

Key Points

1. Chiari patients may end up with a shunt for a number of reasons, such as hydrocephalus and pseudotumor cerebri
2. In some cases, symptoms persist which require regular adjustments of the shunt
3. Study looked at the safety and feasibility of home shunt reprogramming for 20 selected individuals
4. Learning to program the shunts was easy and 95% felt comfortable almost immediately
5. No adverse events related to the shunt programming were reported
6. 95% reported at least some symptom improvement after reprogramming
7. 85% reported benefiting very much from the home programming
8. Shows home programming is safe in limited cases, but does not prove it is effective

Definitions

arachnoid cyst - a fluid filled cyst in the arachnoid (covering of the brain); in some cases can interfere with CSF flow

hydrocephalus - condition where an unusually large amount of CSF collects in the brain

intracranial pressure (ICP) - the pressure of CSF in the skull

programmable shunt - a shunt whose resistance can be set, or programmed, non-invasively

pseudotumor cerebri (PTC) - condition characterized by chronically elevated intracranial pressure

shunt - an implanted tube like device which is used to divert CSF from the brain to another place in the body

Study Examines Feasibility Of Programming Shunts At Home

March 31, 2007 -- While posterior fossa decompression is usually regarded as the primary Chiari surgery, many Chiari patients end up getting shunts as part of their treatment as well. Shunts are implantable medical devices which divert cerebrospinal fluid from the brain to a different part of the body.

In terms of Chiari, children with hydrocephalus will nearly always have a shunt implanted and many people - children and adults - with pseudotumor cerebri also end up with shunts. While shunts are effective in draining CSF and reducing pressure, they also introduce a number of complications. Since shunts sometimes need to be adjusted and can become infected, develop blocks, or malfunction, when a patient with a shunt becomes nauseous, has headaches, or a fever, the shunt must always be considered as a possible cause. Because of this, some people end up frequently going to the doctor or emergency room and have to endure numerous shunt revisions over time.

As shunt technology has improved, manufacturers have developed what are known as externally programmable shunts. The resistance of these types of shunts, which in turn controls how much CSF they drain, can be set magnetically from outside of the body. While this is certainly an advance, patients traditionally have still had to go to a medical center which is capable of programming the shunt when an adjustment is required. For patients who need frequent adjustments due to symptoms such as headaches, and/or live far away from an equipped medical center, this can be quite a burden.

In an attempt to address this situation, three neurosurgeons from the University of Chicago (Sikorski, Rosen, Frimm) evaluated the safety and feasibility of allowing 20 carefully selected patients to program their shunts at home between 2001-2005. They reported the results of their trial in the February, 2007 issue of the journal *Neurosurgery*.

The surgeons did not establish specific criteria for inclusion in the study before starting the program, but rather evaluated each patient's situation individually. Major factors which influenced the decision to allow people to try home programming included:

- A history of frequent shunt reprogramming
- A history of carefully following treatment plans
- Long distance to travel to medical center for programming
- Strong interest on the part of the patient or family (in the case of children)
- Able caregivers if the patients were children
- No history of mental status problems associated with shunt malfunctions

Using these loose guidelines, the doctors identified twenty patients, both adults and children, who were interested in and capable of trying the home programming. There were five males and fifteen females in the group, ranging in age from 6 to 48 years. Emphasizing the logistical problems of frequent doctor visits, the patients lived an average of 260 miles from a medical center capable of performing shunt reprogramming. The vast majority of the patients suffered from pseudotumor cerebri (see Table 1), which sometimes can require frequent changes to the shunt setting to avoid headaches.

Each patient (or caregiver) was carefully instructed on how to use the magnetic programmer before being allowed to take it home. Ninety-five percent of the users reported feeling comfortable with the device almost immediately.

To assess the program, the doctors created a twenty question survey which was mailed to the participants. Every participant responded to the survey and had been using the home programming for an average of more than a year when they answered.

In reviewing the surveys and associated medical records, the doctors found, perhaps most importantly, that there were no adverse events related to the home programming of the shunts. The survey also showed that the programming device was being used frequently. Thirty-five percent of the patients reported reprogramming their shunts at least once a week; 40% once a month; and 25% less than once a month.

Although the patients felt they knew how to use the programming device, they weren't always sure the shunt was programmed correctly (in a medical center a shunt's setting/functioning is often checked with imaging). Specifically, only one third of the participants reported being always sure the shunt was programmed correctly,

slit ventricle syndrome - condition where the ventricles become slit shaped due to overdrainage of CSF

ventricle - one of several fluid filled spaces in the brain

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

Source

Sikorski CW, Rosen DS, Frim DM. [Adjustable shunt valve reprogramming at home: safety and feasibility](#). Neurosurgery. 2007 Feb;60(2):333-6; discussion 336-7

while 42% said they were sometimes unsure and 25% said they were mostly unsure it was programmed correctly.

Although the goal of the study was to evaluate safety and feasibility, the survey did ask patients whether their symptoms improved after shunt reprograms. More than half said that their symptoms always or almost always did get better after reprogramming. Forty-two percent reported that their symptoms sometimes got better and only five percent said their symptoms rarely got better. While these results are encouraging, the authors point out that since the settings on the shunt were not verified after they were changed, the symptom improvements can not be definitely tied to the shunt programming and may instead be due to a placebo effect.

However, one result was very clear in the responses, an overwhelming 85% of the patients said they benefited very much from the home program, and the rest said they benefited somewhat. Since the average patient had to travel more than 260 miles for reprogramming, this is perhaps not surprising.

While the authors believe their results clearly demonstrate the safety and feasibility of home programming, they stress that it is not for everyone and requires careful patient selection, thorough patient education and clear and effective communication between patient and doctor. They also stress that this study did not evaluate the effectiveness of home programming which would require a prospective, randomized trial with well defined inclusion criteria and probably imaging verification of the shunt programming settings.

Still, with 85% of the participants saying they benefited very much, it does show how creative doctors can help improve the quality of life for their patients.

Table 1
Underlying Condition Which Required Shunt (20 Patients)

Condition	# With
Pseudotumor Cerebri	17
Slit Ventricle Syndrome	2
Arachnoid Cyst	1

Table 2
Reported Symptom Improvement After Reprogramming

Always	53%
Sometimes	42%
Rarely	5%

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