Key Points

1. Syringomyelia has a major impact on patients
2. German study looked at the quality of life of 142 syringomyelia patients
3. SM was due to Chiari, SCI, tumors, and for unknown reasons
4. Found that the physical QoL was lower than reported by chronic back pain patients
5. The mental QoL was on par with cancer patients
6. Found no difference between men and women; and no difference between those who had had surgery and those who didn't
7. Did find that duration of symptoms was related to lower physical scores
8. Also found that SM has a big impact on a patient's ability to work

Definitions

ataxia - uncoordinated, staggered walking

SF-36 - widely used, validated quality of life scale, consists of surveys and produces rating on a number of subscales

paresis - partial paralysis

vertigo - dizziness

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

Quality of Life in Syringomyelia Patients

November 30, 2009 -- Syringomyelia, which often involves a slow, progressive deterioration can have a profound impact on patients. In a recent study, published in the Journal of Clinical Neuroscience, a group of German scientists tried to quantify just how syringomyelia impacts quality of life. In addition to the inherent benefit of measuring the quality of life impact, the research team hoped to identify sub-groups of SM patients which might then have implications for treatment.

While a syrinx caused by a Chiari malformation lends itself to a surgical treatment focused on decompressing the area around the cerebellar tonsils, syrinxes can also be a result of spinal cord injury, tumors, infection, and in some cases for no discernable reason. The treatment approach for these types of cases is not nearly as straightforward or clear. Options include conservatively trying to manage symptoms, locally decompressing around the syrinx in order to restore local CSF flow, and even draining the syrinx directly with a shunt. Unfortunately, none of these options is a clear winner, and even with Chiari related syringomyelia, many patients will have residual symptoms, such as pain and loss of sensation, associated with a syrinx. [Editor's Note: When I had surgery in 1999, the general description of surgery if there was a syrinx, was that it would hopefully stop the progression of symptoms, not that the syrinx related symptoms would improve. Now, research has shown that some syrinx related symptoms can improve with Chiari decompression surgery, but that others are less likely to.]

The research involved a large group of 142 syringomyelia patients seen over the course of a year at the University of Tubingen. The patient group was comprised of 88 women and 54 men, and not surprisingly, the syrinxes were due to a variety of causes. Specifically, 26% of the group had Chiari related syrinxes, 25% were associated with a traumatic spinal cord injury, and in another 25%, the underlying cause could not be determined (Table 1). Common symptoms for the group included pain (68%), numbness (62%), ataxia (43%), and paresis (31%) (Table 2). Interestingly, the group was split almost evenly in terms of treatment with 75 patients having undergone some type of surgery, and 67 patients pursuing a conservative treatment plan.

Table 1: Underlying Pathology of SM Patients (142 Total)

Pathology	%
Chiari Malformation	26%
Spinal Cord Injury	25%
Tumors	16%
Other	9%
Unknown	24%

Table 2: Common Symptoms Among SM Patients (142 Total)

Symptom	%
Pain	68%
Numbness	62%
Ataxia	43%
Paresis	31%
Headache	28%
Vertigo	26%

In order to assess the impact syringomyelia had had on the group, the researchers employed widely used, validated measure, the SF-36. The SF-36 is a quality of life survey which can be used to generate both a physical score and a mental score. In addition, the researchers gave the participants a survey called the Syringomyelia Disability Index (SDI), which asks questions about pain level, physical function, and routine activities, and generates a disability score between 0%-100%.

Overall the average SF-36 physical score (PCS) for the group was 33.2 and the mental score (MCS) was 45. These are both well below the established norms in Germany of 50.2 and 51.5 respectively. In fact the physical score of the SM group was lower than the average of people who suffer from chronic back problems, and the mental score was comparable to what has been recorded for people with chronic heart conditions and cancer.

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

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

Source

Evaluation of quality of life parameters in patients who have syringomyelia. Sixt C, Riether F, Will BE, Tatagiba MS, Roser F. J Clin Neurosci. 2009 Oct 7. [Epub ahead of print

The average score on the SDI was 64%, which is very high.

Interestingly, the researchers found no difference in the scores between the men and women of the SM group. Similarly, and somewhat distressing, they also found no real difference in scores between those who had surgery and those who didn't. This would seem to indicate that once a syrinx causes damage to the nervous system it can be very difficult to get that function back (although it is important to note that there are billions of dollars being spent on nerve regeneration research). Of course this does not mean that surgery for those patients wasn't necessary, as the surgical intervention may have prevented further damage. Also of interest is the fact that there was no difference in the quality of life scores based on the underlying pathology, so it appears that a syrinx is a syrinx no matter how or why it forms.

The researchers did find that disease duration was correlated with lower physical scores, but not mental scores. This implies that syringomyelia can progress over time, but also that at least some patients learn to accept and adapt to their situation. One factor that did negatively impact the mental score was not knowing the cause of syringomyelia. In other words, people for whom there was no discernible cause for the SM had significantly lower MCS scores than those who had a readily identifiable cause, such as Chiari.

Finally, it was clear that SM has a big impact on patients' ability to work. In this study group, only 29% were still working at their original jobs. Another 12% had changed careers because of SM, and more than a third were forced to quit or retire early. Although the researchers did end up identifying sub-groups of patients based on their physical and mental scores, it is not clear that any strong conclusions could be drawn from having done this.

Well designed quality of life studies such as this one are a rarity for Chiari and syringomyelia, but the results clearly show that more work in this area is called for.

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