ADJUSTABLE SHUNT VALVE REPROGRAMMING
AT HOME: SAFETY AND FEASIBILITY

OBJECTIVE: Shunt valve resistance changes using a specialized magnetic programming device permit noninvasive changes to cerebrospinal fluid drainage. In selected cases between 2001 and 2005, patients and families used shunt valve programming devices at home. This study examines the safety and efficacy of this practice.

METHODS: We conducted a retrospective review of the medical records of patients who had been given a shunt valve-programming device for home use. A survey was mailed to patients or family members requesting information regarding their experiences with the shunt valve programming device. Patient and family responses were tabulated and a statistical analysis was performed.

RESULTS: Twenty patients or families returned the survey. The median patient age was 19.6 years (range, 6–48 yr); 25% were male. Seventeen patients had pseudotumor cerebri, one had an arachnoid cyst, and two had slit ventricle syndrome. Fifteen patients had lumboperitoneal shunts, one had a ventriculoperitoneal shunt, three had cisterna magna shunts, and one had an arachnoid cyst-to-peritoneal shunt. No adverse events were attributable to the use of the home shunt valve programmer. Thirty-five percent of respondents used the programmer at least once every week, 40% used the programmer between once a week and once a month, and 25% used the programmer less frequently than once per month. Overall, 85% of respondents reported that they benefited “very much” from the use of a home shunt valve programmer and 15% of respondents benefited “somewhat.”

CONCLUSION: Providing shunt valve programming devices to selected patients for home use is a safe practice associated with high patient satisfaction. However, the selection of appropriate patients, comprehensive patient education, and close patient-physician communication are crucial to the success of this practice.

KEY WORDS: Home therapy, Hydrocephalus, Lumboperitoneal shunt, Programmable shunt valve, Pseudotumor cerebri, Ventriculoperitoneal shunt

Programmable shunt valves create additional treatment options for patients requiring cerebrospinal fluid (CSF) drainage (1, 3–6, 8). Programmable shunt valves are equipped with a range of resistance settings that can be changed noninvasively using a magnetic programming device. This feature permits active customization of shunt therapy to alleviate the symptoms of CSF over- or underdrainage (7). However, only a limited number of neurosurgical centers have specialized valve programming devices. Consequently, most patients must visit their treating medical center to have their valve setting changed.

At our medical center, we observed a subgroup of patients who frequently visited the neurosurgery clinic or emergency department for reprogramming of their shunt valves. Because many of these patients were traveling long distances to our medical center for valve reprogramming, we adopted a practice of allowing selected patients to use shunt valve-programming devices at home. The patients and families were trained in the operation of the programmer and frequently communicated with our medical team regarding symptoms and changes in valve settings. This study examines our experience with home shunt valve programming.

PATIENTS AND METHODS

The University of Chicago Hospital Institutional Review Board approved our research protocol. We conducted a retrospective review of the medical records of patients who had
been supplied with a shunt valve programmer for home use. Prospective criteria were not developed to select patients for home programmer use; instead, patients were evaluated individually. Relative indications for home shunt programming included a history of frequent shunt valve reprogramming, a history of adherence to treatment plans, a long distance from home to the treatment center, and family and patient interest in home shunt valve programming. Absolute contraindications included a history or high likelihood of mental status changes associated with shunt malfunction, a history of poor patient follow-up, and, for children, inconsistent caregivers. If the hospital incurred cost, the cost of the valve programmer was reimbursed by third-party payers at the time of shunt revision; if the valve programmers were given to the hospital without charge, there was no cost to the patient or a third-party payer. Patient demographic information was collected and records were reviewed for adverse events that could be attributed to the use of a home shunt valve programmer.

We developed a written survey instrument containing 20 questions designed to evaluate patient and family experiences with a home shunt valve programming device. Five questions requested demographic information, two questions were regarding home programmer education, six questions asked about programming practices, and two questions evaluated patient satisfaction. Five questions asked patients to recall the frequency and outcome of medical center visits before and after they were given a home programmer.

The survey was mailed to all patients who had received home shunt valve programmers. Patients either returned the survey by mail or at a scheduled office visit. Patients were assured that the survey results would be anonymously evaluated. The results of the survey were tabulated and a statistical analysis was performed using Microsoft Excel (Version XP; Microsoft, Seattle, WA).

RESULTS

All 20 patients or families who were sent surveys completed them. Table 1 includes the clinical characteristics of the survey respondents. The median age was 19.6 years (range, 6-48 yr) and 25% were male patients. The approximate distance between the patient’s home and treating medical center was 263.3 miles (range, 5-1125 miles). Seventeen patients had pseudotumor cerebri, one patient had a posterior fossa arachnoid cyst, and two patients had slit ventricle syndrome associated with a previously placed ventriculoperitoneal shunt. Fifteen patients had programmable lumbar-peritoneal (LP) shunts, one patient had a programmable ventriculoperitoneal shunt, two patients were changed from programmable LP shunts to programmable cisterna magna-to-peritoneal shunts,

<table>
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<th>Patient no.</th>
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<th>Valve</th>
<th>Shunt (mo)</th>
<th>Programmable shunt (mo)</th>
<th>Home programmer (mo)</th>
<th>Approximate distance from home to medical center (miles)</th>
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<td>Mean</td>
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<td>16.2</td>
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*LPS, lumbar-peritoneal shunt; CMP, cisterna magna-to-peritoneal shunt; VPS, ventriculoperitoneal shunt; Cyst-PS, arachnoid cyst-to-peritoneal shunt; CM-AS, cisterna magna-to-right atrium shunt.
one patient had a programmable arachnoid cyst-to-peritoneal shunt, and one patient had both a programmable cisterna magna-to-atrial shunt and a programmable LP shunt. For patients with LP shunts, valves were placed superficially in the soft tissue of the back to facilitate valve reprogramming. Eighteen patients had Codman Hakim programmable valves (Codman & Shurtleff, Inc., Raynham, MA) and two patients had Strata programmable valves (Medtronic Neurosurgical, Goleta, CA).

At the time the survey was completed, the mean number of months the patients had any type of shunt system (programmable or nonprogrammable valve) was 30.4 months. The mean length of time was 16.2 months with a programmable shunt valve and 12.9 months with a home shunt valve programmer.

Survey respondents reported that the median amount of time for education regarding the operation of the valve programmer was between 5 and 15 minutes. Ninety-five percent of respondents felt comfortable operating the programmer at the time it was issued. A single person operated the programmer for 70% of patients and multiple operators for 30%. Thirty-five percent of respondents reported using the programmer at least once every week, 40% used the programmer between once a week and once a month, and 25% used it less frequently than once per month. Only 35% of patients always or almost always contacted the neurosurgery office for guidance before reprogramming the valve. Thirty-three percent of respondents reported that they were “always sure” that the valve was reprogrammed properly, 42% were “sometimes unsure” regarding valve reprogramming, and 25% felt “mostly unsure” regarding valve reprogramming. When unsure regarding valve settings, 50% of respondents had gone to the neurosurgery clinic or an emergency department at least once to check valve settings by x-ray. Our staff often reviewed these x-rays using telemetric electronic media.

No adverse events were attributable to the use of the home shunt valve programmer. Fifty-three percent of respondents “always” or “almost always” experienced improvement in symptoms after valve reprogramming, 42% “sometimes” experienced improvement, and 5% “rarely” experienced improvement. Figure 1 shows that patients reported a significantly lower frequency of medical center visits after obtaining a home shunt valve programmer. Thirty-seven percent of respondents never required urgent medical evaluation in the neurosurgery clinic or emergency room after receiving a home programmer. Overall, 85% of respondents reported that they benefited “very much” from the use of a home shunt valve programmer, and 15% of respondents reported that they benefited “somewhat.”

DISCUSSION

The results of this investigation demonstrate that selected patients can safely use shunt valve programmers at home and suggest that home programmers may decrease the number of medical center visits and increase patient satisfaction. The successful use of home shunt valve programmers is dependent on three key elements: 1) rigorous patient selection, 2) thorough patient and family education, and 3) active communication between the patient, the patient’s family, and the healthcare team.

Several large series (1, 2, 4–9) and one randomized, controlled trial (3) have examined the use of programmable shunt valves. Indications for programmable shunt valves include hydrocephalus of various causes, normal pressure hydrocephalus, arachnoid cysts, and pseudotumor cerebri (6, 8). However, not all patients with programmable valves are candidates for home programming and we do not advocate the routine use of home valve programmers for the general shunt population. The present series of patients did not have strict inclusion criteria; instead, patients were evaluated on an individual basis. In general, patients had failed conventional shunt treatment and remained symptomatic, most commonly with headaches, from conditions such as pseudotumor cerebri, arachnoid cysts, or slit ventricle syndrome.

Patient and family education regarding the shunt valve programmer was performed before and after receiving the home programmer. Most programmers were provided during an inpatient hospital admission. During the admission, a patient and family education session was conducted to demonstrate the operation of the programmer. Emphasis was placed on understanding the anatomy and location of the shunt, especially for patients with programmable LP shunts because the soft tissue of the back makes valve programming more challenging. After discharge, an active effort was made to maintain communication through phone calls, email, and office visits to answer questions regarding shunt valve programming. As patients and families developed familiarity with shunt valve programming, many began to make programming decisions independent of the medical team.

Programmable and nonprogrammable valves seem to have similar failure rates (3). Rare complications associated with programmable valves include misprogramming of valve settings, failure of the valve to reprogram, and inadvertent valve reprogramming, especially after magnetic resonance imaging scans.
or exposure to other powerful magnets. Home programming is unlikely to change shunt failure rates. The present series demonstrated no adverse events from home programming; however, the primary potential complication of home programming is misprogramming of the valve settings, leading to CSF under- or overdrainage. Therefore, patients with a history of mental status changes from shunt underdrainage or malfunction are not candidates for home programming. Overdrainage of CSF rarely leads to serious complications but can result in a subdural hematoma; patients should be educated regarding the signs and symptoms of this complication.

Several series have reported a mean number of valve reprogramming between one and two per patient (1, 2, 4, 5, 7, 8). However, the present series includes a large percentage of patients with pseudotumor cerebri. Our clinical experience has demonstrated that this group of patients requires more frequent valve adjustments. Our study also differs from previously reported series in that it includes a large percentage of patients with LP shunts.

The present study was not designed to include a cost analysis, but the financial impact of this practice is important for evaluating its feasibility. Our institution charges approximately $1400 for one of the Codman Hakim programming devices, which was reimbursed by third-party payers at the time of shunt revision. However, the cost for an office visit with shunt reprogramming is $310; for an emergency department visit with shunt reprogramming (excluding x-rays), the cost is $475. Therefore, if this practice prevents five office visits or three emergency department visits for valve reprogramming, the cost savings would justify the cost of the home programmer.

One of the primary limitations of the present study is the use of a survey to measure outcomes. Our survey relied on respondents’ recall, however, our study population may not have remembered accurately and may have introduced recall bias into our analysis. In addition, the accuracy of home shunt valve programming was not measured and, therefore, it is not known whether or not the benefits reported by our survey respondents were caused by actual changes in the valve settings or placebo effect from using the programmer. Finally, it is unclear what physiological mechanisms explain the apparent benefit some patients reported from frequent changes in shunt valve settings.

Despite these unanswered questions, the results of this study indicate that home shunt valve programmer use is a feasible, safe, and possibly effective therapy for selected patients. We do not advocate the routine use of home shunt valve programmers for the general shunt population, but for patients who have failed conventional shunt therapy and remain symptomatic from conditions such as pseudotumor cerebri, arachnoid cysts, or slit ventricle syndrome, home shunt valve programming may be an additional therapeutic option. Although no adverse events were attributed to home shunt valve programming during the study period, this practice has inherent risks that should be thoroughly explained to patients. This report may serve as the basis for a prospective, randomized trial with strictly defined inclusion criteria to better evaluate the efficacy of this practice.

REFERENCES


COMMENTS

Sikorski et al. evaluate a group of patients who were allowed to adjust their cerebrospinal fluid diverting shunts at home. The study was generated by the responses of 20 patients or family members who completed and returned a survey. The authors report no adverse consequences by changing the valve setting in terms of frequency, one of the respondents changed the valve setting at least once per week, 40% changed the setting between once per week and once per month, and 25% changed the setting less frequently than once per month. The authors note that 85% of the respondents indicated that they benefited very much from changing their valve setting at home and 15% reported some benefit. Apparently, there were no responses that indicated no benefit or adverse effects from changing the valve setting. The authors conclude that home programming of shunt valves is feasible, safe, and possibly effective in selected patients.

As the authors note in their discussion, the survey results were dependent on the information supplied by the respondents. Thus, the number of times and the degree to which the valve settings were changed may or may not reflect reality. The fact that 85% of the respondents benefited very much and 15% benefited somewhat from changing the valve is in itself remarkable. I agree with the authors’ conclusion that home adjustment of programmable shunts is safe in some selected situations. Whether or not it is effective is questionable, as the placebo effect may have been the predominant factor. In a pediatric population, we have not found that programmable valves are of benefit over those that are not, except in very rare situations. Obviously, the case series presented differs markedly from that of the usual pediatric shunt population.

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Los Angeles, California

www.neurosurgery-online.com
Neurosurgeons who perform a large number of shunts can generally identify a small subgroup of patients in their own practices who are similar to those patients discussed in this study. These patients all have certain features in common. The condition for which they were shunted is not associated with life-threatening sequelae if the valve setting is wrong or if the shunt malfunctions. Nonetheless, they and their families are plagued by recurring symptoms, particularly headache, that require some sort of shunt adjustments. If they live at a distance from the neurosurgeon, major effort is required to obtain help. Even patients who live near a major medical center may spend painful, frustrating, and expensive hours (usually at night) in the hospital emergency department with their families. This may lead to a tendency to avoid seeking help unless they are quite ill or their anxiety too great, particularly if experience tells them that a minor adjustment of the shunt is all that is needed. For such individuals, the feeling that they can help themselves must be very reassuring. It is not surprising that their responses to the questionnaire were generally positive. We all recognize that such patients must be selected and educated very carefully, as the authors have done in this study.

Paul H. Chapman
Boston, Massachusetts

This is a Phase I safety study of the use of home shunt programming. It is an interesting idea that proved to be safe in a small number of selected patients (mostly pseudotumor adults). Although not designed as an efficacy study, the reader obviously wants to derive information about this. The fact that almost all of the patients subjectively benefited is not particularly revealing because they seemed to reprogram their shunts on a regular basis, which makes no physiological sense. These patients are notoriously fragile from an emotional point of view and, as the authors point out in the discussion, all of the benefits may have been the placebo effect. One wonders if the same benefit would have been found if these patients had been sent home with the programming device without programmable shunts or with a dummy programmer.

We also do not know if the adjustments made at home resulted in any change in the actual shunt parameters. The Codman system (Codman & Shurtleff, Inc., Raynham, MA), in particular, is pretty fainicky and radiographic confirmation is needed to truly prove that the intended change was effected. This technique has the advantage of sparing the neurosurgeon endless visits for reprogramming. On the other hand, it still has the risk that an inadvertent change to a high-pressure valve could result in death. It is also potentially quite expensive, and it is unclear who would pay for the home programmers. This is an idea that deserves further investigation, but a placebo controlled trial would be most helpful, if it could be conducted in an ethical way.

Leslie N. Sutton
Philadelphia, Pennsylvania

"Sugar Ray" Robinson (1921-1989) and Carmen Basilio (1927-) in the 10th round of their classic middle-weight championship match at Chicago Stadium, 1958.