

Key Points

1. In the Chiari medical literature, there is no standard definition of a successful surgery; many studies report on primary symptom only or use MRI results
2. This study used the Sickness Impact Profile to determine the change in self-perceived quality of life of 112 Chiari patients 1 year after surgery
3. Survey showed that 84% of patients had a significant improvement in quality of life
4. Open-ended questions showed 75% thought their quality of life had improved significantly, 15% thought there was no change, and 10% thought they were worse
5. Syringomyelia, size of tonsillar herniation, and age were not related to the outcome

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 - 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

cine MRI - type of MRI which can measure CSF flow

cranium - the skull

craniectomy - surgical technique where part of the skull is removed

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

Surgery Improves Quality of Life for 80% of Patients

One of the most common questions this publication receives from patients is, "Does the surgery work?" This is a difficult question to answer for two reasons. First, there is no standard definition of success for Chiari surgeries, so it can be difficult to compare, or even evaluate, the results of different studies. Some surgeons report success based on the primary symptom, others use MRI's and their own judgment, while in many reports, success is not even defined.

The second reason it is a difficult question to answer is that every person is different, with different symptoms, history, and health status. Because of this, it is important that each person discuss in detail with their physician the topic of what to expect after surgery. In past Editorials, this publication has encouraged patients to ask specifically: "What are the chances I will be symptom free?", "What are the chances I will be significantly better?", and "What are the chances I will get continue to get worse?"

While, each person's case is unique, with thousands of people going under the knife each year, it is still important to get an overall sense of how successful decompression surgery is. Recently, Dr. Diane Mueller, a PhD neurosurgical nurse practitioner at the University of Missouri-Columbia, and a Director of the C&S Patient Education Foundation, and Dr. John Oro, a neurosurgeon at the same University, took an important step in doing just that. In the February 15, 2005 issue of the journal *Neurosurgical Focus*, they reported the results of a study which examined the change in the self-perceived quality of life of 112 Chiari patients after surgery.

To measure quality of life, Dr. Mueller chose to use the Sickness Impact Profile (SIP). The SIP has been in wide use since 1976 and measures quality of life dimensions such as physical, psychosocial, recreation, sleep, work, and social interaction. The profile is a self-report questionnaire with 127 questions related to activities such as sleep, balance, movement, hygiene, home maintenance, concentration, social interactions, etc. The survey is scored such that the higher the score, the more impaired the perceived quality of life is. In other words, a score of 0 represents a good quality of life with no impairments.

One hundred seventy two Chiari patients were given the opportunity to participate in the study. One hundred fifty two agreed and completed the SIP survey before their surgery. The participants were asked to complete the same survey one year after undergoing their decompression surgery. In addition, the post-op survey included open-ended questions asking people their perception of their quality of life since surgery, their general health status, and activity level. Forty people failed to return the one year follow-up survey, leaving 112 patients as participants in the study.

The study group was comprised mainly of women, with only 8 men versus 104 women. The average age of the group was 40 and almost 20% of the group had syringomyelia in addition to Chiari. The size of herniations ranged from 3mm to 30mm, with an average of 9.4mm. The group endured the usual range of symptoms (see Table 1), with 97% reporting headaches. Other common symptoms included dizziness, neck pain, and weakness and numbness in the extremities. Each patient underwent a decompression surgery which included a craniectomy, laminectomy, and duraplasty. There were very few complications, with only one patient requiring additional surgery for a cyst which had developed.

One year after surgery, the survey showed 84% patients had experienced a significant improvement in their quality of life (see Table 2). All of the dimensions of the survey showed improvement with the total physical scale improving by 77% and the total psychosocial scale improving by 79%. While the number of patients who became asymptomatic was not explicitly reported, it can be inferred from graphs in the publication that at least half of the patients had an overall post-op score of 10 or less. Interestingly, neither syringomyelia, the size of the Chiari herniation, nor age were related to quality of life after surgery.

The open-ended questions included in the follow-up survey yielded slightly different results, with 75% of the people reporting their quality of life had improved after surgery, 15% reported no change, and 10% said it is worse. Among the improved group, patients included statements such as, "I have my life back", "I wish I had done the surgery sooner", and "I did not realize how sick I was before". When the authors dug deeper into the responses of those who reported worsening of their quality of life and general health, they found that many reported adverse events and incidents outside the scope of their Chiari experience.

Finally, in an attempt to account for the 40 patients who did not respond to the follow-up survey, the researchers used their own notes and anecdotal reports from follow-up visits to classify the change in quality of life of as many of these people as they could. They were able to rate 35 of the 40 and found that in this group 71% had improved, 20% were unchanged, and 9% had gotten worse. It is interesting to note that the improved rate for the group who did not return the form is lower than for the group who did. When the results of the two groups were combined, 79% of patients showed improvement in their quality of life one year after surgery.

to relieve compression

dura - tough, outer covering of the brain and spinal cord

duraplasty - surgical technique where the dura is opened and expanded by sewing a patch into it

intradural exploration - general term referred to a surgeon finding and removing any scarring or obstructions to CSF flow that exist underneath the dura

laminectomy - surgical technique where part of a vertebra is removed

magnetic resonance imaging (MRI) - diagnostic device which uses a strong magnetic field to create images of the body's internal parts

posterior fossa - depression on the inside of the back of the skull, near the base, where the cerebellum is normally situated

syringomyelia (SM) - neurological condition where a fluid filled cyst forms in the spinal cord

syrinx - fluid filled cyst in the spinal cord

tinnitus - ringing in the ears

tonsillar herniation - descent of the cerebellar tonsils into the spinal area; often measure in mm

ventricle - a CSF filled space in the brain

Source

Mueller D, Oro' JJ. [Prospective analysis of self-perceived quality of life before and after posterior fossa decompression in 112 patients with Chiari malformation with or without syringomyelia](#). Neurosurg Focus. 2005 Feb 15;18(2):ECP2.

While previous reports on surgical outcome have not used consistent, or well-defined, definitions of success, it is interesting that the results of this study are in line with most reports on the success rate of surgery. Namely, that about 80% of people get better to some degree, while 20% experience no change or continue to get worse.

While this study is an important first step in establishing scientifically how successful decompression surgery is in treating Chiari, the authors acknowledge that the study reflects the results from one surgeon and clinic, and that results from other surgeons - who might use different techniques - may vary. It is for this reason that Chiari & Syringomyelia News continues to call for all Chiari researchers to adopt a standard measure of surgical outcome (including how many people become asymptomatic), so that the results from different studies can be compared, and combined, to create an accurate picture of surgical outcomes.

Editor's Note: *I also believe that the amount of time that has passed since surgery is a key issue in measuring outcomes. Specifically, a single data point is not enough to get an accurate picture. Ideally, data would be collected a short time after surgery, 1 year, 3 years, 5 years, and 10 years post-op. I believe that people recover differently from surgery, with some improving quickly, and others not as fast. Personally, while today I would rate my quality of life as significantly better than before surgery, at the one year post-op mark, I think I would have rated it unchanged. One year after surgery, I still had headaches, neck pain, and was very weak in the arms and legs. Similarly, many people have reported anecdotally that symptoms have come back years after surgery. For these reasons, I believe long-term follow-up, with periodic measures, is required to really understand the success of surgery.*

Table 1
Most Common Symptoms

Symptom	% of Patients
Headache	97
Dizziness	85
Neck Pain	78
Vision Changes	71
Fatigue	70
Trouble Sleeping	68
Tinnitus	66
Arm/Let Numbness	65
Arm/Leg Weakness	65
Memory or Concentration Problems	61

Table 2
Change In Quality Of Life 1 Year After Surgery (112 Patients)

Measure	Better	Same	Worse
Survey	84%	Not Avail.	Not Avail.
Open-ended questions	75%	15%	10%

Note: When survey results are combined with verbal assessment of 35 patients who did not return post-op survey, 79% showed improvement.

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