

## Chiari1000 Study Identifies Factors Linked to Surgical Outcome

Conquer Chiari researchers recently published a study which used data from the Chiari1000 project to identify 12 factors related to patient reported symptom improvement after surgery. The Chiari1000 (which recently closed to new participants) was a web-based research project which collected a broad range of information on Chiari patients, including symptom history, surgical history, neuropsychological testing, and imaging.

For this study, the researchers examined the data of 653 adult females who had undergone at least one Chiari decompression surgery. To determine the impact of surgery on symptoms, they selected a single question from the database:

“Overall, how did surgery impact your symptoms [completely resolved, improved significantly, improved slightly, no change, got worse]”

Responses were converted to a numerical scale (1=Got Worse to 5=Completely Resolved) for analysis. Next, sixty-five patient specific factors were selected from self-report questionnaires, scales, and imaging measurements for statistical analysis. First each factor was tested independently to see if it had a significant relationship to the surgical impact on symptoms. This testing revealed 12 such factors, including: having a diagnosed family member, Ehlers-Danlos Syndrome (EDS), migraines, duration of symptoms greater than 2 years, multiple surgeries, symptom severity, two different depression scales, anxiety, stress, loneliness, and a test of hypermobility.

Interestingly, age at time of surgery was NOT significantly related to outcome. This supports other research which has found that while children tend to have better outcomes than adults, among adults undergoing surgery, age is not a factor. The duration of symptoms finding also supports previous research. In this study, patients with symptom duration less than 2 years averaged a robust outcome score of 3.24 versus 2.91 for those with symptoms greater than 2 years.

While several related conditions were examined, only EDS and migraines were found to be significant negative predictors of outcome. Numerically, EDS had the highest impact on outcomes with Chiari/EDS patients averaging 2.77 versus 3.03 for those without EDS.

Psychological factors were also found to play a significant role, with depression showing the strongest link to poorer outcomes. This is NOT to be interpreted as meaning the Chiari symptoms of these patients were not real. Recall that every one of these patients underwent surgery. Rather this indicates that clinically measured depression is an issue that limits the impact of how patients feel after surgery. This finding, combined with the earlier report from the Chiari1000 which found very high rates of moderate-severe depression among Chiari patients, indicates that screening and treating Chiari patients for depression and anxiety should become part of the standard of care. Somewhat surprisingly, no pain or imaging measures were found to be related to the outcome scores.

Next, the researchers used these factors (and a couple others) to build a statistical model which identified 5 factors that contributed uniquely to the outcome differences. Overall, this model accounted for more than a third of the variation in outcome scores. Having a family member diagnosed with Chiari was the largest single contributor, and by itself accounted for 17% of the outcome variation. While it is tempting to attribute this to those patients with EDS (which is known to be heritable), theoretically this finding is independent of EDS status. Rather, this may indicate that familial Chiari represents a unique subset of patients with poorer outcomes, but this finding needs to be examined further with additional research.

Some clinicians are skeptical of research like the Chiari1000 because it collected information over the web. In theory, this can introduce bias in that the respondents may tend to be patients with more severe Chiari and poorer outcomes. However, the authors presented a strong defense of the Chiari1000 data by showing that participation rates, surgical rates, and overall outcomes are in line with similar, clinically based studies. In addition, the authors pointed out that the Chiari1000 data in terms of geography, surgeons, and surgical techniques is more representative of the adult, female Chiari population than a study drawn from a single practice.

Since this study identified about one third of the outcome variation, additional work is needed to see what other factors play a significant role. Likely candidates include individual surgical skill, non-Chiari comorbidities such as diabetes and hypertension, and patient expectations before surgery.

**Source:** Factors Associated With Patient Reported Post-surgical Symptom Improvement in Adult Females with Chiari Malformation Type I: A Report from the Chiari1000 Dataset. Labuda R, Loth D, Allen PA, Loth F. World Neurosurg. 2022 Feb 24:S1878-8750(22)00230-3. doi: 10.1016/j.wneu.2022.02.083. Online ahead of print. PMID: 35219914

**Note:** *Rick Labuda is the author of this research update and is an author of the journal paper it is based upon.*

*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 at [www.conquerchiari.org](http://www.conquerchiari.org).*

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