Adult Hydrocephalus Clinical Subtypes

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KEYWORDS

• Adult hydrocephalus • Health care transition • Idiopathic normal pressure hydrocephalus
• Acquired hydrocephalus • Secondary hydrocephalus

KEY POINTS

- Hydrocephalus is more common in adults than in children.
- The transition population comprises patients treated for hydrocephalus of any etiology before age 18 years who need continuing care in the adult health care system.
- Unrecognized congenital hydrocephalus includes patients with imaging, or enlarged head circumference consistent with congenital hydrocephalus but who were not treated before the age of 18 years.
- Acquired hydrocephalus comprises patients with hydrocephalus secondary to known risk factors (eg, subarachnoid hemorrhage, brain tumor).
- Suspected idiopathic normal pressure hydrocephalus (iNPH) includes patients aged $\geq$ 65 years referred for the evaluation of iNPH.

INTRODUCTION

Hydrocephalus is one of the most commonly encountered disorders in the practice of adult neurologic surgery. However, the adult hydrocephalus population (age 19 years and above) is not monolithic. Significant variation in the clinical presentation, diagnostic approach, and treatment decision making exists across the spectrum of adult hydrocephalus, which are influenced by the etiology, age of onset, symptoms, and neurologic examination findings of the hydrocephalus. Despite this variability, however, in the experience of this author, it appears common for the term *normal pressure hydrocephalus* (NPH) to be applied to many adults whose hydrocephalus does not match the clinical criteria of this well-known disorder, an error that can lead to misunderstandings regarding symptoms, as well as the approach to treatment. Therefore, the purpose of this article is to describe a pragmatic approach to the care of adults with different types of hydrocephalus.

EPIDEMIOLOGY

Worldwide and across the lifespan, hydrocephalus is the fourth most common of 10 conditions that require essential neurosurgical care, defined as *those conditions in which treatment neglect would directly result in severe disability or death*. Hydrocephalus accounts for 7% of all cases requiring operation, following traumatic brain injury (TBI) (45%), cerebrovascular accidents (20%), and epilepsy (10%).[1] The overall prevalence of hydrocephalus of all etiologies and ages worldwide is 85/100,000 according to a 2018 systematic review.[2] When evaluated by age groups, in children (perinatal to 18 y) the prevalence is 88/100,000; in adults (ages 19 – 64 y) the prevalence is 11/

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Abbreviations	
AHCRN	Adult Hydrocephalus Clinical Research Network
ASPN	American Society of Pediatric Neurosurgeons
CSF	cerebrospinal fluid
ED	emergency department
ETV	endoscopic third ventriculostomy
HCT	health care transition
ICP	intracranial pressure
iNPH	idiopathic normal pressure hydrocephalus
TBI	traumatic brain injury

100,000; and in the elderly (age 65 y and above) the prevalence is 175/100,000. Put another way, children account for one-third (32%) of the hydrocephalus population and adults account for two-thirds (68%). This estimate closely aligns with a 2020 analysis of surgical treatment of hydrocephalus in the United States that found that adults and elders accounted for nearly 3-quarters of all surgical procedures performed for hydrocephalus.[3]

With respect to emergency department (ED) visits for hydrocephalus, in the United States approximately 80% of patients are adults or elders.[4] More than 50% of all ED visits for patients of all ages resulted in hospital admission. Approximately, 7% of those patients whose reason for the ED visit was deemed neurosurgical required transfer to another acute care facility. Among these, adults were slightly less than half as likely as children to be transferred to an acute care facility, and elders were only about 30% as likely to need transfer. Thus, the care of adults with hydrocephalus is a major responsibility of adult neurosurgical practice.

ADULT HYDROCEPHALUS CATEGORIZATION

A confounding aspect of the taxonomy of hydrocephalus is variation and inconsistency either in the terms used to describe hydrocephalus, or the principles used to define separate groups. Examples include internal versus external; communicating versus noncommunicating/obstructive; congenital versus acquired; compensated versus decompensated; idiopathic versus secondary or symptomatic; normal pressure versus low or high pressure; and so on. A recent conceptual framework for classification of chronic hydrocephalus in adults incorporates many of these characteristics and describes 7 Groups: (1) *Hakim Disease*, better known as NPH; (2) Early Midlife Hydrocephalus; (3) Late Midlife Hydrocephalus; (4) Secondary Hydrocephalus; (5) Compensated Hydrocephalus; (6) Genetic Hydrocephalus; and (7) Transitioned Hydrocephalus.[5]

A more pragmatic classification scheme with only 4 groups for both research and clinical care has been used by the Adult Hydrocephalus Clinical Research Network (AHCRN) since its inception in 2014.[6]

- Transition, defined as patients who were treated for hydrocephalus of any etiology before the age of 18 years.
- Unrecognized congenital—patients with imaging features, or enlarged head circumference, or both, determined to be consistent with congenital hydrocephalus but who were not recognized or treated before the age of 18 years.
- Acquired—patients with hydrocephalus secondary to known risk factors (eg, subarachnoid hemorrhage, brain tumor), whether treated or untreated.
- Suspected idiopathic normal pressure hydrocephalus (iNPH)—patients aged $\geq$ 65 years referred for the evaluation of iNPH who had not previously received surgical treatment.

Transition

Patients who are treated for hydrocephalus of any etiology before the age of 18 years comprise the Transition category. While the age of hydrocephalus onset ranges from pre-natal to the teenage years, the common bond for all these patients is that they initially receive their care from pediatric specialists, and once they reach the ages of 18 to 21 years, most must receive their care from adult specialists. The process of this change, which applies to teens and young adults not only with hydrocephalus but also with a wide range of complex health care issues, has been termed health care transition (HCT). Got Transition, a national resource center on HCT in the United States, has identified 6 Core Elements for effective transition.[7] The Hydrocephalus Association, the largest patient advocacy group for persons with hydrocephalus and their families provides resources to help patients navigate the transition process.[8]

A significant challenge of HCT for young adults with hydrocephalus is the lack of adequate resources for the transition of to the adult health care system, including the lack of adult neurosurgeons willing to care for these patients, according to the proceedings of a 2017 Hydrocephalus Association Transition Summit that included adult and pediatric neurosurgeons and neurologists; neuropsychologists; patients with hydrocephalus; parents of patients with hydrocephalus; and

other specialists.[9] The American Society of Pediatric Neurosurgeons (ASPN) recognized the need for HCT in pediatric neurosurgery in 2020 in response to a survey of its members that concluded that *the majority of pediatric neurosurgeons have transition practices that are poor, do not meet the needs of patients and families, and should be improved*.[10] The ASPN also identified the need for *a structured approach to transition, local engagement with adult neurosurgical providers, and national partnerships between pediatric and adult neurosurgery organizations* to address current gaps in care.

A qualitative study of patients' and families' concerns regarding HCT found 4 prevailing themes:[11]

1. Achieving independence for the young adult;
2. Gaps in communication between the health care team and the patient and family regarding the transition process, as well as between the pediatric and adult specialists regarding the patient's care needs;
3. Loss of significant relationships and the environment associated with their care in the pediatric health system; and
4. Fear of uncertainty regarding the adult specialist's understanding of their hydrocephalus care and the steps the patient and family should take when potential problems with their hydrocephalus arise.

Adult neurosurgeons have an important role in the care of patients in the Transition population. The participants of the Hydrocephalus Association Transition Summit recommended that longitudinal care with planned, periodic visits is preferred and that it is inadequate to advise these patients and their families that there is no need for follow-up unless something bad happens and then they should go to the ED.[9] At the same time, the Transition Summit participants agreed that neurosurgeons should not be the only physicians participating in longitudinal care of adults with hydrocephalus.

The range of specialists and health care services involved in the care of the Transition population for hydrocephalus in adulthood depends on the etiology of the hydrocephalus and associated comorbidities, as well as comorbidities associated with the complications of treatment of the hydrocephalus. For example, young adults who have not had complications or comorbidities may need only an adult neurosurgeon. On the other hand, patients with myelomeningocele, cerebral palsy, or motor and intellectual developmental delay may need specialists in rehabilitation medicine, epilepsy, headache, pulmonology, urology, or others involved in their care. For adults who may not have been seen for their childhood onset hydrocephalus for years or even decades after their last follow-up in a pediatric setting, referrals to appropriate specialists for their care needs are often in order.

The surgical challenges in the care of the Transition population may include:

- Lack of records regarding their previous care, including implant records for the shunt system, or documentation of the rationale for complex shunt systems;
- Lack of prior brain imaging or information regarding the patient's signs or symptoms of shunt failure; however, when available, indicating the symptoms clearly and including images in the current medical record can be of future benefit;
- Calcification of the distal shunt catheter, whether it is the current tubing or remnants of a previous shunt system, that is sometimes painful enough to require surgical removal or replacement;
- Discovery of a fracture or disconnection of the shunt tubing in patients who appear to be asymptomatic with respect to the hydrocephalus;
- Shunt valves that can be decades old, frequently fixed-setting (non-programmable), that may or may not be MRI compatible;
- When shunt revision surgery is required, the decision whether to remove and replace the entire shunt system, and whether to replace an old fixed-setting valve with a modern programmable valve; and
- Whether to explore the possibility of *secondary* endoscopic third ventriculostomy (ETV) versus shunt surgery in the case of failure of previous ETV or shunt surgery.[12]

Unrecognized Congenital Hydrocephalus

This group of patients typically presents in 1 of 3 clinical scenarios:

1. Incidental: The patient has had a brain MRI or computed tomography for another purpose, such as headache or concussion, and the hydrocephalus is discovered as an incidental finding.
2. Chronic: The patient presents with chronic signs and symptoms suggestive of hydrocephalus.
3. Acute: The patient has symptoms of acute or decompensating hydrocephalus.

The determination that the hydrocephalus is likely congenital is based on enlarged head circumference, but it may also be related to the appearance of a so-called *aqueductal pattern* of

triventricular enlargement of the lateral and third ventricles and a normal-sized fourth ventricle, with or without obstruction at the cerebral aqueduct.[6] Other names have been applied to this disorder, including LIAS (late-onset idiopathic aqueductal stenosis), LOVA (longstanding overt ventriculomegaly in adults), or SHYMA (syndrome of hydrocephalus in young and middle-aged adults).[13–15]

Generally, the etiology of the hydrocephalus in this group is simple or uncomplicated, such as aqueductal stenosis or tectal glioma, and because many of these patients have otherwise been healthy, their clinical presentation is less affected by comorbidities.

The symptoms of hydrocephalus in the incidental or chronic scenarios in this group, when present, are generally more heavily weighted toward headache and cognitive difficulty (not dementia), rather than gait or balance difficulty or urinary incontinence as seen in NPH.[5,6,15,16] The headache may be chronic or intermittent. Cognitive impairment may be present, ranging from intellectual delay to minimal.[17]

Signs and symptoms of the acute or decompensating hydrocephalus clinical presentation include transient loss of consciousness, coma, severe headache, and papilledema. These patients are often admitted to the intensive care unit.

The decision to treat depends on the clinical presentation. Patients with incidentally discovered hydrocephalus often have no symptoms at all, or only minimal symptoms. Because many of them are employed or in their working years, neuropsychological testing may have a value to determine whether any impairment that could require workplace accommodations is present.[18] A common practice is to have asymptomatic patients return at periods of 1 to 3 years for clinical reevaluation and imaging.

Patients with chronic or acute symptoms can be treated either with shunt surgery or ETV, with ETV commonly recommended as the initial treatment when feasible due to a lower complication rate.[16,17,19] Some centers will assess cerebrospinal fluid (CSF) dynamics or craniospinal compliance to guide treatment decisions.[20,21] Follow-up is recommended for all patients. Improvement in neuropsychological performance can be seen.[19]

Acquired Hydrocephalus

Many disorders affecting adults can cause hydrocephalus, including subarachnoid hemorrhage, intraventricular hemorrhage, TBI, meningitis, brain tumor, and so on. The decision for shunt surgery when patients are in the intensive care unit is often made on the basis of signs and symptoms of elevated intracranial pressure (ICP), brain imaging, and ICP monitoring. The decision for shunt surgery after patients have been discharged from the hospital or are in the rehabilitation setting can be more challenging. Specifically, the challenge is to determine whether the appearance of ventricular enlargement on brain imaging is a consequence of impaired CSF circulation, that is, hydrocephalus, or whether it is due to the loss of brain tissue secondary to the primary injury.

Findings suggestive of hydrocephalus include:[22,23]

- Persistence of impaired consciousness when recovery is expected;
- Initial recovery followed by deterioration in level of consciousness not explained by other factors;
- Brain imaging features that are more characteristic of hydrocephalus than atrophy, such as effacement of sulci or bowing of the corpus callosum.

A multidisciplinary approach for patients with severe acquired traumatic and non-TBI to diagnose and treat hydrocephalus found hydrocephalus in 13% of patients, and that treatment was associated with a significant reduction in the Disability Rating Scale.[22] Further, more than 85% had improvement in cognitive function by discharge, and over 55% achieved functional improvement. Of note, the risk of complications was 16 times higher with fixed-setting shunt valves in comparison to programmable valves.

A challenging subgroup after TBI is patients who had a craniectomy for management of ICP and cerebral edema, and then appear to develop hydrocephalus following a cranioplasty procedure. Published guidelines suggest that most of the time, the enlargement of the ventricles is not from hydrocephalus. Accordingly, the guidelines recommended that the cranioplasty should be performed before consideration of shunt surgery.[24] Following patients closely for signs of hydrocephalus after cranioplasty and considering treatment with CSF diversion was recommended, and CSF infusion studies were considered helpful to determine the presence of hydrocephalus, but no other specific recommendations were offered.

Patients with risk factors for hydrocephalus who have initially made a good recovery can present months or years later with the syndrome of NPH. This is sometimes referred to as secondary NPH. Depending on the time interval between the original brain injury and the development of symptoms, as well as the contributions of any

comorbidities to the patient's clinical presentation, evaluation with CSF infusion testing or assessment of the response to temporary CSF drainage may be useful to determine whether shunt surgery is likely to be beneficial.

Suspected Idiopathic Normal Pressure Hydrocephalus

iNPH is a disorder of insidious onset in persons over age 60 that is characterized by:

- Enlarged cerebral ventricles on brain imaging
- Impaired gait and balance
- Urinary urgency and incontinence
- Cognitive impairment

The diagnostic challenge for persons referred for evaluation of suspected iNPH is that each of these 4 main features has multiple potential causes in the older population.[25] The international and the Japanese guidelines for iNPH recommend searching for other causes of the symptoms and, if possible, treating them first.[26,27]

Both of these guidelines use the terms *probable iNPH* and *possible iNPH*.

- Probable iNPH refers to patients with the idiopathic syndrome whose imaging, symptoms, and the results of physiological testing, such as CSF removal or CSF infusion testing, are consistent with iNPH.
- Possible iNPH refers to patients whose imaging and symptoms suggest iNPH, but have not had physiologic testing or whose presentation is atypical or who may have secondary NPH.

Although gait and balance impairment are widely considered to be essential symptoms, the entire clinical syndrome does not need to be present to consider the diagnosis of iNPH.[28] Neither the combination of the presenting symptoms nor the order of their onset accurately predict the outcome of shunt surgery.[28] Nonetheless, the process of differential diagnosis is critical to the process of evaluating patients with possible iNPH before proceeding either with tests of response to CSF drainage or with shunt surgery. Referral to appropriate specialists or testing is often indicated.

Key differential diagnostic considerations include but are not limited to:[25]

- Gait: cervical or lumbar spinal stenosis; peripheral neuropathy; arthritis of the hips or knees; and Parkinsonism and related disorders
- Balance: vertigo and vestibular dysfunction; peripheral neuropathy; and orthostatic hypotension
- Urinary Incontinence: prostatic hypertrophy; pelvic organ prolapse; and myelopathy
- Cognitive impairment: neurodegenerative dementia (eg, Alzheimer, Lewy body); vascular cognitive impairment; and medication side effects

Brain imaging should be evaluated for aqueductal stenosis or other causes of obstructive hydrocephalus, which in the elderly can present with a syndrome similar to iNPH and may be amenable to ETV. The Evans ratio, which is the widest frontal horn span divided by the widest cranial span on the same imaging slice is a screening tool, with a value $\geq$0.3 considered to suggest enlarged ventricles in the older population; however, the value does not correlate with symptom severity or likelihood of responding to shunt surgery. The so-called high-tight convexity appearance associated with DESH (disproportionately enlarged subarachnoid spaced hydrocephalus) may help to identify patients with iNPH, but its absence does not exclude the possibility.[29] No individual imaging finding can predict the outcome of shunt surgery in iNPH.[30] The Radscale provides a structured scoring system of brain imaging that may help identify patients more likely to have iNPH.[31]

The assessment of the response to CSF drainage can be performed either with lumbar puncture and removal of 40 to 50 mL CSF, or with extended lumbar drainage, which requires hospital admission for insertion of a temporary spinal catheter for 24 to 72 hours of CSF drainage. Characteristics of the gait, including velocity, should be formally assessed shortly before and after the CSF drainage trial. In iNPH, gait velocity is typically less than 1 m/s.[32,33] Gait velocity increase with CSF drainage of 0.1 - 0.2 m/s is usually considered objective improvement, as is an increase in gait and balance scores in standard instruments, such as the Tinetti assessment tool.

A protocolized approach to the diagnosis and treatment of iNPH by the AHCRN that followed the iNPH guidelines showed that 74% of patients with possible iNPH underwent assessment of response to CSF drainage, and of those, only 46% had shunt surgery, that is, only 34% of patients with possible iNPH eventually had shunt surgery. The rate of serious complications resulting in the need for surgery or an extended hospital stay was only 6%, and 91% of patients had no complications.[32]

Shunt surgery is effective in treating iNPH. A 2024 Cochrane review of 4 small placebo-controlled studies concluded that both gait speed and disability likely improve in the first 6 months after shunt surgery.[34–38] Other prospective studies

have shown improvement in gait, as well as bladder symptoms and cognition after shunt surgery for iNPH, and longitudinal follow-up to assess response to shunt surgery and adjust shunts settings is recommended.[39,40]

CLINICS CARE POINTS

- All adults with hydrocephalus benefit from longitudinal care for monitoring of their symptoms or assessing response to treatment.
- In addition to periodic visits with their neurosurgeon, patients in the Transition population often need other specialists and healthcare services, depending on the etiology of the hydrocephalus and its associated comorbidities.
- Acquired hydrocephalus should be suspected for patients after severe brain injuries who do not improve as expected or who improve and then worsen without an apparent cause.
- Patients with suspected iNPH require careful consideration of differential diagnosis as well as assessment of response to CSF drainage to guide decisions for shunt surgery.

DISCLOSURE

The author has no disclosures.

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