

## **Physical Impact of Chiari Malformation Type 1 on Adults – A Cross-Sectional Study**

### ***Progress Report Submitted to ASAP***

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### **Purpose**

This study has two primary objectives:

1. Characterize and quantify the physical impact of CMI adults through an on-line survey comprised of validated physical function scales
2. Determine the association between cranio-cervical anatomy (pre-surgical) and current levels of physical function and disability

### **Survey**

A Qualtrics survey was constructed comprised of the following question categories and validated scales:

- Demographics
- CM surgical history, orthopedic surgical history, physical therapy history
- Current exercise habits
- Neck Disability Index (NDI) – Widely used scale assesses limitations in performing tasks such as driving, work, reading, etc. due to neck pain
- Short-form McGill Pain Questionnaire 2 (SF-MPQ-2) – Widely used, multi-dimensional, self-report, pain scale
- Quick Disabilities of Arm, Shoulder, and Hand (QDASH) – Assesses physical function and symptoms of people with musculoskeletal disorders of the upper body
- Quebec Back Pain Disability Scale (QBPDSS) – Measures the level of functional disability for people with back pain
- Lower Extremity Functional Scale (LEFS) – Assesses functioning of the lower limbs in performing everyday tasks
- Activities Balance Confidence – 6 (ABC6) – Assesses self-perceived balance issues by asking respondents to rate their percent confidence in performing six different tasks that require balance
- Tampa Kinesiophobia Scale (TKS) – Kinesiophobia is the fear of engaging in movement or activity from the belief that it will cause pain or injury; the TKS is widely used to assess kinesiophobia with an established clinical cut-off score
- Pain Catastrophizing Scale (PCS) – Pain catastrophizing is a cognitive-emotional response to pain characterized by negative thoughts, feelings, and beliefs that exaggerate the severity and impact of pain; the PCS has an established cut-off score
- Pittsburgh Sleep Quality Index (PSQI) – Assesses sleep quality over the previous month

- EuroQoL 5 Level (EQ-5L) – Globally used quality of life measure which results in a morbidity index standardized by country; it can be used to compare overall morbidity between conditions or to calculate Years Living Disabled
- Cleveland Clinic Headache Survey – Comprehensive headache questionnaire used clinically by the Cleveland Clinic
- Request to share diagnostic MRI

After IRB approval, the survey was posted on 11/29/23 and participants were recruited through Conquer Chiari and ASAP's website, social media and contact lists. Inclusion criteria included age >18 years at time of survey response, physician diagnosis of CMI (self-reported) and consent. Note that the survey asked for the name of the diagnosing physician to minimize selection bias.

### **Data Collection**

By 10/6/24 200 qualified respondents had completed the entire survey. A comparison of this data to an interim analysis of the first 130 responses indicated that the survey had reached saturation and further responses were unlikely to provide additional, meaningful insights. Therefore the survey was subsequently closed.

Currently, 32 MRIs have been received, but we anticipate being able to acquire at least an additional 50 for analysis which should be sufficient to identify any meaningful associations between anatomy and physical impact.

### **Study Population**

Table 1 shows the characteristics of the respondents. The average age was 47 years, 92% were female, and 87% were white. Fifty-six percent had a history of decompression surgery, while 86% currently experience headaches at least weekly.

### **Data Analysis to Date**

All scales have been scored except for the EQ-5L, the PSQI, and the headaches questionnaire. Note the Cleveland Clinic Headache questionnaire does not generate a single score and will be analyzed separately. Descriptive statistics have been calculated based on the scale scores. Table 2 shows the mean and standard deviation for each scale along with an interpretation of the mean if available. Table 3 shows the categorical frequency (as defined by the literature) of the scale responses and Table 4 shows the response frequency above the accepted clinical cut-off for falling risk, kinesiophobia, pain catastrophizing.

Key findings include:

- 78.5% have moderate to complete neck related disability
- 61% have a low level of physical function due to lack of balance confidence
- 72.5% are at risk for falling as defined by the ABC-6
- 89% are above the clinical cut-off score for kinesiophobia

- 54% are above the clinical cut-off score for pain catastrophizing on the PCS

In addition, respondents with and without kinesiophobia have been compared using t-tests for the continuous variables and chi-square tests for categorical variables (Table 5). Respondents with kinesiophobia scored significantly worse on every other function scale, even correcting for multiple observations. However, there was not a significant difference between the groups in terms age, gender, or Chiari surgery. Interestingly, only 38% of the kinesiophobia group reported exercising on a regular basis compared to 73% of the no kinesiophobia group.

Multivariable linear regression is ongoing, but initial results indicate that pain catastrophizing is the strongest independent predictor of kinesiophobia among CMI patients. This indicates that the precise nature of an individual's disability (neck, balance, legs, etc.) may be less important than how they react to it psychologically. If this finding is confirmed, it also suggests that a combined physical and psychological intervention may achieve the best results.

### Next Steps

There is a wealth of data to continue to analyze. The current plan is to focus this effort to start on kinesiophobia, balance confidence, sleep quality, overall morbidity (EQ-5L), and headaches. Each focus area will be analyzed using comparison of means tests, regression, and if warranted an exploration of mediation and moderation using Hayes Process model. In addition, once a sufficient number of MRIs have been obtained they will be measured morphometrically and the results analyzed for significant associations with the functional scale scores. We anticipate at least 6 separate journal papers will be produced from this data. Finally, these results will form the theoretical foundation for clinical trials to assess various interventions designed to mitigate the physical impact of Chiari.

### Tables

**Table 1: Demographic, Medical History, and Exercise Status of 200 Adult CMI Respondents**

Characteristic	Mean (SD) or N (%)
Age (years)	47.0 (12.5)
Gender (F)	184 (92.0)
Race (W)	173 (86.5)
Race (B)	9 (4.5)
Ethnicity (Hispanic)	12 (6.0)
CM Surgery (Y)	111 (55.5)
Orthopedic Surgery (Y)	74 (37.0)
Physical Therapy (Y)	166 (83.0)
Exercise Regularly (Y)	78 (39.0)
Current Headaches (Y)	172 (86.0)

**Table 2: Physical Function Scale Means and Standard Deviations (N=200)**

Scale	Mean (SD)	Notes
NDI	43.9 (17.6)	Mean is at moderate disability level
SF-MPQ-2	3.7 (2.1)	Comparable to other chronic pain conditions
QDASH	37 (21.4)	Mean is at mild/moderate disability level
QBPDS	35.9 (23.0)	N/A
LEFS	45.3 (21.4)	Mean is at mild limitation level
ABC6	44 (27.4)	Mean is at low level of physical function
TKS	44.95 (6.4)	Mean is above clinical cut-off for kinesiophobia
PCS	35.7 (19.5)	Mean is above clinical cut-off for pain catastrophizing

**Table 3: Categorical Frequency for Responses to Neck Disability, Upper Body Disability, Balance Confidence, Back Pain, and Lower Extremity Function Scales (N=200)**

Scale	Category	N (%)
NDI	None (0-8)	4 (2.0)
	Mild (10-28)	39 (19.5)
	Moderate (30-48)	84 (42.0)
	Severe (50-68)	58 (29.0)
	Complete (70+)	15 (7.5)
QDASH	None/Mild (0-24)	65 (32.5)
	Mild/Moderate (25-50)	76 (38.0)
	Moderate/Severe (51-75)	49 (24.5)
	Severe/Unable (75-100)	10 (5.0)
ABC6	Low (<50)	122 (61.0)
	Moderate (50-80)	54 (27.0)
	High (81+)	24 (12.0)
QBPDS	0-20	54 (27.0)
	21-40	65 (32.5)
	41-60	49 (24.5)
	61-80	24 (12.0)
	80+	8 (4.0)
LEFS	Severe Limitation (0-20)	25 (12.5)
	Moderate Limitation (21-40)	56 (28.0)
	Mild Limitation (41-60)	66 (33.0)
	Normal Function (61-80)	53 (26.5)

**Table 4: Frequency of Fall Risk, Kinesiophobia, and Pain Catastrophizing (N=200)**

Scale	Interpretation	N (%)
ABC-6	<60 = At risk for falling	145 (72.5)
TKS	>37 = Kinesiophobia	178 (89.0)
PCS	31+ = Pain catastrophizing	108 (54.0)

**Table 5: Comparison of Respondents With and Without Kinesiophobia (TKS > 37)**

Factor	TKS Score		p value*
	Mean (SD) or N (%)		
	Kinesiophobia (n=178)	No Kinesiophobia (n=22)	
Age (years)	47.2 (12.4)	44.7 (13.4)	0.3816
CM Surgery (Y)	99 (55.6)	13 (59.1)	0.7569
Orthopedic Surgery (Y)	68 (38.2)	6 (27.3)	0.3165
Physical Therapy (Y)	148 (83.1)	18 (81.8)	0.7721**
Exercise Regularly (Y)	68 (38.2)	16 (72.7)	0.0021
Current Headaches (Y)	155 (87.1)	17 (77.3)	0.2111
NDI	45.9 (16.8)	27.5 (14.9)	<.0001
SF-MPQ-2	3.9 (2.1)	2.3 (1.3)	<.0001
QDASH	39.0 (20.8)	19.9 (18.5)	<.0001
QBPDS	38.1 (22.4)	18.0 (20.3)	<.0001
LEFS	43.2 (20.9)	61.9 (18.2)	<.0001
ABC6	40.6 (26.3)	67.2 (24.7)	<.0001
PCS	37.3 (19.5)	22.5 (14.7)	0.0007

\* t-test or chi-square

\*\* Fisher's exact test