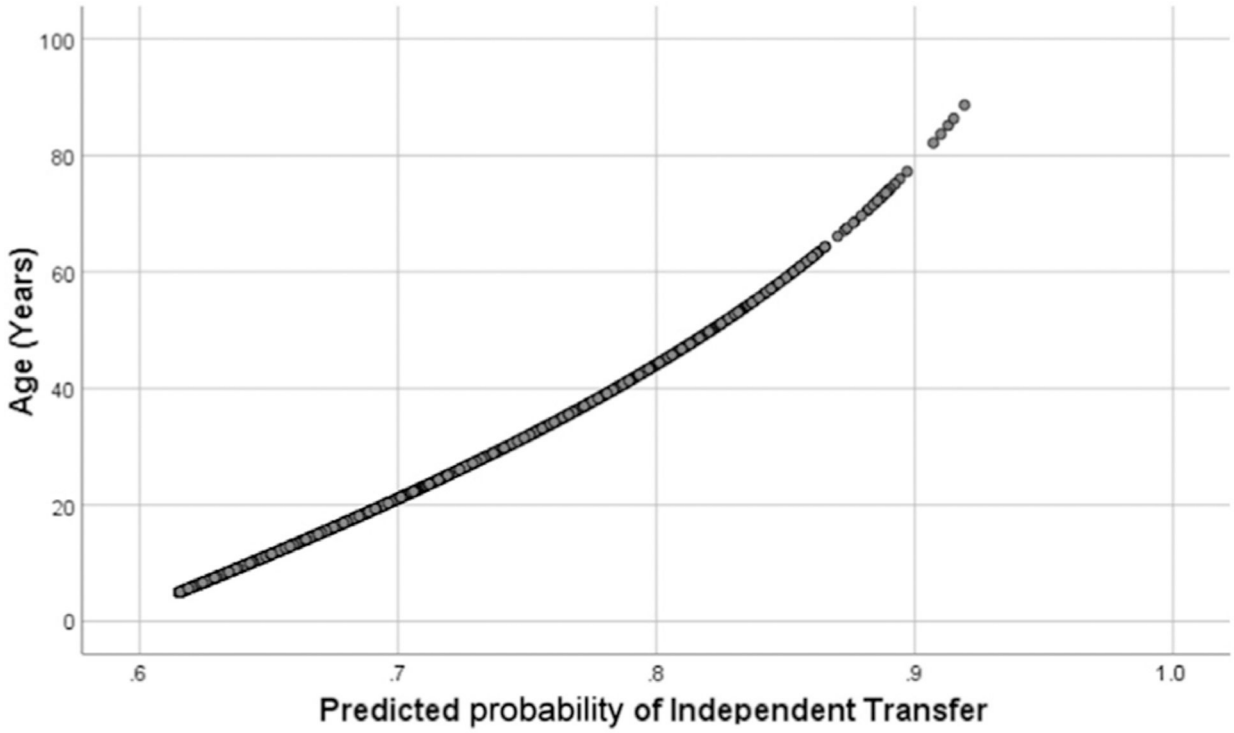

Fig 6.
Relationship between age and probability of transfer.

Table 1

Demographics

SB Subphenotype	Age (y), Median (IQR)	% Female	% Hispanic or Latino	% White	% Black	% Asian	% American Indian	% Native Hawaiian
MMC (n = 1687)	11.8 (8.5)	51.5	17.4	85.3	7.5	2	1.2	0.2
Non-MMC (n = 58)	13.7 (10.3)	51.3	15.4	87.2	0	5.1	2.6	0

Abbreviations: IQR, interquartile range; SB, spina bifida.