



Observations from Social Media Regarding the Symptomatology of Adult Hydrocephalus Patients

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■ **BACKGROUND:** Patients with hydrocephalus experience symptoms related to hydrocephalus in an age-dependent manner. However, prevalence estimates of hydrocephalus symptoms in young and middle-aged (YMA) adult patients are rare and variable. Highlighting the importance of hydrocephalus symptom management, the persistence and intensity of headache or gait disturbance have been associated with signs of brain white matter integrity loss, including in treated YMA adult patients. Thus, it is important to ascertain which symptoms adult patients with hydrocephalus report most to confirm their relative importance.

■ **METHODS:** Observations of symptom complaints were made from publicly viewable online responses to an inquiry posted by the Hydrocephalus Association to 2 Facebook webpages.

■ **RESULTS:** Within 7 days of inquiry posting, 381 complaints of signs and symptoms were identified in 82 online responses. Headache, cognitive deficits (cognition and memory), and mobility issues (dizziness, balance, or gait problems) were most commonly reported by 63%, 45%, and 40% of respondents, respectively. Results were highly similar for the subgroup of 53 patients reported as treated. For self-identified YMA patients (<60 years old), results were similar, but with fewer mobility complaints. Not previously reported, hypersensitivity to external stimuli was reported by one-half of the patients that reported headache.

■ **CONCLUSIONS:** The current results provide further quantitative support for the prioritization of study of headache, cognitive deficits, and mobility issues in YMA adult patients with hydrocephalus. Warranting further study, cranial hypersensitivity to external stimuli may represent a novel outcome measure, and treated YMA adult hydrocephalus patients continue to report symptoms associated with signs of brain damage.

INTRODUCTION

Hydrocephalus is a condition of excessive accumulation of cerebrospinal fluid that can create harmful pressure and a variety of neurologic complications and symptoms, including brain damage. Hydrocephalus can be congenital or with later onset due to injury, infection, mass lesion, hemorrhage, or unknown reasons.¹⁻³ Cerebrospinal fluid diversion via shunt implantation has decreased early mortality associated with hydrocephalus, permitting patients to avoid life-threatening events for varying durations.⁴ However, treated and untreated adult patients with hydrocephalus may continue to endure symptoms associated with signs of brain damage between neurosurgical consults⁵⁻⁷ but with unknown or unconfirmed prevalence, intensity, and persistence.

Patients with hydrocephalus experience symptoms related to their hydrocephalus in an age-dependent manner.⁸⁻¹² Young and middle-aged (YMA) adults are said to experience common symptoms, including headache, lethargy, visual disturbances, loss

Key words

- Cognition
- Headache
- Memory
- Mobility
- Patient participation
- Review
- Social Media

Abbreviations and Acronyms

- HDI:** Headache Disability Inventory
NPH: Normal-pressure hydrocephalus
YMA: Young and middle-aged

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of coordination or balance, loss of bladder control or frequent urge to urinate, and a decline in memory, concentration, and other cognitive functions (<https://www.mayoclinic.org/diseases-conditions/hydrocephalus/symptoms-causes/syc-20373604>). However, the few available reports for the least well-studied age group of YMA adult hydrocephalus patients provide symptom prevalence estimates that can vary widely (e.g., headache in 43%–94% of adult patients before treatment and in 5%–48% of treated adults),^{8,9,11-16} making it challenging to prioritize the symptoms for further study in YMA adults.

Akin to patients with other disease processes, patients with hydrocephalus use social media networks for support and information sharing, including Facebook, Twitter, and YouTube networks.¹⁷⁻²⁰ Facebook users are mostly YMA adults in their 20s to 40s, with 84% younger than 55 years old (as of January 2018; <https://www.statista.com/statistics/376128/facebook-global-user-age-distribution/>). Thus, the current study aims to capitalize on habitual information sharing among adult patients with hydrocephalus, caregivers, and the Hydrocephalus Association via Facebook webpages to rank the relative importance of an adult patient-generated list of hydrocephalus-related symptoms.

MATERIALS AND METHODS

On October 30, 2017, the following question was posted independently by the Hydrocephalus Association to the Facebook webpages at <https://www.facebook.com/HydroAssoc> (with >30,000 followers) and <https://www.facebook.com/adulthcrn> (with >500 followers). “As an adult, what signs and symptoms do you experience that are related to your hydrocephalus and how does hydrocephalus impact your daily life?” Responses were posted on the webpage.

Approval was obtained from the institutional review board of the University of Pittsburgh to analyze the publicly viewable free-form responses, which were copied from the webpages and analyzed by University of Pittsburgh investigators for mention of any sign or symptom. Frequency of report was calculated as the proportion of respondents that reported the sign or symptom. The respondent was counted only once for a sign or symptom described in more than one way. Closely related signs and symptoms were placed in general categories (e.g., “headache” for the multiple descriptions of headache, including tension, pressure, migraine, and shunt-related; “mobility” for balance, gait, and dizziness complaints; and “cognition” for general cognitive processes and memory combined).

Where possible, subgroup analyses were performed to test for significant differences in frequencies of report between subgroups or compared with the larger group using 2-tailed (or 1-tailed, where appropriate) χ^2 tests with Yates’ correction and critical $P = 0.05$ (using Prism 7.04, GraphPad Software, La Jolla, California, USA).

RESULTS

Respondent Characteristics

Within 7 days of posting of the question, there were 86 respondents, with 83% responding within 32 hours. Four respondents gave no information relevant to the question and

were excluded. Although not requested, many respondents provided information regarding patient characteristics, shown in **Table 1**. Eight of the respondents self-identified as caregivers responding on behalf of adult patients with hydrocephalus. Nineteen respondents described the hydrocephalus as congenital, communicating, noncommunicating, or obstructive (by 7, 3, 2, and 1 patient, respectively) and as due to Dandy–Walker syndrome, herniated brain and dura tears, meningitis, arachnoid cysts, complications at birth, aqueductal stenosis, aqueductal web, status post Chiari decompression, subarachnoid hemorrhage, or normal-pressure hydrocephalus (NPH) (by 1–2 patients each).

Impact on Daily Life

Respondents rarely answered the second part of the question about impact on daily life. The few responses reported an impact on activities, work, education, dependence of living, and relationships (16, 15, 4, 4, and 2 responses, respectively). Reported impact on activities ranged from not being able to walk for long or drive, to shopping or functioning at home with children being challenging, to no impact on daily life. Reported impact on work ranged from being unable to work or being forced to retire due to the symptoms, to having no problem working a full-time job. These ranges of reported impact are consistent with previous reports.²¹⁻²³

Most Commonly Reported Symptoms

Consistent with previous reports,^{9,24} several respondents explicitly distinguished between the severe and potentially life-threatening signs and symptoms associated with shunt malfunction or failure (including extreme headache, seizure, nausea, vomiting, falls or near falling, and fainting) and the milder symptoms endured between surgeries. Only descriptions not related to shunt failure were included and analyzed.

The 82 included respondents of the final study cohort made a total of 381 complaints of signs and symptoms experienced. Despite the large total number of complaints, most respondents reported signs and symptoms with some specificity (median: 4 complaints; mode: 2). Almost one-third of the respondents (24 patients, 29%) reported only 1 or 2 signs or symptoms, and 72% of the 82 respondents reported 5 or fewer signs and symptoms of any kind. Twelve percent of respondents reported worsening (5%) or no improvement (7%) of symptoms after shunt implantation, and 6% reported no symptoms.

Table 2 shows the most commonly reported signs and symptoms, descriptors used, and the frequency of report. Headache was the most common complaint, made by 52 (63%) of the 82 respondents. Whereas most descriptions of headache were unqualified, 12 respondents described the headache as migraine, pressure, tension, or shunt headache (**Table 2**). Three patients reported headache refractory to treatment, including unrelenting headache at near maximal intensity levels (e.g., 8 on 10) for years.

One-half of those who reported headache also reported sensitivity to external stimuli including light, noise, heat, weather changes, or other stimuli (**Table 2**). Six respondents (7%) reported headache sensitive to postural changes. Patients did not appear to be somaticizing as pain or hypersensitivity was not commonly reported in other parts of the body (**Table 3**).

Table 1. Patient Characteristics Based on Spontaneous Reports of Respondents

Characteristic	Based on	Results
Patient or caregiver	All 82 included responses	74 patients, 8 caregivers
Sex	Respondent report or common sex of first name	52 females, 24 males, 6 undetermined
Age	46 responses	18–86 years; average, 42 years
Age at diagnosis	37 responses	0–75 years; average, 39 years; 14 in first year of life; 18 in adulthood
Years since diagnosis	30 responses	2–56.5 years; average, 19; median, 18; mode, 3, for 6 patients
Treatment	56 responses	53 reported shunt implanted or “multiple surgeries”; 3 reported no shunt.
Number of surgeries	30 responses	1–65 surgeries; 5 patients, 1 surgery; 10 patients, 2–5; 7 patients, 6–13; 8 patients, 19–65 surgeries

Memory problems were the second most commonly reported, by 30 (37%) of the 82 respondents, one-half of whom specified short term memory problems (Table 2). Seventeen (21%) patients

expressed difficulties with cognitive processes such as multitasking, planning, organizing, or directions, 10 of whom also reported memory problems. Combined, difficulties with memory, and other cognitive processes were reported by 45% of respondents (Cognition category, Table 2). Balance was the third most commonly reported problem (by 26%). Combined with other difficulties related to mobility including gait problems and dizziness, mobility issues were reported by 40% of respondents (Mobility category, Table 2).

Seventy-six (93%) of the 82 respondents reported at least 1 sign or symptom. Of these symptomatic patients, 99% reported at least one of headache, cognition-related complaints, and mobility-related complaints with significant comorbidity among the symptoms (Figure 1A).²⁵

Subgroup Analyses

Fifty-three (65%) of the respondents spontaneously reported previous surgical treatment of the patient, 45 with shunts, and 8 with “multiple surgeries” unspecified. Nineteen percent of the surgically treated patients reported worsening (8%) or no improvement (11%) of symptoms after treatment, and 9% reported no symptoms. Symptom report frequencies of the subgroup of 53 reportedly treated patients were remarkably similar to those for the entire group of 82 patients (Table 2), which is likely to include additional treated patients who did not report treatment. Comorbidity of report of headache, cognition-related complaints, and mobility-related complaints of the 53 treated patients was nearly identical to the entire group (Figure 1B).

Forty-six (56%) of the 82 included respondents spontaneously reported the age of the patient, mostly in their 20s to 50s (median: 39.5 years; third quartile: 54 years; Table 1), consistent with the

Table 2. Signs and Symptoms Most Commonly Reported by Adult Hydrocephalus Patients

Sign or Symptom Reported by All 82 Respondents (Other Descriptors Used—Number of Patients)	Number of Patients	Percent of All 82 Respondents	Percent of 53 Treated Patients*	Percent of 41 YMA Patients*	Percent of 35 Treated YMA Patients*
Headache (migraine—6, pressure—3, shunt—2, tension—1)	52	63	62	59	60
Sensitivity to external stimuli (bad weather—9, light—7, noise—7, heat—5, weather changes—4, season changes—3, altitude—3, airplanes—2, barometric pressure—1, wind—1, motion—1, cold—1, humidity—1, crowds—1)	26	32	32	34	34
Cognition category (includes memory and cognitive processes)	37	45	45	49	46
Memory (memory/forgetful—15, short-term memory—15, long-term memory—1, new learning—2, loses time—1, needs visual aids—1)	30	37	38	37	37
Cognitive processes (cognition/foggy—12, multitasking—1, focus—1, planning—1, organizing—1, directions—1, spatial awareness—1, grogginess—1, dementia—1)	17	21	23	27	23
Mobility category (includes balance, dizziness, and gait)	33	40	43	32	31
Balance (fall—5)	21	26	32	24	23
Dizziness (lightheadedness—2, fainting—2, vertigo—1)	13	16	13	5	6
Gait (shuffling—3, cannot walk—1)	10	12	9	7	6

YMA, young and middle-aged.
*Frequencies were not significantly different from those of the larger group (χ^2 test, 2-tailed, $P > 0.05$).

Table 3. Signs and Symptoms Less Commonly Reported by Adult Hydrocephalus Patients

Sign or Symptom Reported by All 82 Respondents (other Descriptors Used—Number of Patients)	Number of Patients	Percent of All 82 Patients	Percent of 53 Treated Patients*	Percent of 41 YMA Patients*	Percent of 35 Treated YMA Patients*
Fatigue (excessive sleep—4, lethargy—4, exhausted—3, sleepy—1)	19	23	26	22	17
Visual disturbances (double vision—5, blurry vision—5, impairment—3, seeing spots—1, cloudiness in eye—1)	16	20	17	12	9
Non-headache pain category (abdominal—6, at shunt tube—3, eyes—2, behind eyes—2, neck—2, back—2, ear—1, surgery—1, all body—1, referred—1, not specified—3)	6 or less each	7 or less each	11 or less each	12 or less each	14 or less each
Affect category (anxiety—6, depression—5, mood swings—5, fear—1, suicidal—1, irritability—1, PTSD—1)	6 or less each	7 or less each	9 or less each	10 or less each	11 or less each
Other signs and symptoms (vomiting—6, urinary incontinence—5, nausea—4, seizures—3)	6 or less each	7 or less each	6 or less each	7 or less each	9 or less each

YMA, young and middle-aged.
*Frequencies were not significantly different from those of the larger group (χ^2 test, 2-tailed, $P > 0.05$).

expected age distribution of Facebook users (see the Introduction). Forty-one (41) of the 46 age-reporting respondents were YMA adults younger than 60 years old, and 35 of those were treated YMA adults. Worsening of symptoms or no symptoms after treatment were each reported by 6% of treated YMA patients. Notably, treated YMA patients made fewer reports of no improvement of symptoms after treatment (2 patients or 6% vs. 11% of 53 treated patients) due to exclusion of the 5 treated patients 60 years or older, 4 of whom reported no improvement after treatment. The most commonly reported symptoms for the two subsets of YMA patients were highly similar to those for the groups of all 82 respondents and of the 53 treated patients, except that reports of mobility impairment were less common due to less frequent reports of dizziness and gait difficulties (Table 2), resulting in less comorbid mobility-related complaints (Figure 1C).

In contrast, in a previous report of initial presentation of headache, and “dementia” and “gait” problems (vs. milder cognitive impairment and mostly “balance” complaints in YMA adults),²⁵ comorbidity was within 0%–3% of that for all respondents and all treated patients for each possible combination, except 2 (Figure 1D). There were less complaints of headache only and more comorbid dementia and gait (Figure 1D). This is likely due to the inclusion of NPH patients 60 years old or older who typically report less headache and more gait issues,²⁶ as the report was of complaints made by a compilation of 50 adult patients from 11 case report studies of hydrocephalus patients with various etiologies including NPH.²⁵

Less Commonly Reported Signs and Symptoms

Less commonly reported were several signs and symptoms often grouped with the most commonly reported symptoms. Fatigue and visual disturbances were the next most commonly reported symptoms, by 23% and 20% of the group of 82 respondents, respectively (Table 3). The 53 treated patients showed similar rates of report, and the subgroups of YMA and treated YMA patients

reported fewer visual disturbances than the larger group (Table 3). Urinary incontinence or other urinary symptoms were not commonly reported (by 6% of all respondents) (Table 3). Notably, only 2% of the YMA patients and none of the treated YMA patients reported urinary symptoms. Anxiety and depression were not commonly reported (by 7% and 6% of all respondents, respectively) (Table 3).

DISCUSSION

Most Commonly Reported Symptoms

Our analysis of publicly available online reports of signs and symptoms of adult hydrocephalus found headache, cognitive impairment, and mobility issues to be the most commonly reported in this convenience sample and in the subgroup of YMA adult patients younger than 60 years old. The results are consistent with the report of the most common pretreatment symptoms of headache, cognition problems, and mild “gait” issues in 67%–72% of adult hydrocephalus patients mostly (43/46) younger than 60 years old at presentation⁹ and in 69%–86% of 35 patients 16–65 years old at the time of diagnosis.²⁷ Our results provide further quantitative support for the top concerns of adult hydrocephalus patients recently identified by the Translation to Transform project (Patient-Centered Outcomes Research Institute Engagement Award Initiative Notice 2627) including headache, cognitive deficits, and physical impairment.²⁸

Headache was reported by 63% of all respondents and 59% of the YMA adult patients. Lower than the highest estimate of 94% of 17 YMA adult aqueductal stenosis patients presenting with headache,¹³ our observed frequency of headache report is greater than the 44% prevalence of “frequent or chronic headaches” in 386 YMA adults (20–45 years old) of a nascent Hydrocephalus Association patient registry.¹⁵ Our results are consistent with previous reports of presentation with headache by 58% of 103 aqueductal stenosis patients 36–62 years old; by 67% of 46 patients 16–53 years old with congenital, acquired, or idiopathic

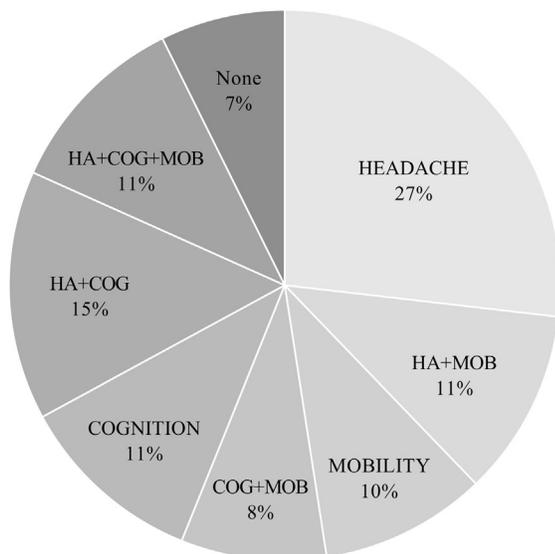
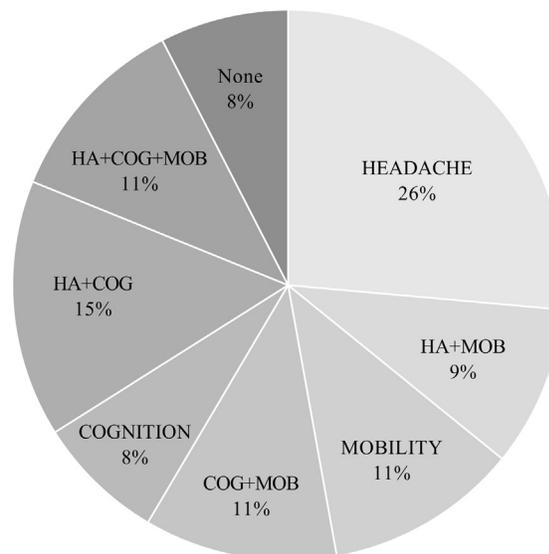
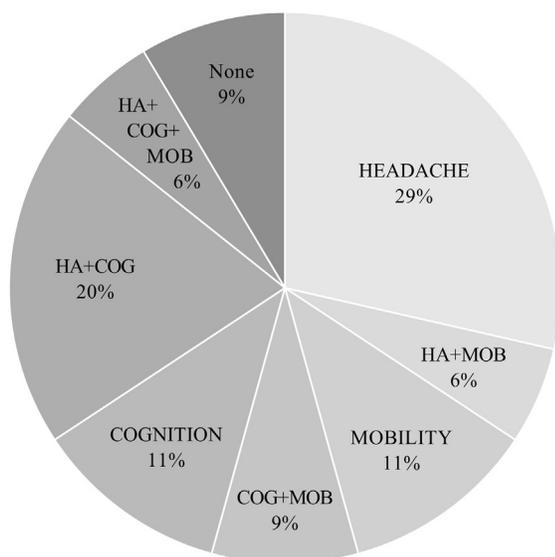
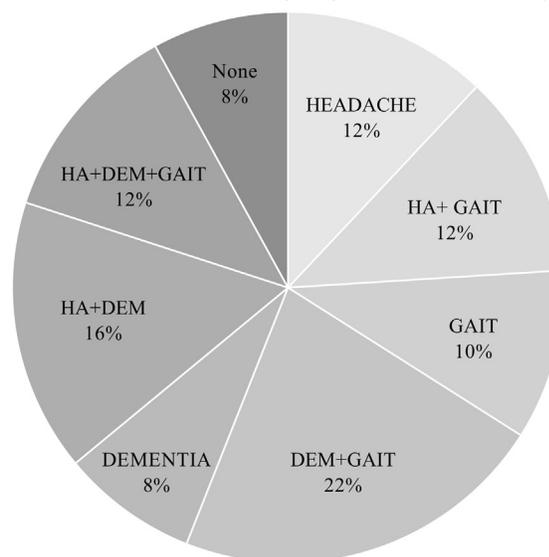
A All 82 Respondents**B** 53 Treated Patients**C** 35 Treated YMA Patients**D** 50 Adult Patients (Hogan and Woolsey 1966)²⁵

Figure 1. Pie charts showing comorbidity among the 3 most commonly reported categories of signs and symptoms of headache, mobility-related complaints, and cognition-related complaints. **(A)** For the entire group of 82 respondents, 76 (93%) patients reported at least 1 of the 3 categories of complaint. The 6 patients (7%) reporting none of the 3 include the 5 patients who reported no signs or symptoms. Significant comorbidity was observed with 58% of headache sufferers, 76% of patients with mobility issues, and 76% of patients with cognition complaints, reporting at least 1 of the other categories. **(B)** For the 53 patients self-identified as treated, comorbidity is

remarkably similar to that of the entire group. **(C)** For the 35 treated patients self-identified as YMA adults, comorbidities are similar to the group of 53 treated patients, but with slightly less comorbid mobility-related complaints (21% vs. 31%). **(D)** In contrast, the previous report²⁵ of comorbidity of complaints at initial presentation of 50 adults including older NPH patients was highly similar, but with slightly less complaints of headache and more comorbid "dementia" and "gait" complaints. HA, headache; COG, Cognition category; MOB, Mobility category; YMA, young and middle-aged; DEM, dementia.

hydrocephalus^{9,14}; and by 69% of 35 patients 16–65 years old with decompensated congenital, acquired, or idiopathic hydrocephalus.²⁷

Headache is common in the general population, with almost everyone (90%) expected to have experienced headache in their lifetime and 50% of the general population expected to have headaches during any given year.²⁹ However, chronic or persistent headache (for 15 or more days per month) is not common, with an estimated prevalence in the general population of 3%, and migraine prevalence is estimated at 10%.²⁹ Thus, YMA adult hydrocephalus patients report headache significantly more than the general population. A recent survey found that one-half of the pediatric neurosurgeons surveyed provide only reassurance for chronic headaches in shunted patients.³⁰ This indicates room for improvement in patient care, as a history of chronic headaches has recently been associated with signs of white matter integrity loss in YMA adult hydrocephalus patients compared with healthy controls.⁷

Cognition and mobility deficits were reported by 45% and 40% of the respondents, respectively. Greater frequencies of cognitive deficits (55%, 62%, 72%, and 86%) and mobility impairment (50%, 60%, 62%, 70%, and 74%) have been reported for YMA adult patients at initial presentation.^{8,9,14,16,27}

Less Commonly Reported Signs and Symptoms

The current study identified fatigue and visual disturbance as less commonly reported, and urinary incontinence, anxiety, depression, and other symptoms in **Table 3** as much less commonly reported, including in the subgroups of treated or YMA only adult patients. This is in contrast with the report of visual sequelae affecting up to 83% of patients with hydrocephalus³¹ but is consistent with other reports of lower frequencies of presentation of these symptoms relative to the three most common symptoms.^{9,14,21,27} The frequencies of report in our sample are consistent with published estimates of prevalence in YMA adult patients of visual disturbances (14%, 17%, 27%, 32%, and 34%),^{9,14,21,23} and fatigue and energy complaints (26%).⁹ Our frequencies of report are lower than published estimates of urological complaints (40%, 41%, and 50%)^{9,14,16} and depression (43%)³² in YMA adult patients, and of treated depression in adult patients with childhood hydrocephalus (45%).³³

Because the posted responses are publicly viewable, respondents may have been reluctant to report symptoms associated with social stigma. Thus, the frequencies of report for anxiety, depression, and urologic symptoms may be lower than if patients were privately surveyed. Nonetheless, our results are consistent with reports that these symptoms are among the least commonly reported relative to more commonly reported symptoms.^{9,14,21,32}

Reports of Symptoms by Treated Patients

A portion of respondents provided sufficient information to perform subgroup analyses, including of self-identified treated patients and treated YMA patients. We found that more than 90% of treated patients report at least 1 of the 3 most common symptoms. This result is consistent with previous reports of incomplete symptom resolution and of symptoms reported months or years after treatment.^{5,8,9,14,15,21,32} Cowan et al.⁹ observed complete resolution of all symptoms after treatment in

only 56% of mostly YMA adult patients and Vinchon et al.²¹ highlight that only a minority (18%) of 456 patients shunted in childhood were symptom free as YMA adults with a mean follow-up period of 23.0 years (95% confidence interval 24.0–24.3) after treatment.

Previous reports of frequency of headache after treatment in YMA adults range from 5% to 48%, with the lowest values observed soonest after treatment.^{5,8,14,32} Perhaps indicative of the natural course of symptoms in treated YMA adult hydrocephalus patients, significant improvement of intractable headache was achieved in YMA adult pseudotumor cerebri patients 1 month after shunt placement in 95% of 42 patients studied; however, headaches recurred in 19% and 48% of patients by 12 and 36 months after shunt placement, respectively.⁵

Cognition and mobility deficits were reported by the subgroups of treated patients and treated YMA patients, consistent with report of only partial improvement of gait impairment after treatment⁸ and with the 47% and 48% prevalence of motor and cognitive deficits, respectively, in YMA adults shunted in childhood.²¹ Thus, a significant portion of YMA adult hydrocephalus patients endure cognition and mobility problems that may benefit from new, renewed, or continued rehabilitation effort.

Novel Finding of Patient-Reported Hypersensitivity to External Stimuli

We report for the first time the novel finding of adult hydrocephalus patient-generated complaints of hypersensitivity to a range of external stimuli in approximately one third of all respondents, all treated patients, or treated YMA patients. One-half of those who reported headache also reported sensitivity to external stimuli, suggesting that the hypersensitivity may be a primary symptom of hydrocephalus or is secondary to the headache.³⁴

Limitations

The current observational study is of a convenience sample of adult patients with hydrocephalus that use Facebook webpages to share information. Thus, it has inherent limitations due to the self-selection of the respondents to join the Facebook webpages and to notice, and respond to, the posted question. This selection bias could result in overestimation of the prevalence of signs and symptoms in the adult patient population as asymptomatic patients are less likely to seek information via social media. Mitigating this bias, 9% of the treated patients and 6% of the entire group reported no symptoms, demonstrating inclusion of asymptomatic patients. Unbiased estimates of symptom prevalence in the YMA adult population require a prospectively and privately surveyed, sufficiently large, randomly recruited group of YMA adult patients for analysis of comorbidity with complete patient characteristics and confidential medical history.

Utility for Hydrocephalus Research

The field of hydrocephalus research would benefit from additional outcomes to be used in mechanistic and treatment effectiveness studies.³⁵ We found that almost all symptomatic respondents reported at least one of the most common symptoms of headache, cognitive deficits, and mobility impairments. Thus,

measures of the 3 most common symptoms represent clinical outcomes with high priority for continued and improved use in hydrocephalus research. Validated scales and methods for the measurement of cognition and mobility impairments are available and widely used including in hydrocephalus research.^{36,37} For the study of YMA adults with milder impairments expected compared to older NPH patients displaying dementia,⁹ the use of the Mini-Mental State Examination has limited sensitivity to detect treatment effects, as noted previously.^{8,14,22} Instead, more elaborate batteries or measures with greater sensitivity and broad applicability in measuring and characterizing neuropsychological function, and that are also relatively quick to administer, should be used, such as the Repeatable Battery for the Assessment of Neuropsychological Status (R-BANS).³⁸

Measures of headache intensity, duration, and associated disability may be the best choice for further development in hydrocephalus studies as the intensity, frequency, and duration of headache bouts remain to be characterized for YMA adult hydrocephalus patients. Headache is quantifiable with sensitive and validated scales and measures including visual analog scales, numerical rating scales, and the Headache Disability Inventory (HDI).^{39,40} In patients with shunt-treated hydrocephalus, outcome measures from the HDI (total, emotional, or functional subscores) recently have been shown to be inversely correlated with left frontal ventricular volume and with the diffusion tensor imaging-based measure of fractional anisotropy of the posterior thalamic radiation and external capsule.⁷ Poor outcomes of increased HDI scores (but not the number of surgical revisions) have been associated with decreased ventricular volume and with decreased fractional anisotropy, indicating changes in white matter integrity along axonal pathways,⁷ further highlighting the potential value of measures of headache, which may be related to brain damaging consequences.

Characterization of the newly detected hypersensitivity to external stimuli also is warranted. This can be accomplished using

available standardized methods of quantitative sensory testing of cutaneous sensitivity of the head and face to mechanical and thermal stimuli.⁴¹ Quantitative sensory testing may find symptomatic patients to be more sensitive to standardized stimuli but also may find patients without concomitant headache to have sensory abnormalities as detected in asymptomatic trigeminal neuralgia patients.⁴²

CONCLUSIONS

Based on observations of a convenience sample of adult hydrocephalus patients, we report further quantitative support to prioritize study of the most commonly reported symptoms of headache, cognitive deficits, and mobility issues in YMA adult hydrocephalus patients. Especially for headache symptoms, almost unanimously reported in binary fashion as present or absent, development of quantitative measures of intensity, duration, and chronicity is warranted. From the patient-generated list of symptoms, we report for the first time the novel finding of hypersensitivity to external stimuli associated with headache reports. This phenomenon warrants further investigation in YMA adult patients as it may represent a novel measure of cranial sensitivity in hydrocephalus patients. Finally, similar frequencies of symptoms associated with signs of brain damage^{6,7} were reported by treated YMA adult patients, indicating that further assessment and treatment is warranted in these patients.

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