Placement of CSF shunts has been an accepted treatment option for hydrocephalus for many years. A 1995 paper estimated that there were more than 125,000 shunts and up to 33,000 new shunts implanted every year. Estimates of shunt placement in the US range from 5500 to 18,000 annually, with pediatric shunt placement in the US numbering 3378 procedures in 2003. In children with shunts, concern regarding shunt malfunction/failure or infection exists at almost any sick visit encounter, leading to numerous imaging studies to exclude the shunt as the etiology of the illness. A 2015 study examining the practices of 31 hospitals in the Pedi-
atrial Health Information System found that CT scanning was performed in half of emergency room visits involving children with a ventricular shunt.9 Children often live distant from the medical center that placed their shunt, and they may receive health care in a number of other settings where access to the type of device is not readily retrievable. Despite available references on the radiographic appearance of some shunt valves, not all shunt valve types or settings can be identified radiographically, which poses a problem for those providing emergency care to patients who are new to their practice.17

Because programmable shunts have become more widely used, it is important to know the shunt setting and whether the device needs to be reprogrammed after the patient undergoes MRI. Concern regarding radiation exposure in this vulnerable and frequently imaged population has prompted increasing use of MRI to determine ventricular size in evaluations for shunt malfunction.5,9,16,19,22 Other providers may order MRI to evaluate other body systems and may not be aware that the patient has a programmable shunt. This, in turn, poses a problem when it is not recognized that the patient has a programmable shunt and is sent home without the shunt being reprogrammed or when the setting to reprogram the shunt is not known. The study may also be performed in a facility that is unable to provide reprogramming and the facility where reprogramming can be accomplished is geographically distant from the patient. For many reasons, it is imperative that parents and caregivers are knowledgeable regarding the type of implanted shunt their child has.

It is also important for parents and caregivers to be aware of the symptoms of shunt malfunction or infection. Although numerous studies have been done on how to best predict whether a shunt is failing,6–8,10,13,14,18 the patient needs to have someone who recognizes symptoms of shunt failure or infection to bring the child to the hospital or clinic for evaluation. This education is often ongoing. Access to references such as the booklet by the Hydrocephalus Association (About Hydrocephalus: A Book for Families) and other materials is useful; however, a study of parental recognition of shunt failure found that parents value education they receive from neurosurgery staff more than any other source.18

Our study objective was to evaluate how well our practice was performing in providing parents/guardians with information regarding the type/name/setting of the child’s shunt valve and to assess their knowledge of symptoms of shunt malfunction or infection. In addition, access to educational materials to assist in the above objectives was also explored.

Methods

Data Collection

This study was reviewed by the institutional review board at Indiana University/Riley Hospital for Children. Data were collected prospectively by providers who saw consecutive patients with shunts in the neurosurgery outpatient clinic between January 13, 2016, and July 13, 2016. Patients were seen by the physician who had performed the patient’s most recent shunt surgery or by a nurse prac-
titioner. New patients to the practice were randomly distributed based upon availability of clinic appointment openings. Providers were asked to complete a short assessment tool regarding knowledge of their child’s shunt (Fig. 1). The parent/guardian was given the form to fill out or the provider who saw the patient posed the questions and recorded the parent/guardian’s response.

Data were collected regarding knowledge of shunt type (programmable vs nonprogrammable, setting if programmable, and name of shunt valve) and whether the parent/guardian had access to information about the shunt (e.g., Hydrocephalus Association booklet, wallet card listing shunt type/setting, and cards listing symptoms of shunt malfunction). They were also asked to list 3 symptoms of shunt malfunction. Parents/guardians were allowed to refer to sources they carried with them to answer the questions (e.g., wallet cards listing shunt name/type/setting or symptom cards). All parents/guardians of 148 consecutive patients participated in the data collection. After administration of the questionnaire, parents/guardians were given materials to correct any identified knowledge deficiencies or lack of access to educational materials.

For several years prior to data collection, one provider had made it a practice to give parents cards with shunt valve names, designation of programmable or nonprogrammable valve, and the setting of the valve if applicable. Cards were generally distributed immediately after surgery when talking with the family about the procedure, with the suggestion to keep the cards in their wallet. The parent/guardian(s) were told that they would be queried regarding this information in the future. At subsequent clinic appointments, they were asked to produce the cards and to identify the type of shunt their child had. These patients were placed into group I. Other providers in the clinic were not following this practice, and their patients constituted group II.

Laminated cards with symptoms of shunt malfunction or infection had been available at all providers’ clinic appointment checkout areas for several years. The cards included a statement regarding the need to reprogram programmable shunts after undergoing MRI, as well as the need to keep strong magnets at least 5 cm (2 inches) from the child’s head. All providers gave families a copy of About Hydrocephalus: A Book for Families by the Hydrocephalus Association, either at the time of shunt implantation, during prenatal hydrocephalus visits, or at follow-up clinic visits. Booklets and cards containing information regarding symptoms of shunt malfunction or infection were available in English and Spanish for groups I and II.

Statistical Analysis

Data were collected and analyzed using SAS software. Descriptive statistics were computed for shunt malfunction or infection reporting and percentage of patients with different shunt valve characteristics and possession of educational materials. All percentages were rounded to the nearest whole number. Wilcoxon tests were used to compare continuous variables (age at surgery, age at follow-up, and time from surgery to follow-up), and chi-square tests were used to compare categorical variables (age > or < 1 year at surgery, type of surgery, valve name/type/
setting, possession of Hydrocephalus Association booklet/laminated cards, and ability to identify signs/symptoms of shunt malfunction).

**Results**

**Demographic Data**

A total of 148 surveys were collected and available for analysis. Table 1 summarizes patient characteristics. The mean age (± SD) at shunt implantation/revision was 3.71 ± 4.91 years (range 0–22 years), and at follow-up it was 6.12 ± 5.4 years (range 0–22 years). The average time from surgery to the most recent follow-up and administration of the questionnaire was 2.38 ± 3.22 years (range 1 month to 17 years). Sixty-eight patients (47%) were younger than 1 year of age and 76 (53%) were older than 1 year at the time of the most recent surgery. Data regarding age at most recent surgery were not available in 4 patients who came from other facilities. New shunt insertions were performed in 86 patients (58%) and shunt revisions in 62 (42%).

**Shunt Type, Valve, and Setting Identification**

Most parents/caregivers could correctly identify whether the patient had a programmable or nonprogrammable shunt, with 128 (86%) knowing this information and 20 (14%) unable to articulate the information (Table 2). Seventy-two parents/caregivers (49%) were able to identify the name of the implanted shunt valve and 76 (51%) could not. The number of implanted programmable versus nonprogrammable valves was almost evenly split at 73 (49%) and 72 (49%), respectively. We were unable to identify the valve type in 3 patients. Among those with programmable

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**SHUNT INTAKE FORM**

*please circle the correct answer or write in the correct response.*

1. What type of shunt does your child have?
   a. Programmable (needs to be reset after MRI)
   b. Non programmable
   c. I don’t know

2. If your child has a programmable shunt what is the shunt set at? __________

3. Do you know the name of the shunt valve? ____________________________

4. Did you receive a booklet about shunts when your child’s shunt was placed?
   a. Yes
   b. No

5. Do you have a card for your wallet that lists the type of shunt your child has?
   a. Yes
   b. No

6. Do you have cards listing symptoms of shunt malfunction for your home and your child’s school or other caregivers?
   a. Yes
   b. No

7. Name 3 symptoms of shunt malfunction:
   a. __________________________________________
   b. __________________________________________
   c. __________________________________________

*Thank you. We are working to try to make sure you have the best information available to assist in the care of your child!*

**Physician Only:**

A. Date of last Shunt Intervention: ________

B. Insertion? _____ Revision? _____

C. Date of Clinic Visit: __________

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FIG. 1. Shunt intake form.
valves, 54 of 73 parents/caregivers (74%) identified the correct valve setting.

Possession of Teaching/Information Adjuncts

One hundred parents/caregivers (68%) recalled having a copy of the Hydrocephalus Association booklet. One hundred three (70%) possessed the laminated cards with shunt malfunction or infection information. Eighty (54%) were able to produce a card or other source with information regarding shunt type/valve name/valve setting upon request, whereas 68 parents/caregivers (46%) could not.

Report of Signs/Symptoms of Shunt Malfunction or Infection

Most parents/caregivers were able to identify 3 signs/symptoms of shunt malfunction or infection, with 127 (86%) able to complete this portion of the questionnaire. Twenty-one parents/caregivers were unable to name 3 signs/symptoms. Eight parents/caregivers named 2 signs/symptoms, 2 named only 1 sign/symptom, and 11 could not recall any signs/symptoms of shunt malfunction or infection (Table 3). Vomiting, headache, and sleeps more/lethargic were the 3 most frequently reported signs/symptoms; fever, irritability, nausea, and a full fontanelle were also commonly reported.

Comparison of Group I Versus Group II

Group I patients and families/guardians had a single provider who had been requiring patients and families/guardians to carry cards identifying shunt valve names, designation of programmable or nonprogrammable valve, and the setting of the valve if applicable for several years prior to data collection; all other providers’ patients and families/guardians constituting group II were not carrying such cards. There were no significant differences between groups I and II regarding whether parents/caregivers had Hydrocephalus Association booklets (p = 0.1288) or the ability to list 3 symptoms of shunt malfunction (p = 0.8812) (Table 4). Group I more often had cards with symptoms of shunt infection or malfunction (p = 0.015). Group I performed much better in naming the implanted valve (p < 0.001), knowing whether the valve was programmable or not (p = 0.001), and identifying the valve setting if programmable (p = 0.0016). Group I was also more likely to have a wallet card listing shunt characteristics (p < 0.001).

Analysis of patients in group I versus group II showed no significant difference in age at surgery (p = 0.354), age at follow-up (p = 0.1847), or whether the patient had an insertion or revision (p = 0.1217). The average time from surgery to last follow-up for group I patients was 1.66 versus 3.17 years for group II patients; this difference was statistically significant (p = 0.0001) (Table 5).

Patients < 1 Year Versus > 1 Year of Age

There were no significant differences in any parameters examined in the comparison of patients younger or older than 1 year of age. These included ability to identify the type of shunt (p = 0.4671), valve name (p = 0.0621), valve setting (p = 0.118), and the ability to list 3 symptoms of shunt malfunction or infection (p = 0.3302). Similarly, no appreciable differences were found in whether parents/guardians of patients had Hydrocephalus Association booklets (p = 0.9448), symptom cards (p = 0.9113), or cards with implanted shunt characteristics (p = 0.4393) (Table 6).

Discussion

Patients receive care from multiple caregivers in a variety of settings. Therefore, it is imperative that parents/guardians of patients with shunted hydrocephalus are familiar with signs/symptoms of possible shunt malfunction or infection and that they have the correct information regarding the implanted device. This is particularly

### TABLE 1. Characteristics of 148 patients

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age at surgery, yrs</td>
<td>3.71 ± 4.91 (0–22.27)</td>
</tr>
<tr>
<td>Mean age at follow-up, yrs</td>
<td>6.12 ± 5.4 (0.07–22.31)</td>
</tr>
<tr>
<td>Mean time from surgery to follow-up, yrs</td>
<td>2.38 ± 3.22 (0.02–17.03)</td>
</tr>
<tr>
<td>Age at most recent op*</td>
<td></td>
</tr>
<tr>
<td>&lt;1 yr</td>
<td>68 (47)</td>
</tr>
<tr>
<td>&gt;1 yr</td>
<td>76 (53)</td>
</tr>
<tr>
<td>Type of shunt op</td>
<td></td>
</tr>
<tr>
<td>Insertion</td>
<td>86 (58)</td>
</tr>
<tr>
<td>Revision</td>
<td>62 (42)</td>
</tr>
</tbody>
</table>

Values expressed as the mean ± SD (range) or as the number of patients (%).

* Data not available in 4 patients from other facilities.

### TABLE 2. Results of 148 parent/guardian shunt knowledge surveys

<table>
<thead>
<tr>
<th>Shunt Knowledge Parameter</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Correctly identified valve type (programmable vs nonprogrammable)*</td>
<td>128 (86)</td>
<td>20 (14)</td>
</tr>
<tr>
<td>Correctly identified valve setting if programmable (n = 73)</td>
<td>54 (74)</td>
<td>19 (26)</td>
</tr>
<tr>
<td>Correctly identified valve name</td>
<td>72 (49)</td>
<td>76 (51)</td>
</tr>
<tr>
<td>Had a copy of the Hydrocephalus Association shunt booklet</td>
<td>100 (68)</td>
<td>48 (32)</td>
</tr>
<tr>
<td>Had laminated cards w/ shunt malfunction/infection information</td>
<td>103 (70)</td>
<td>45 (30)</td>
</tr>
<tr>
<td>Able to produce a card (or other source) w/ shunt type/valve/setting information</td>
<td>80 (54)</td>
<td>68 (46)</td>
</tr>
<tr>
<td>Able to identify 3 symptoms of shunt malfunction/infection</td>
<td>127 (86)</td>
<td>21 (14)</td>
</tr>
</tbody>
</table>

Values reported as number of respondents (%).

* Actual type of valve implanted (determined by physician): 73 programmable (49%), 72 nonprogrammable (49%), and 3 unknown (2%).
important in cases of patients with programmable valves, because MRI may occur in a facility that does not realize the patient has a programmable shunt or that does not have the capabilities to check or reprogram the shunt. For many reasons, it is important that caregivers are knowledgeable about the implanted shunt.

Programmable Valves and MRI

Although a recent study showed no radiation-induced malignancies in a single-institution study of high-risk patients with shunted hydrocephalus (with high risk defined as shunt placement prior to 6 years of age, minimum follow-up 10 years), the number of MRI procedures that are done to assess for symptoms of shunt malfunction continues to increase. Several manufacturers of programmable valves are now marketing MRI-resistant valves that are purported not to reset with scanning, although manufacturers do not go so far as to guarantee that this is the case. Despite advances in technology, a large number of valves that do reset with MRI are currently implanted, and the population of patients with these valves will persist for many years.

Parent/Guardian Knowledge of Symptoms of Shunt Malfunction or Infection

Little literature exists on patient teaching in the neurosurgical population. Parents have indicated that they value education received from neurosurgery staff, past experiences with shunt failure, self-education, and primary care physicians, in that order. A 2014 study examined how to improve information provision for neurosurgical patients with brain tumors. Almost all patients searched for information on the Internet. Suggestions for improving information provision included allowing patients to see their imaging results and avoiding the use of medical jargon. Almost all patients requested suggestions for reliable Internet sources that were vetted by neurosurgical professionals, frequently updated, and written in plain language.

Providing written information was also cited as important, given that up to 40%-80% of information deliv-
ered verbally by medical professionals is forgotten almost immediately.12 Others have focused on the importance of structure in improving recall.15 In a study of college students who watched a video of physician discharge instructions, on average, study participants recalled 7 of 28 items constituting information that was deemed essential by expert physicians. Breaking down the information into structured chapters was statistically significant in improving recall.

There have been attempts to correlate a parent’s ability to identify shunt failure on the basis of clinical signs and symptoms, with mixed results.10,13,14,18,20 Watkins et al. reported that parental direct referrals were more accurate than referrals originating from medical professionals. Kim et al.13 found that more experienced parents (that is, those whose children had > 3 prior shunt malfunctions) were more likely to predict shunt failure than parents whose children had experienced fewer shunt malfunctions. However, Naftel et al. found that parents with previous shunt failure experiences were more likely to overestimate the likelihood of malfunction.18

Other studies have shown that it is also difficult for medical practitioners to predict shunt malfunction on the basis of sign/symptoms report alone. Only lethargy and shunt site swelling were statistically significantly predictive of shunt malfunction in a chart review of 363 emergency room encounters.14 Analysis of data from the Pediatric Shunt Design Trial found that although some symptoms and signs were strongly associated with shunt failure, no 1 symptom or sign was individually sensitive.10 Most studies have indicated that symptom or sign clustering in conjunction with imaging is important in diagnosing shunt failure.10,14,18

The importance of educating caregivers about signs of shunt failure cannot be overstated. Studies evaluating deaths of children with shunted hydrocephalus have found that patients often had symptoms of increased intracranial pressure that were not recognized prior to their death.1,11 Iskandar et al. reported a 2% mortality rate in patients with shunts, and among patients who died, 10 of 28 exhibited symptoms of increased intracranial pressure for at least 24 hours prior to their death.1 The decline in mortality was attributed to increased nursing staff and effective patient family education. The clinic visit was identified as an opportunity to reinforce teaching, hopefully promoting early recognition of symptoms of shunt failure.

Importance of Teaching Aids and Reinforcement of Information

In this study, we demonstrated that an intervention such as providing written materials to parents/guardians at the time of shunt implantation significantly improved these individuals’ understanding and knowledge of device types, as well as specific considerations that the device type might warrant. By telling parents/guardians upfront that they need to know the information and then asking follow-up questions during clinic visits, caregivers are given the opportunity to rehearse the information and reinforce their knowledge. We believe that it also empowers the caregiver to become more comfortable in discussing the information with a health care provider. In turn, the health care provider can easily identify gaps in the caregiver’s knowledgebase and correct them at the time of the encounter.

### TABLE 4. Survey responses of group I compared with group II

<table>
<thead>
<tr>
<th>Variable</th>
<th>Group I, n = 75</th>
<th>Group II, n = 73</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identified correct shunt type*</td>
<td>72 (96)</td>
<td>56 (78)</td>
<td>0.001</td>
</tr>
<tr>
<td>Identified valve name*</td>
<td>53 (71)</td>
<td>19 (26)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Correctly identified valve setting†</td>
<td>28 (93)</td>
<td>26 (60)</td>
<td>0.0016</td>
</tr>
<tr>
<td>Had booklets</td>
<td>55 (73)</td>
<td>45 (62)</td>
<td>0.1288</td>
</tr>
<tr>
<td>Had symptom cards</td>
<td>59 (79)</td>
<td>44 (60)</td>
<td>0.015</td>
</tr>
<tr>
<td>Identified 3 symptoms of shunt malfunction/infection</td>
<td>65 (87)</td>
<td>62 (85)</td>
<td>0.8812</td>
</tr>
<tr>
<td>Had card w/ shunt type/setting</td>
<td>61 (81)</td>
<td>19 (26)</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

NS = not significant.

Values reported as number (%).

* Missing data for 1 patient on shunt type and valve name in Group II.

† Number of programmable valves: Group I, n = 30; Group II, n = 43.

### TABLE 5. Comparison of patient demographic data between groups I and II

<table>
<thead>
<tr>
<th>Variable</th>
<th>Group I</th>
<th>Group II</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of patients</td>
<td>75</td>
<td>73</td>
<td></td>
</tr>
<tr>
<td>Mean age at surgery (yrs)</td>
<td>4.13</td>
<td>3.25</td>
<td>0.3540</td>
</tr>
<tr>
<td>Mean age at follow-up (yrs)</td>
<td>5.79</td>
<td>6.46</td>
<td>0.1847</td>
</tr>
<tr>
<td>Mean time from op to follow-up (yrs)</td>
<td>1.66</td>
<td>3.17</td>
<td>0.0001</td>
</tr>
<tr>
<td>No. of shunt insertions</td>
<td>48</td>
<td>38</td>
<td>0.1217</td>
</tr>
<tr>
<td>No. of shunt revisions</td>
<td>27</td>
<td>35</td>
<td>NS (chi-square test)</td>
</tr>
<tr>
<td>Age &lt;1 yr at op*</td>
<td>35</td>
<td>33</td>
<td>0.8893</td>
</tr>
<tr>
<td>Age &gt;1 yr at op*</td>
<td>40</td>
<td>36</td>
<td>NS (chi-square test)</td>
</tr>
</tbody>
</table>

* Age data not available in 4 patients from other facilities.
Admittedly, wallet cards seem low tech in an increasingly high-tech world. There are now apps to keep track of shunt information, such as HydroAssist, which is featured on the Hydrocephalus Association’s website (http://www.hydroassoc.org/hydroassist-mobile-application/). However, if apps are maintained on a phone that is lost, stolen, or otherwise compromised, the information is also gone. Also, unless files can be shared among devices, it is not likely that multiple family members would have access to the information. These applications will probably improve in the future. But although a wallet card is low tech, most adults still carry a wallet, which allows for easy retrieval of the information. It is likely that a multimodal approach with both the written material and the use of HydroAssist may be beneficial.

Limitations of the Study

This is a retrospective study, and no attempt was made to control the timing of clinic visits. Patients are typically seen 2 weeks to 3 months postoperatively and every 1–2 years subsequently. These times can vary based on practitioner preference and patient/family request. Patients in group I did have a statistically significant shorter interval between surgery and follow-up (1.66 vs 3.17 years). No information was available on the educational or socioeconomic background of participants, which may be useful to examine in future studies.

Future Directions

We believe that the knowledge gains demonstrated by group I prove that a structured approach to providing information for patients with shunts improves recall of this information as well as patient safety. Early identification of shunt failure or infection symptoms should improve the time frame in which the patient receives medical care. Knowing whether the shunt is programmable and the setting (if programmable) should decrease errors in terms of not reprogramming after the patient undergoes MRI.

We have implemented a program to ensure that patients and caregivers have access to information regarding the implanted shunt valve and symptoms of malfunction or infection. Following surgery for shunt implantation or revision, parents/guardians are given a business card with contact information for the neurosurgery practice. In addition, the surgeon records the implanted valve name, designation of whether it is programmable, the valve setting if programmable, and the date. Inclusion of the date is important because patients may undergo shunt revision and placement of a new valve or the setting may be changed over time. Including the date on the card makes it clear which is the most recent iteration of the information. The parent/guardian is instructed to place the card in their purse/wallet and to keep it with them at all times.

Information about the implanted valve is also placed in the home-going electronic discharge instructions. This form is retained in the electronic medical record, which makes it accessible to other providers, and parents also receive a printed copy of this form. The discharging doctor or nurse practitioner also makes sure that the parent has the wallet card, a Hydrocephalus Association booklet, and the laminated card with symptoms of shunt malfunction or infection.

Parents/guardians are then queried at follow-up clinic appointments to identify the information on the valve name/type/setting and whether they have access to the booklets and cards. Any knowledge deficiency or lack of access to educational materials is corrected at the time of the clinic visit. We have found that this reinforces the importance of parents owning the information too. As patients enter their teens, if they are cognitively capable, we also query them about the information. As patients with previously implanted programmable valves enter our practice, we obtain records from previous physicians to validate patient reports and to determine whether the information is correct.

Conclusions

This study has implications for both pediatric patients and adult patients with shunts, particularly those with normal pressure hydrocephalus, many of whom have programmable valves. We hope to expand this program to our adult counterparts, and this may have implications for patients with implanted baclofen pumps as well. Further research linking education with improved outcomes is warranted.

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1. Acakpo-Satchivi L, Shannon CN, Tubbs RS, Wellons JC III,

Disclosures
The authors report no conflict of interest concerning the materials or methods used in this study or the findings specified in this paper.

Author Contributions
Conception and design: Ackerman. Acquisition of data: Ackerman, Fulkerson, Smith. Analysis and interpretation of data: all authors. Drafting the article: all authors. Critically revising the article: all authors. Reviewed submitted version of manuscript: all authors. Approved the final version of the manuscript on behalf of all authors: Ackerman. Statistical analysis: all authors. Administrative/technical/material support: all authors. Study supervision: all authors.

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