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ORIGINAL RESEARCH

Access to Healthcare for Hydrocephalus in the United States: Analyzing the Hydrocephalus Association Patient-Powered Interactive Engagement Registry (HAPPIER)

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Purpose: The hydrocephalus patient community has reported difficulties accessing medical care. The Hydrocephalus Association Patient Powered Interactive Engagement Registry (HAPPIER), a self-reported patient registry, provides a unique opportunity to examine the current landscape of healthcare access and barriers. This study aimed to identify and describe patterns in reported access to care among individuals with hydrocephalus in the United States.

Methods: HAPPIER participants completed a survey which captured information about physician access and insurance information. Analyses focused on US-based respondents and included measures of insurance coverage, access to neurosurgeons and neurologists, frequency of specialist visits, first point of contact in non-emergency situations, and reported barriers due to cost.

Results: HAPPIER included 606 US-based respondents. Half reported private health insurance, while 23.6% had Medicare and 20.1% Medicaid. A total of 17.2% reported lacking access to a neurosurgeon and 43.2% lacked access to a neurologist. Adults were significantly more likely than pediatric participants to lack access to specialists (23.0% vs 1.8% for neurosurgeons; 45.9% vs 36.1% for neurologists). Adults also reported less frequent visits to both neurosurgeons ($p < 0.0001$) and neurologists ($p = 0.0013$). In non-emergency situations, 50.5% of respondents identified a neurosurgeon as their first point of contact. 33.3% of participants reported financial barriers, particularly for medications (10.4%), medical specialists (9.9%), and rehabilitation services (8.4%). Adults more frequently reported difficulty accessing medications, specialists, and procedures, while pediatric patients reported more difficulty with rehabilitation services and genetic testing. Household income levels did not influence difficulty accessing care, other than for medications ($p = 0.0075$).

Conclusion: Findings from HAPPIER highlight substantial barriers to accessing specialized care for individuals with hydrocephalus, with disparities by age and insurance type. These results underscore the need for standardized long-term care guidelines and healthcare policies that ensure equitable access to specialized providers and services for all hydrocephalus patients.

Plain Language Summary: Hydrocephalus is a chronic condition that often requires lifelong medical care, yet many patients face challenges accessing the specialists and services they need. To better understand these and other challenges, the Hydrocephalus Association created the Hydrocephalus Association Patient Powered Interactive Engagement Registry (HAPPIER), where patients and caregivers report on their healthcare experiences. This study analyzed responses from 606 people in the United States.

Half of the participants had private insurance, about one in four had Medicare, one in five had Medicaid, and a small number (1.8%) reported no insurance at all. Many reported problems accessing specialists: 17% said they did not have access to a neurosurgeon, and

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43% did not have access to a neurologist. Adults were more likely than children to report lacking access, and they also reported seeing their specialists less often. In non-emergency situations, half of participants said they would first contact a neurosurgeon if they suspected a hydrocephalus-related problem.

Cost created another major barrier. One in three participants said high cost kept them from getting care, especially medications, rehabilitation services, and visits with specialists. Adults most often reported problems paying for medications, procedures, and specialist visits, while children more often reported challenges accessing rehabilitation services and genetic testing.

These findings show that people with hydrocephalus struggle to access the specialized care they need, often because of insurance type or financial barriers. More consistent healthcare guidelines and policies are needed to make sure all patients can get timely, affordable, and appropriate care.

Keywords: hydrocephalus, access to care, healthcare barriers

Introduction

Hydrocephalus is characterized by the imbalance of cerebrospinal fluid in the ventricular system.[1] This chronic medical condition requires frequent monitoring and medical intervention throughout the patient's lifetime, with total treatment-related costs surpassing two billion dollars each year in the United States.[2] Management of this complex neurological disease typically requires a ventriculoperitoneal shunt or an endoscopic third ventriculostomy.[1] Each year in the United States, hospitals perform over 36,000 shunt-related procedures with more than half of those representing emergencies.[2,3]

There are no standardized guidelines for the long-term treatment of hydrocephalus, resulting in poor care coordination among neurosurgeons, neurologists, and primary care physicians.[4] For adults with hydrocephalus, access to care is shaped not only by financial barriers but also by the ability to navigate a healthcare system that often lacks clear pathways for specialized care. Thus, comparative analyses between pediatric and adult healthcare systems are critical to identify key challenges.[5,6] Significant gaps also remain regarding how those with hydrocephalus should handle non-emergency situations. Furthermore, patients with hydrocephalus are particularly vulnerable to the costs of healthcare, underscoring the need for current and reliable data on health insurance coverage within this community.[2] Insurance status and type may influence where and how individuals with hydrocephalus seek care, yet empirical data supporting this are lacking. Still, quality of care fluctuates amongst insurance types today.[7,8]

To address these uncertainties, the Hydrocephalus Association (HA) included data on access to care in the Hydrocephalus Association Patient Powered Interactive Engagement Registry (HAPPIER), a self-reported patient registry, established in 2015.[9] HAPPIER provides a unique opportunity to examine patterns of healthcare access in the hydrocephalus community by capturing information such as health insurance type, frequency of neurosurgeon or neurologist visits, and difficulties receiving care due to high out-of-pocket costs. Because healthcare systems and insurance structures vary internationally, this study focuses on individuals with hydrocephalus in the United States. The hydrocephalus community identified access to care as a top research priority, including efforts to improve patient access to medical care, care coordination, and the transition from pediatric to adult specialists.[10] In this study, we identify and describe patterns in reported access to care and barriers experienced by individuals with hydrocephalus in the United States.

Methods

Ethics Statement

In May 2017, the University of Utah Institutional Review Board (IRB) approved HAPPIER. The IRB granted the study exemption status because it poses minimal risk, aligns with the Belmont Report, complies with the principles stated in the Declaration of Helsinki, and includes orderly monitoring and accounting of research activities. After reviewing a consent cover letter containing the study investigator's contact information, participants completed all surveys on an HA patient portal maintained through a REDCap instance. HA conducted analyses exclusively on de-identified data to protect participant privacy. A prior publication describes the full methods on the development of HAPPIER, explanation of the surveys, and participant recruitment.[9]

Participant Recruitment into the HAPPIER Registry

After a committee of HA staff, researchers, volunteers, and physicians conceived the concept of a patient registry in 2015, HA promoted HAPPIER through its communications and advertising, including on social media platforms like Facebook, Instagram, and Twitter (now X), at conferences, and through neurosurgeons and neurologists. Eligible participants included (1) individuals diagnosed with hydrocephalus and over the age of eighteen and (2) caregivers of patients with hydrocephalus responding on behalf of patients who, regardless of age, did not complete the survey themselves.

Surveying Participants

Upon registration in the HAPPIER registry, subjects completed an initial survey encompassing demographics; the type and cause of the subject's hydrocephalus; additional diagnosed health conditions; shunts and ETVs; doctors and insurance; educational, cognitive, and emotional disorders; and issues with movement (Supplemental File 1). The survey posed questions in either multiple-choice or free-response format. These responses served as the baseline for the patients with hydrocephalus. This paper highlights the data relevant to access to healthcare; responses on types of insurances; the source of primary health insurance; whether the subject had difficulty receiving care; and first contact point in non-emergency situations. Access to a neurologist or neurosurgeon is defined as the participant having an identified specialist. As a self-reported registry, HAPPIER captures participant perspectives on healthcare access rather than clinician-confirmed diagnoses. Accordingly, certain variables—particularly etiology—should be viewed as descriptive context rather than definitive medical classification. This limitation does not affect the interpretation of findings related to access to care.

Data collection commenced on June 29, 2018. Data was retrieved from the HAPPIER registry on March 8, 2022 (n = 773). The analyses excluded incomplete or non-compliant responses (n = 82) and participants living abroad (n = 85) to focus exclusively on the hydrocephalus population in the United States (n = 606). To estimate annual household income, each individual respondent's zip code was matched with the corresponding median household income in the American Community Survey's "Income in the Past 12 Months (in 2020 Inflation-Adjusted Dollars)" provided by the United States Census Bureau using 5-year estimates subject tables.

Analysis

We included respondents who selected having X-linked hydrocephalus (L1 syndrome) into the congenital hydrocephalus category for all analyses. We conducted descriptive analyses, comparing pediatric to adult access to care. Where appropriate, the analyses included chi-square tests and pairwise chi-square tests to determine statistical significance with an alpha level of 0.05.

To evaluate pediatric versus adult patients' access to a specialist, we performed two pairwise chi-square tests: one for access to neurosurgeons and another for access to neurologists. We excluded respondents who selected "Unknown" from these analyses. To examine associations between health insurance status and hydrocephalus etiology or estimated household income levels, we conducted individual chi-square tests for each insurance category. Given that respondents could select multiple health insurance plans, we limited each analysis to mutually exclusive respondent groups to ensure valid statistical inference. To examine difficulty in receiving care due to high cost between pediatric versus adult patients or between respondents with varying household income levels, we also performed chi-square tests for each type of care category given that respondents could select multiple options.

Data Access Statement

Please Email the Hydrocephalus Association National Director of Research (research@hydroassoc.org) to conduct a study using data from the HAPPIER registry.

Results

Demographics and Medical Characteristics

HAPPIER consisted of 606 participants residing in the United States from all but four states – North Dakota, South Dakota, Vermont, and West Virginia. From these 606 US-based respondents, 398 had hydrocephalus (65.7%) and 208 were caregivers (34.3%). HAPPIER collected information on patients' demographics (Table 1). 27.4% were under the age of 18 and 72.6% were adults (18+). Participants were predominantly White/Caucasian (87.8%) with 23 Black/African American (3.8%), 10 Asian (1.7%), 7 American Indian/Alaska Native (1.2%), and 29 Other (4.8%) participants. 482 participants identified as Not Hispanic or Latino (79.5%), 63 identified as Hispanic or Latino (10.4%), 23 identified as Ashkenazi Jewish (3.8%), and 38 responded Prefer not to answer or Unknown (6.2%).

The majority of participants self-reported having congenital hydrocephalus (43.7%), followed by idiopathic normal pressure hydrocephalus (iNPH) (17.8%), acquired hydrocephalus (17.7%), unknown (10.9%), or posthemorrhagic hydrocephalus of prematurity (PHHP) (9.7%) (Table 2). 514 participants (84.8%) reported receiving a permanent shunt at some point in their hydrocephalus treatment, whereas only 111 participants (18.3%) underwent an endoscopic third ventriculostomy (ETV), with or without choroid plexus cauterization (CPC) (Table 2).

Access to Neurosurgeons and Neurologists

Most participants selected a family practice doctor (47.4%) or pediatrician (27.2%) as their primary care physician (Table 2). Only 24 participants (4.0%) selected that they do not have one. Participants also reported whether they have a neurosurgeon or neurologist (Figure 1). A total of 104 participants (17.2%) reported lacking access to a neurosurgeon,

Table 1 Demographics of 606 US Respondents with Hydrocephalus

Demographics	**n (%)**
Age at time of survey	
Infant (0–11 months)	30 (5.0)
Toddler (1–3 years)	57 (9.4)
Child (4–12 years)	54 (8.9)
Teenager (13–17 years)	25 (4.1)
Young Adult (18–34 years)	196 (32.3)
Adult (35–59 years)	161 (26.6)
Older Adult (60+ years)	83 (13.7)
Gender	
Female	330 (54.5)
Male	273 (45.0)
Transsexual	1 (0.2)
Prefer not to answer	2 (0.3)
Race	
White or Caucasian	532 (87.8)
Black or African American	23 (3.8)
Asian	10 (1.7)
American Indian or Alaska Native	7 (1.2)
Other	29 (4.8)
Prefer not to answer	4 (0.7)
Unknown	1 (0.2)
Ethnicity	
Not Hispanic or Latino	482 (79.5)
Hispanic or Latino	63 (10.4)
Ashkenazi Jewish	23 (3.8)
Prefer not to answer	22 (3.6)
Unknown	16 (2.6)

Table 2 Healthcare Characteristics of 606 US Respondents with Hydrocephalus

Healthcare Characteristics	**n (%)**
Hydrocephalus etiology	
Congenital	265 (43.7)
iNPH	108 (17.8)
Acquired	107 (17.7)
PHHP	59 (9.7)
Unknown	66 (10.9)
Prefer not to answer	1 (0.2)
Permanent shunt	
Yes	514 (84.8)
No	83 (13.7)
Unknown	9 (1.5)
ETV (with or without CPC)	
Yes	111 (18.3)
No	437 (72.1)
Unknown	57 (9.4)
Prefer not to answer	1 (0.2)
Primary Care Physician	
Family Practice Doctor	287 (47.4)
Pediatrician	165 (27.2)
Internist	70 (11.6)
Advance Practice Provider	26 (4.3)
Do not have one	24 (4.0)
Unknown	16 (2.6)
Other	13 (2.1)
Prefer not to answer	4 (0.7)
OB/GYN	1 (0.2)

Abbreviations: iNPH, Idiopathic Normal Pressure Hydrocephalus; PHHP, Posthemorrhagic Hydrocephalus of Prematurity; ETV (with or without CPC), Endoscopic Third Ventriculostomy (with or without Choroid Plexus Cauterization).

and 262 (43.2%) participants reported lacking access to a neurologist. Access differed between adults and children, with 101 out of 440 adult participants (23.0%) reporting lacking access to a neurosurgeon, against only 3 out of 166 pediatric participants (1.8%). There was a smaller but still substantial difference between adults and children in access to a neurologist, with 202 adult participants (45.9%) reporting lacking access to a neurologist, against 60 pediatric participants (36.1%).

For those with access to a neurosurgeon (n = 502), adults reported seeing their neurosurgeon less frequently than pediatric patients ($p < 0.0001$) (Table 3). Compared to the 87.2% of pediatric patients who reported seeing their neurosurgeons at least once a year, only 46.0% of adult patients reported seeing their neurosurgeon in that same time frame. 128 adults with access to a neurosurgeon (37.8%) reported visiting their neurosurgeon only when problems arose contrasted to 9 pediatric patients (5.5%). This trend persisted as adults reported seeing their neurologists less frequently than pediatric patients ($p = 0.0013$). Among patients with access, pediatric individuals visited their neurologist more than once a year 19.3% more frequently than adults.

Health Insurance

Participants reported various types of health insurance available in the United States (Table 4). Half of all US-based participants had private health insurance. Moreover, 143 participants (23.6%) had Medicare, and 122 participants

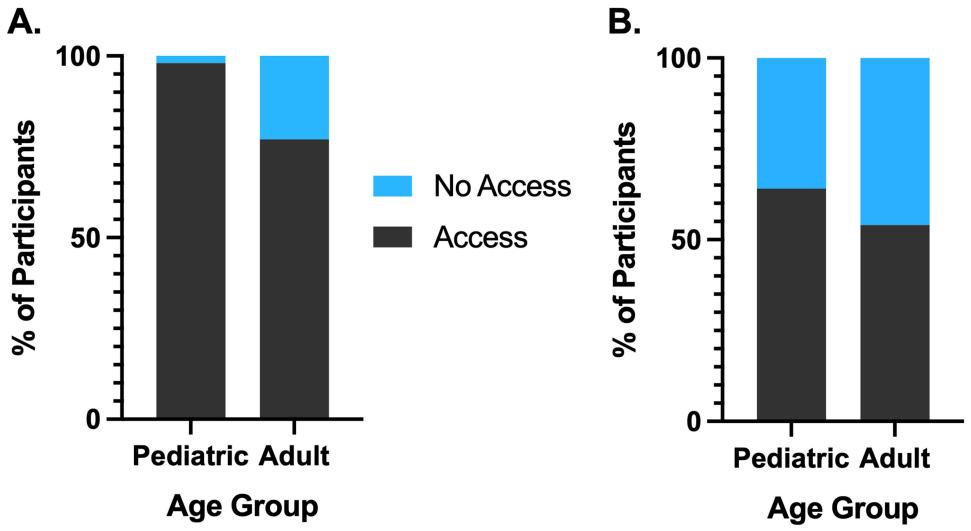

Figure 1 Access to Neurosurgeons (**A**) and Neurologists (**B**) by Age Group. Proportion of pediatric and adult participants reporting access to a (**A**) neurosurgeon or (**B**) neurologist. Adults reported substantially lower access than pediatric participants, with the gap between age groups being more pronounced for access to a neurosurgeon.

(20.1%) had Medicaid. 11 participants (1.8%) did not have health insurance coverage. Of the 606 US-based participants, 118 (19.5%) selected multiple health insurance plans. Compared to all hydrocephalus etiologies in our dataset, those with posthemorrhagic hydrocephalus of prematurity (PHHP) relied on Medicaid the most of all etiologies ($p = 0.0013$) and those with iNPH relied on Medicare the most ($p < 0.0001$) (Table 4). A similar trend was observed when comparing type of health insurance by age: older adults (60+ years) predominantly relied on Medicare, whereas about half of the participants in other age ranges held private insurance (Figure 2). Older adults (60+ years) were also more likely to have multiple health insurance plans (34%) compared to any other age ranges (<12%).

Median household income was significantly associated with insurance type (Table 5). Participants from higher-income households more often reported private insurance coverage ($p = 0.0070$), whereas participants from lower-income households more often relied on Medicaid ($p = 0.0095$). Income levels did not influence health plan coverage for Medicare, military health care, lack of insurance, or other insurance types ($p > 0.05$), although participants from lower-income households showed a nonsignificant trend toward greater reliance on Medicare than higher-income households.

Table 3 Frequency of Accessing Care for Those with Hydrocephalus

		How Often They See Their Hydrocephalus Provider						
	US Respondents n(%)	**More Than Once a Year**	**Once a Year**	**Every 2 to 3 Years**	**Every 4 Years or More**	**Only When Problems Arise**	**Unknown**	**P-Value**
Neurosurgeons								< 0.0001
Ages 0–17 with access	163	77 (47.2)	66 (40.5)	4 (2.5)	1 (0.6)	9 (5.5)	6 (3.7)	
Ages 18+ with access[a]	339	54 (15.9)	102 (30.1)	37 (10.9)	4 (1.2)	128 (37.8)	13 (3.8)	
Neurologists								0.0013[b]
Ages 0–17 with access	106	57 (53.8)	24 (22.6)	3 (2.8)	–	15 (14.2)	7 (6.6)	
Ages 18+ with access	238	82 (34.5)	63 (26.5)	18 (7.6)	3 (1.3)	63 (26.5)	9 (3.8)	

Notes: [a]1 adult respondent preferred not to answer when asked about the frequency of seeing their neurosurgeon and was excluded from the analyses. [b]Calculations for this P-value required the categories of "Every 4 years or more" and "Only when problems arise" to be combined for a valid chi-square test.

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Table 4 Health Insurance Differentiated by Hydrocephalus Etiology

		Hydrocephalus Etiology				
	US Respondents[a] N = 606	**Congenital N = 265**	**Acquired N = 107**	**iNPH N = 108**	**PHHP N = 59**	**P-value**
Type of health insurance	n (%)	n (%)	n (%)	n (%)	n (%)	
Private	303 (50.0)	146 (55.1)	53 (49.5)	43 (39.8)	33 (55.9)	0.0492
Medicare	143 (23.6)	42 (15.8)	23 (21.5)	61 (56.5)	5 (8.5)	< 0.0001
Medicaid	122 (20.1)	64 (24.2)	15 (14.0)	12 (11.1)	19 (32.2)	0.0013
Military health care	19 (3.1)	3 (1.1)	3 (2.8)	7 (6.5)	3 (5.1)	0.0342
No coverage	11 (1.8)	4 (1.5)	3 (2.8)	1 (0.9)	1 (1.7)	NS
Other[b]	95 (15.7)	43 (16.2)	24 (22.4)	11 (10.2)	9 (15.3)	NS

Notes: [a]Respondents had the option to select multiple health insurance plans. [b]The "Other" category is a generalized category that includes the responses of state-sponsored health plan, other government program, single service plan (eg, dental, vision, prescription), and coverage but unsure of type.
Abbreviations: iNPH, Idiopathic Normal Pressure Hydrocephalus; PHHP, Posthemorrhagic Hydrocephalus of Prematurity.

Challenges Accessing Care

In non-emergency situations when a hydrocephalus-related problem is suspected, 306 US-based participants (50.5%) reported they would contact a neurosurgeon first. The choice of first contact varied by type of insurance (Figure 3). Among those with private insurance, the majority (173, 57.1%) would contact a neurosurgeon first, while 44 (14.5%) would see a primary care physician, 34 (11.2%) would go to the emergency room, and 33 (10.9%) would contact a neurologist. Among respondents with Medicaid, 60 (49.2%) would contact a neurosurgeon, 27 (22.1%) would go to the emergency room, 22 (18.1%) would see a primary care physician, and only 8 (6.6%) would contact a neurologist first. Respondents with Medicare most often contacted a neurosurgeon first (64, 44.8%), followed by a primary care physician (26, 18.2%) or a neurologist (24, 16.8%), and 19 (13.3%) would go to the emergency room. Respondents without coverage were equally likely to go to the emergency room (3, 27.3%) or a neurosurgeon (3, 27.3%), but none went to a neurologist (0%). Across all insurance types, contacting a specialized clinic was rare (4, 0.7%), and a small proportion of respondents reported uncertainty or preferred not to answer (29, 4.8%).

31.3% of pediatric patients and 34.1% of adult patients, totaling 33.3% of the HAPPIER population, reported difficulty in accessing care due to high cost, particularly for medications (10.4%), medical specialists (9.9%), and

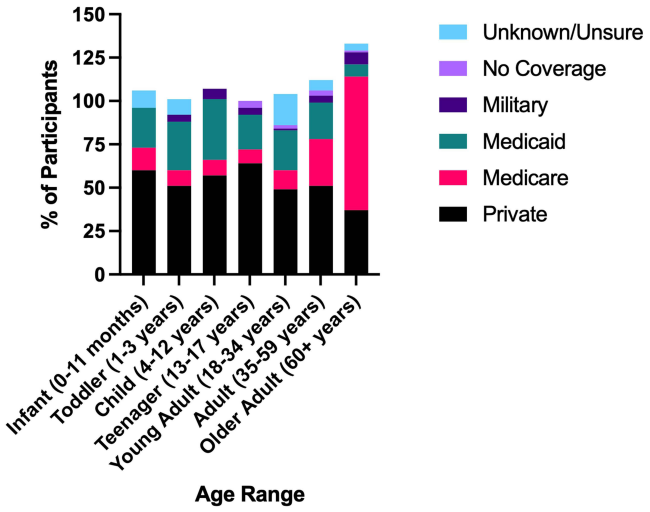

Figure 2 Health Insurance Differentiated by Age. Type of insurance based on age of participants. The majority of participants, regardless of age, held private insurance, except for older adults (60+ years) who predominantly had Medicare. Bar graphs over 100% indicate that participants within that group had multiple types of insurance simultaneously.

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Table 5 Health Insurance Based on Household Income

	Median Household Income							
	$20,000 - $39,999 N = 33 (5.4)	**$40,000 - $59,999 N = 160 (26.4)**	**$60,000 - $79,999 N = 156 (25.7)**	**$80,000 - $99,999 N = 90 (14.9)**	**$100,000 - $119,999 N = 67 (11.1)**	**$120,000+ N = 54 (8.9)**	**Unavailable Data[a] N = 46 (7.6)**	**P-value**
Type of health insurance	n (%)	n(%)	n (%)	n (%)	n (%)	n(%)	n(%)	
Private	12 (36.4)	67 (41.9)	76 (48.7)	50 (55.6)	43 (64.2)	33 (61.1)	22 (47.8)	0.0070
Medicare	9 (27.3)	50 (31.3)	42 (26.9)	18 (20.0)	10 (14.9)	10 (18.5)	4 (8.7)	NS
Medicaid	9 (27.3)	42 (26.3)	35 (22.4)	15 (16.7)	6 (9.0)	5 (9.3)	10 (21.7)	0.0095
Military health care	1 (3.0)	8 (5.0)	3 (1.9)	0 (0.0)	3 (4.5)	3 (5.6)	1 (2.2)	NS
No coverage	1 (3.0)	2 (1.3)	2 (1.3)	2 (2.2)	1 (1.5)	1 (1.9)	2 (4.3)	NS
Other[b]	4 (12.1)	21 (13.1)	26 (16.7)	16 (17.8)	11 (16.4)	7 (13.0)	10 (21.7)	NS

Notes: [a]Participants whose median household income data was unavailable were excluded from the analyses. [b]The "Other" category is a generalized category that includes the responses of state-sponsored health plan, other government program, single service plan (eg, dental, vision, prescription), and coverage but unsure of type.

rehabilitation services (8.4%) (Figure 4 and Table 6). However, specific types of care affected adults more than pediatrics: adults reported more difficulty accessing medications (p = 0.0057), medical specialists (p = 0.0233), and operations/procedures (p = 0.0483). Conversely, pediatric participants reported more difficulty accessing rehabilitation services (p = 0.0479) and genetic testing (p = 0.0006) compared to adult participants.

Income category did not significantly influence overall self-reported difficulty accessing medical care due to high out-of-pocket costs (Table 7). However, lower-income households reported significantly greater difficulty accessing medications because of cost compared with higher-income households (p = 0.0075). There were no significant income-based differences for other cost-related barriers, including access to medical specialists, rehabilitation services, procedures, or other high out-of-pocket costs (p > 0.05).

Discussion

The HAPPIER patient-powered registry provides information about hydrocephalus patient experiences to researchers and the physicians treating this condition. HAPPIER provides pertinent information regarding access to healthcare and the barriers that patients face.

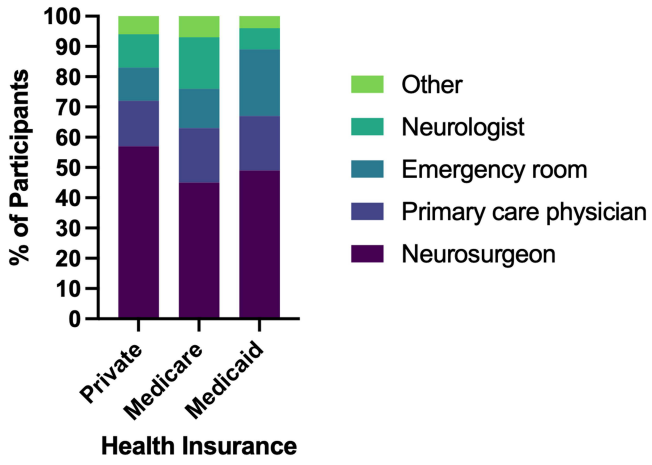

Figure 3 Initial Contact in Non-Emergency Situations by Insurance Type. Participants reported their first point of contact in non-emergency situations when they suspect a hydrocephalus-related problem. Regardless of whether they had private, Medicare, or Medicaid health insurance, most participants reported a neurosurgeon as their initial contact.

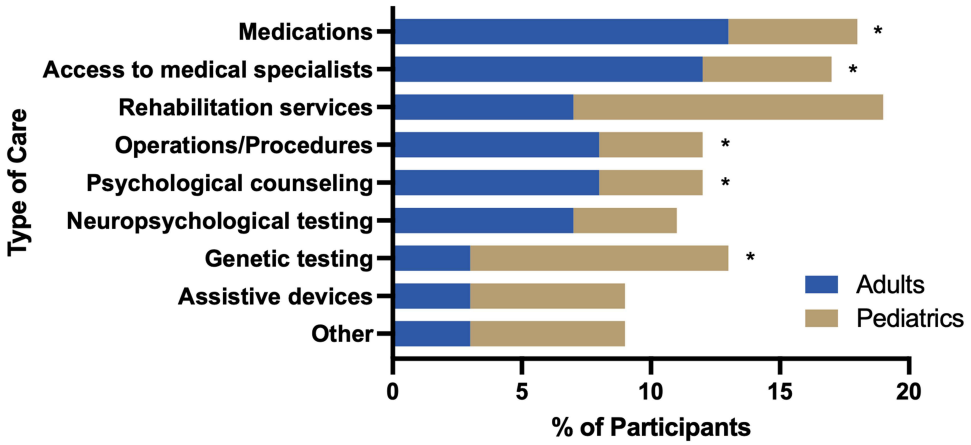

Figure 4 Type of Care That Was Difficult to Receive Due to High Cost. Percentage of pediatric versus adult participants reporting difficulty accessing different types of care due to high cost. Asterisks (*) indicate statistically significant differences between adult and pediatric respondents ($p < 0.05$).

Access to Adult Neurosurgical Care is Limited

The HAPPIER data revealed that adults with hydrocephalus are far more likely than pediatric patients to lack access to a neurosurgeon. This finding reflects a persistent challenge identified at the Hydrocephalus Association's Transition of Care Workshop: many patients have difficulty finding neurosurgeons who will care for them as adults, even those who were previously treated as children.[4] Barriers included gaps in health insurance coverage, limited longitudinal care, and differing expectations for follow-up. In some cases, neurosurgeons explicitly declined to follow adult patients, leaving them with limited options for ongoing care or shunt management. The underlying reasons are multifactorial, but many adult neurosurgical practices are not structured to provide the long-term, multidisciplinary care that hydrocephalus often requires, and adult surgeons tend to focus on acute surgical interventions rather than lifelong shunt maintenance.

The lack of accessible adult neurosurgical care creates substantial risks to those living with hydrocephalus. Shunt failure remains frequent in adults, with up to 64% of patients undergoing a revision within one year of insertion of a primary shunt.[11–13] Patients without an established neurosurgeon may face delays in treatment during a shunt emergency and rely on emergency departments instead of coordinated specialty care. For young adults transitioning from pediatric to adult systems, the absence of willing providers can disrupt continuity and leave patients without important follow-up.[14]

Table 6 Type of Care That Was Difficult to Receive Due to High Cost by Age Group

		Age Group at Time of Survey		
	US Respondents N = 606	**Pediatric N = 166**	**Adult N = 440**	**P-value**
Type of care	n (%)	n (%)	n (%)	
No Difficulty	404 (66.7)	114 (68.7)	290 (65.9)	NS
Medications	63 (10.4)	8 (4.8)	55 (12.5)	0.0057
Access to medical specialists	60 (9.9)	9 (5.4)	51 (11.6)	0.0234
Rehabilitation services	51 (8.4)	20 (12.0)	31 (7.0)	0.0479
Operations/Procedures	42 (6.9)	6 (3.6)	36 (8.2)	0.0483
Psychological counseling	39 (6.4)	6 (3.6)	33 (7.5)	NS
Neuropsychological testing	37 (6.1)	7 (4.2)	30 (6.8)	NS
Genetic testing	29 (4.8)	16 (9.6)	13 (3.0)	0.0006
Assistive devices	23 (3.8)	10 (6.0)	13 (3.0)	NS
Other	9 (1.5)	5 (3.0)	4 (0.9)	NS
Unknown	35 (5.8)	9 (5.4)	35 (8.0)	NS

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Table 7 Type of Care That Was Difficult to Receive Due to High Cost Based on Household Income

	Median Household Income							
	$20,000 - $39,999 N = 33 (5.4)	**$40,000 - $59,999 N = 160 (26.4)**	**$60,000 - $79,999 N = 156 (25.7)**	**$80,000 - $99,999 N = 90 (14.9)**	**$100,000 - $119,999 N = 67 (11.1)**	**$120,000+ N = 54 (8.9)**	**Unavailable Data[a] N = 46 (7.6)**	**P-value**
Type of Care	n (%)	n(%)	n (%)	n (%)	n (%)	n(%)	n(%)	
No Difficulty	19 (57.6)	105 (65.6)	96 (61.5)	70 (77.8)	48 (71.6)	39 (72.2)	0 (0.0)	NS
Medications	7 (21.2)	20 (12.5)	22 (14.1)	4 (4.4)	3 (4.5)	2 (3.7)	2 (7.4)	0.0075
Access to medical specialists	4 (12.1)	21 (13.1)	17 (10.9)	3 (3.3)	4 (6.0)	5 (9.3)	2 (7.4)	NS
Rehabilitation services	3 (9.1)	17 (10.6)	16 (10.3)	2 (2.2)	5 (7.5)	5 (9.3)	3 (11.1)	NS
Operations/ Procedures	2 (6.1)	18 (11.3)	12 (7.7)	4 (4.4)	1 (1.5)	3 (5.6)	3 (11.1)	NS
Psychological counseling	2 (6.1)	12 (7.5)	13 (8.3)	3 (3.3)	3 (4.5)	5 (9.3)	3 (11.1)	NS

Note: [a]Participants whose median household income data was unavailable were excluded from the analyses.

The HAPPIER data also revealed that adults with hydrocephalus who have access to specialists see their neurosurgeons and neurologists less frequently than pediatric participants. This reduced engagement may have stemmed from multiple factors: the limited number of specialists able to manage long-term hydrocephalus care,[15] an incorrect perception that fewer shunt revisions occur in adulthood (1-year shunt revision rate of 64% versus 78% in pediatrics) which reduces the need for regular monitoring,[12,16] and general tendencies among older adults to avoid medical visits.[17] However, reliance on emergency departments for urgent care, as some neurosurgeons recommend,[18] further fragments continuous care and may contribute to preventable complications.[19]

Addressing these gaps will require deliberate efforts to improve transition planning, expand specialist training and availability, and incentivize adult neurosurgical follow-up to ensure continuity across the lifespan.

Access to Neurologists is Limited

Neurologists can diagnose and aid in treating hydrocephalus, including but not limited to cases of iNPH.[20] Unlike neurosurgeons, who are typically involved at the point of surgical intervention, neurologists often manage symptoms and comorbidities on a routine basis. This ongoing involvement may allow neurologists to identify subtle clinical changes and initiate earlier referrals for surgical evaluation when necessary. For example, many patients in the hydrocephalus community experience chronic headaches, memory problems, and difficulty walking.[21] By developing individualized treatment plans and monitoring symptoms over time, neurologists are well-positioned to detect signs of shunt malfunction or progression of the condition.

Despite their critical role, the HAPPIER data revealed that 43.2% of participants lacked access to a neurologist. Even among those with access, adults with hydrocephalus see a neurologist less frequently than pediatric patients. This gap may reflect broader systemic challenges, as the more than 16,000 neurologists currently providing patient care in the United States are increasingly overwhelmed by the demands of the aging population.[15,22,23] As a result, their involvement is often limited to the initial diagnosis, with less consistent participation in long-term monitoring and follow-up care.[20] However, for many patients, neurologists can provide significant value through ongoing monitoring of disease symptoms and management of comorbid conditions.

Disparities in Care Based on Insurance Type

Socioeconomic factors can influence disparities in access to care. Lower estimated household income was associated with greater reliance on Medicaid, whereas higher income was associated with private insurance coverage. Insurance type, in turn, influenced where individuals with hydrocephalus sought care in non-emergency situations. While the appropriate point of contact should depend on clinical factors, such as the patient's history, etiology, and age, the variation in responses based on health insurance type raises concern about structural barriers to appropriate access. Participants with Medicaid more frequently reported the emergency department as their initial point of contact compared

with participants with other insurance types. This may reflect a broader issue: some physicians and specialists decline to accept Medicaid, limiting options for routine or preventative care. As a result, Medicaid patients often experience delays in accessing appropriate services, which can result in more frequent routine emergency room visits.[24]

Research further supports the connection between insurance type and outcomes. One study that explored racial and socioeconomic disparities in preterm infants with posthemorrhagic hydrocephalus found that infants insured through Medicaid had increased mortality rates than those with private health insurance.[25] Another study demonstrated that insurance type was a significant predictor of hospital readmissions and shunt revisions among hydrocephalus patients.[26] These findings highlight the urgent need to improve access to specialized scare for all individuals with hydrocephalus, regardless of income levels or insurance status, to reduce disparities in outcomes.

Financial Constraints

Financial barriers presented an additional challenge to accessing care. Treatment for hydrocephalus is expensive, with costs accumulating over time due to repeated hospitalizations, surgeries, and specialist visits and additional medical services.[27,28] For example, the average hospital cost for an infant with posthemorrhagic hydrocephalus of prematurity is nearly half a million dollars.[29] Even with health insurance, many patients still face financial challenges, particularly when care involves out-of-network specialists or services not fully covered by their plan. Insurance types may also limit access to certain providers or treatments, especially when long-term or repetitive care is needed. While only 1.8% of HAPPIER participants reported having no health insurance coverage—well below the national average[30]—financial barriers were still present, particularly in accessing medications, medical specialists, and rehabilitation services. This suggests that coverage alone is not sufficient; gaps in insurance networks and limitations in coverage can make access to necessary care financially burdensome, even for those who are insured. Additionally, these barriers occurred across all household income levels, indicating that cost-related access challenges affect individuals regardless of socioeconomic status. Delays in accessing necessary healthcare may result in worsened cognitive, neuropsychological, and overall health outcomes, greater reliance on emergency departments which can fragment care, and increased economic burden.[31,32]

Need for Structured Care Models

Collectively, these findings support the need for structured models of care for hydrocephalus. The observed loss of neurosurgical and neurological access after pediatric care, infrequent specialist follow-up in adulthood, reliance on emergency departments, and difficulty in accessing services indicate that care delivery remains reactive rather than longitudinal. Structured transition pathways that formally link pediatric and adult neurosurgical services, define expectations for ongoing surveillance, and embed multidisciplinary collaboration between neurosurgery, neurology, and primary care could mitigate gaps in access and continuity. Recommendations from the Hydrocephalus Association's Transition of Care Workshop similarly emphasize the need for coordinated transition planning and dedicated adult care pathways to reduce care fragmentation and loss to follow-up.[4] Health systems may leverage these findings to develop referral networks, transition protocols, and care coordination frameworks that support lifelong management of hydrocephalus rather than episodic, crisis-driven care.

Limitations

The HAPPIER dataset does not represent the full diversity of the hydrocephalus population. One notable limitation is the lack of racial and ethnic diversity among respondents.[9] Additionally, the registry population may be skewed toward individuals with more severe or complex cases of hydrocephalus, reflecting the characteristics of those more likely to engage with the Hydrocephalus Association. Participation in HAPPIER is voluntary and recruitment occurs primarily through an advocacy organization, which may preferentially capture individuals who are more engaged in their care, more connected to patient communities, or experiencing greater unmet needs, thereby introducing selection bias and limiting the generalizability of findings to the broader hydrocephalus population.

Because HAPPIER is a self-reported registry, findings reflect participants' perspectives and experiences rather than clinician-verified records. This design provides valuable insight into patient experiences but may limit precision for certain medical variables (ie, etiology of hydrocephalus). To mitigate the potential impact of etiologic misclassification

on interpretation, most analyses in this study were stratified by age group rather than by hydrocephalus subtype, allowing the results to focus on age-related differences in access to care. However, etiology and age at onset of hydrocephalus likely play an important role in shaping care pathways, access to specialists, and perceived barriers. These factors were not examined in depth in the present analysis and represent an important direction for future work, as etiology-specific care needs may substantially influence where individuals seek care and the challenges they encounter.

Additionally, the HAPPIER survey did not distinguish between routine follow-up and urgent or emergency care, nor did it capture the specific clinical reasons for seeking neurosurgical or neurological evaluation. As a result, reported difficulties in access likely reflect a range of care needs, rather than a uniform problem. In addition, the survey did not capture the clinical consequences of access difficulties, limiting our ability to link reported barriers to specific health outcomes. The registry also does not capture whether alternative access pathways, such as nurse-led triage systems or direct contact mechanisms used in some healthcare systems, were available to participants, which may mitigate the impact of delays in certain settings.

Several aspects of the dataset also constrain interpretation. Participants could select multiple types of health insurance, preventing mutually exclusive statistical analyses. Medical care affordability varies widely across the United States;[33] however, HAPPIER did not collect information on socioeconomic status or annual household income, and estimates derived from participants' zip codes provide insight into the collective neighborhood, rather than individual financial circumstances. Moreover, questions on cost-related barriers to care addressed only direct financial costs and did not capture indirect burdens such as time off work, travel distance, or other logistical barriers.

Finally, HAPPIER can only provide indications of access to care. There are no benchmark data to define how many patients should have access to a neurosurgeon or neurologist, or how often they should be seen. Therefore, these findings should serve as a foundation for further investigation into the extent and impact of access disparities.

Conclusion

HAPPIER demonstrates the urgent need for increased access to specialized care. Adults reported infrequent neurosurgical follow-up, and both pediatric and adult patients visit neurologists infrequently. Compounded by the high cost of healthcare in the United States, health insurance barriers further limit access to necessary care. To address these challenges, findings from HAPPIER should inform action by policymakers, hospital administrators, and physicians alike.

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Disclosure

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