

### Key Points

1. Outcome studies are often short-term and fail to take into account the real impact of symptoms on a patient's life
2. Study from Sweden looked at long-term outcomes for 24 Chiari patients
3. After 3+ years, patients scored the disease impact on work, family life, and leisure activities
4. 50% of patients were considered to be asymptomatic and 75% had decreased headaches
5. On average, the patient reported impacts were considerably less
6. However, impact on work and leisure still averaged more than 20 on a scale of 0-100
7. Authors also provided detailed description of Chiari headaches to help distinguish from migraines
8. Propose that duration of less than an hour is predictive of Chiari

### Definitions

**cerebellar tonsils** - portion of the cerebellum located at the bottom, so named because of their shape

**cerebellum** - part of the brain located at the bottom of the skull, near the opening to the spinal area; important for muscle control, movement, and balance

**cerebrospinal fluid (CSF)** - clear liquid in the brain and spinal cord, acts as a shock absorber

**Chiari malformation I** - condition where the cerebellar tonsils are displaced out of the skull area into the spinal area, causing compression of brain tissue and disruption of CSF flow

**decompression surgery** - general term used for any of several surgical techniques employed to create more space around a Chiari malformation and to relieve compression

### Study Looks At Long Term Impact Chiari Has On Quality Of Life

**July 31st, 2009** -- As this publication has pointed out repeatedly, outcome studies in Chiari research are often hampered by being short-term and by not sufficiently taking into account the impact of residual symptoms on a patient's employment, family life, and recreational activities. A recent study from Sweden, involving 24 Chiari patients and published on the website of Acta Neurologica Scandinavica, tried to address some of the limitations which are prevalent in this type of research.

The study involved 14 women and 10 men with an average age of 26. Each had Chiari and exactly half had syringomyelia. It is interesting, and somewhat distressing, to note that on average it took more than 3 years for the group to be properly diagnosed. Twenty-two out of the twenty-four patients suffered from headaches. Other common symptoms included vertigo, eye problems, and loss of sensation. On average, the patients had slightly more than 15mm of herniation.

Each patient underwent decompression surgery, although the specifics of the surgery varied among the group. One quarter of the patients required a re-operation due to scarring, CSF issues, or other complications. In the short-term, three months after surgery, more than 90% of the patients had improved, with 13 having no symptoms.

However, the authors point out that there are many surgical procedures which provide a benefit in the first year which then disappears over time. Whether this is due to a placebo effect of something else, similar results have been seen with Chiari surgery. To that end, the researchers used someone who had not been involved with the patients previously to contact them several years later to determine their status. At an average of more than 3 years after surgery, half of the patients were still symptom free, 75% had reduced headaches, and 88% had fewer other symptoms (note, one person could not be contacted).

The researchers then went further and asked the patients to rate the impact Chiari had on their work/studies, their family life, and their leisure activities on a scale of 0-100. It is important to note that the patients were asked to do this rating for both how they felt now, and how they remembered feeling prior to surgery. Obviously, it would have been better to have done the actual rating before surgery for each person rather than relying on their memory.

Nevertheless, the researchers found that on average there was a significant reduction in the impact Chiari had on the patient's quality of life in each area (Table 1). Specifically, prior to surgery, the impact in each of the three areas was rated at over 60, while after surgery, this had dropped to between 14-27. It would have been useful to see how the scores of the asymptomatic patients compared to those who still reported symptoms, but this data was not provided. It is troubling, and validates the view of Conquer Chiari, that while most clinicians would say that based on symptoms alone the success rate for this group was quite high, but the average impact on work was still scored as 20 and the impact on leisure was scored at 27. This may reflect the reality that after a period of years most Chiari patients have learned to manage their residual symptoms through lifestyle modifications and have accepted, mentally, that they will likely never feel 100%. It is this adaptation and accommodation which is often not adequately captured in current outcomes research.

In discussing their findings, the authors also pointed out the difficulties in identifying Chiari headaches from migraines in making an accurate diagnosis. Based on the patient reported descriptions from their group (Table 2), they propose that the duration of each individual headache may have some diagnostic value.

**Table 2: Patient Reported Headache Characteristics**

**syringomyelia** - condition where a fluid filled cyst forms in the spinal cord

### Source

Long-term outcome after surgery for Chiari I malformation. Tisell M, Wallskog J, Linde M. Acta Neurol Scand. 2009 Jun 11

Description of preoperative headache (n = 21)	Number of patients
<b>Characteristics of headache (one or more)</b>	
Localized	19
Enhanced by physical activity	15
Pulsating	12
Nausea	6
Neurological symptoms	5
Lateralized	5
Vomiting	4
Photophobia	1
Sound sensitive	2
<b>Localization of headache (one or more)</b>	
Occiput	16
Neck	13
Temporal	7
Parietal	6
Forehead	4
<b>Factors triggering headache (one or more)</b>	
Movement of neck	15
Cough/sneeze	15
Body position	14
Valsalva	11
Laughter	6
Trauma	7
Psychological stress	2
<b>Duration of headache (one or more)</b>	
<1 h	9
1-3 h	9
4-12 h	7
12-24 h	4
>24 h	4
<b>Recovery after headache attacks (one or more)</b>	
Complete recovery	8
Some recovery	9
No recovery	4

Specifically, they found that a number of the Chiari patients (9) had what would be considered as short duration headaches, which lasted less than one hour. In adults, most migraines last more than an hour, so if a patient has migraine like headaches, but of short duration, it could indicate Chiari.

Although this study was limited because the patients were asked to remember how they felt prior to surgery, it will benefit Chiari research in general if more investigators try to take into account the impact Chiari has on specific areas of a patient's quality of life.

**Table 1: Patient Reported Impact of Chiari on Quality of Life (0-100)**

	Pre-op	Post-op
Impact on Work/Study	62	20
Impact on Family Life	68	14
Impact on Leisure Activities	74	27

**Note:** Both pre and post-op scores were rated at long-term follow up (3+ years)

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