

# The Subjective Experience of Patients Undergoing Shunt Surgery for Idiopathic Normal Pressure Hydrocephalus (INPH)

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The counseling of patients with idiopathic normal pressure hydrocephalus (iNPH) is difficult; there is variability in the diagnostic criteria, and a definitive diagnosis can only be made postoperatively. A patient's clinical response to shunting is also difficult to predict. This study examines the subjective experience of patients treated for iNPH, in order to identify the challenges patients face and to improve patient outcomes and satisfaction.

### Methods

We reviewed a consecutive series of patients diagnosed with iNPH who underwent ventriculoperitoneal shunt surgery between January 2012 and March 2016 at our institution. Semi-structured telephone interviews were conducted with 31 patients. Interviews were analyzed using the principles of grounded theory.

### Figure 1. Semi-structured interview template used to conduct patient interviews.

#### Figure 1. Interview template

Please describe how e doing prior to neurosurgery and the events that lead you to see a

How did you make the decision whether or not to have shunt neurosurgery? What factors did you What did you hope to gain from the surgery's

Was there any anxiety surrounding the surgery and what factors were res Postonerative Outcomes

What was the most significant benefit that you experienced after shunt surgery? Has your ability to walk improved after shunt surgery? Describe how you feel it has improved Has your ability to clearly think improved after shunt surgery? Describe how you feel it has

Have your urinary symptoms improved after shunt surgery? Describe how you feel they have improved. Patient Reflection

Are you satisfied with your decision to have shunt surgery? Are you satisfied with the outcom after surgery? Please explain. What were some things the neurosurgeon did well or did not do well in your inte

Is there anything during the course of your illness and treatment that you would have done differently? What have been the most difficult things for you throughout the course of your illness? How would you counsel another patient with normal pressure hydrocephalus? Would you recommend shunt surgery? What things would you discuss with them?

Other than what the doctors told you, did you use any outside resources or information?

### Results

Thirty-one patients who underwent shunt surgery for iNPH were interviewed to reach saturation of themes. Seven themes were identified: 1) long preoperative course causes morbidity; 2) the decision to have shunt surgery is easy to make; 3) patients primarily desire to gain independence; 4) patients display variable levels of anxiety; 5) comorbid conditions interfere with postoperative assessment; 6) patients stand by their decision to have shunt surgery; 7) outside information is utilized prior to surgery.

Characteristic	Number of Patients (%)
Age	
Median	77 years
Range	64 - 90 years
Sex	
Male	14 (45%)
Female	17 (55%)
Race	
Caucasian	29 (94%)
African-American	1 (3%)
Asian	1 (3%)
Medications	
Anti-hypertensive	23 (74%)
Lipid lowering	19 (61%)
Anti-platelet or anti-coagulation	17 (55%)
Anti-diabetic	10 (32%)
Anti-psychotic	4 (13%)
Anti-depressant	15 (48%)
Benzodiazepine	8 (26%)
Anti-Parkinson's disease*	4 (13%)
Cognition enhancing**	6 (19%)
Comorbid cardiovascular disease	
Any	26 (84%)
Hypertension	21 (68%)
Hyperlipidemia	15 (48%)
Coronary artery disease	8 (26%)
Comorbid neurological disease	
Stroke	7 (23%)
Alzheimer's disease	0 (0%)
Parkinson's disease	3 (10%)
Other comorbid condition	
Diabetes mellitus	10 (32%)

Characteristic	Number of Patients (%)
reoperative symptoms	
Gait disturbance	31 (100%)
Cognitive impairment	22 (71%)
Urinary incontinence	25 (81%)
uration of preoperative symptoms	
≤1 year	21 (68%)
> 1 year	10 (32%)
ime between surgery and interview	
Median	30 months
Range	16 - 56 months
atient reported outcome at interview	
Gait improvement	23 (74%)
Cognitive improvement	10 (45%*)
Urinary improvement	11 (44%**)
ther interview information	
Satisfied with shunt surgery	25 (81%)
Would recommend surgery to another patient	28 (90%)
Caregiver participated in interview	12 (39%)

# Conclusions

Patients often present to the neurosurgeon frustrated and desperate after a long preoperative course. It is important to acknowledge the uncertainty regarding diagnosis and response to shunting when counseling patients. Comorbid conditions interfere with the ability to assess progression of iNPH and the effectiveness of the shunt. Patient caregivers play a large role in decision-making and clinical course, and should be included when counseling patients.

#### References

1. Mori E et al. Guidelines for management of iNPH (2nd edition). Neurol Med Chir (Tokyo) 52:775-809:2012.

2. William MA et al. Diagnosis and management of iNPH. Neurol Clin Pract 3:375-85;2013.

## Learning Objectives

To understand the subjective experience of patients with iNPH who undergo VP shunt insertion.

