

High Levels of Neck Related Disability Common Among Adult Chiari Women

In a study involving nearly 500 adult, female patients who participated in the Chiari1000, Conquer Chiari researchers found that high levels of neck related disability are common. Specifically, 80% of the patients are dealing with a *Moderate* level of disability or higher, with nearly a third at a *Severe* level of disability (see Table 1).

The Chiari1000 included the Neck Disability Index (NDI), a widely used assessment of the impact that neck pain has on daily activities such as sleeping, driving, reading, recreation, and work. The NDI is comprised of 10 questions and produces a score of 0-100. Disability level is then categorized as None, Mild, Moderate, Severe, or Complete (Table 1).

Table 1: Neck Disability in Adult Female CM Patients (N=474)

Category (score range)	N	%
None (0-8)	12	2.5%
Mild (10-28)	85	17.9%
Moderate (30-48)	167	35.2%
Severe (50-68)	153	32.3%
Complete (70-100)	57	12%

While this finding may not be surprising to those living with Chiari's impact every day, it does highlight in dramatic fashion, the limitations of existing treatments for Chiari and the reality that many adult patients face. Many studies, including the Chiari1000, have found that for adults, decompression surgery improves symptoms 70-80% of the time. However, this is only part of the story as clearly while individual symptoms may improve, many patients still struggle with various aspects of daily living.

The researchers also looked at 70 variables, such as demographics, related conditions, psychological assessments, cognitive tests, surgical history, and anatomic measurements (morphometrics), to see which ones were predictive of NDI score. They found that 16 of these variables were significantly related to a patient's disability score.

Patients with EDS, migraines, or scoliosis on average scored 13-20% higher on the NDI scale than those without those related conditions (see Table 2), and those with multiple decompressions and more severe symptoms also scored higher. Interestingly, there was *not* a significant difference in the scores between patients who had surgery and those who didn't.

One of the most dramatic findings involved patients who experienced symptoms for 2 years or more before diagnosis. The long symptom duration patients scored 77% higher than patients who were diagnosed quickly. In fact, the average NDI score for patients who were diagnosed in less than 2 years was only in the *Mild* category. This clearly shows the importance of early diagnosis and treatment before long-lasting damage is done.

Table 2: Differences in NDI Scores For Selected Variables

Variables	Total #	# 'Yes'	Avg NDI 'Yes'	Avg NDI 'No'
Scoliosis	474	103	50.7	44.67
Ehlers-Danlos	474	46	54.8	45.0
Migraines	474	313	48.6	40.8
Symptom Duration > 2 Years	162	58	44.7	25.3

Multiple Decompressions	474	21	53.6	43.8
Continuous Variables	N		r	
Symptom Severity	474		0.33	

The researchers also found that both pain and depression levels were highly correlated with the disability scores. In fact, a statistical model showed that those two factors alone accounted for more than half of the variation in NDI scores among the group. However, the model also showed that disability scores were driven by the complex interplay of a number of variables, including pain, depression, and other psychological factors. This finding is similar to what has been found in neck disability research involving other diseases and whiplash injuries.

Finally, the study found that patients with *Severe* or *Complete* levels of neck related disability scored significantly worse on both short-term and long-term memory assessments than patients with *None* or *Mild* NDI scores. This supports the hypothesis that Dr. Allen of the CCRC has proposed that the pain and psychological distress that many Chiari patients deal with can interfere with cognitive functioning.

It is important to note that these findings can't be extended to children or adult men. However, these finding do show that the daily struggle faced by many Chiari women has not gotten the attention it deserves.

Source: Labuda R, Loth D, Loth F, Allen PA. Pain and Depression Account for More Than Half of the Neck Disability Variance Among Adult Females with Chiari I. *World Neurosurg.* 2022 Dec 13:S1878-8750(22)01747-8. doi: 10.1016/j.wneu.2022.12.046. Epub ahead of print. PMID: 36526226.

Conquer Chiari's research updates highlight and summarize interesting publications from the medical literature while providing background and context. The summaries do contain some medical terminology and assume a general understanding of Chiari. Introductory information and many more research articles can be found in the [Conquer Chiari Library](#).

Conquer Chiari is a 501(c)(3) public charity dedicated to improving the experiences and outcomes of Chiari patients through education, awareness and research.