REPORT OF THE
DIVISION OF NEUROLOGICAL SURGERY AT
THE MEDICAL COLLEGE OF VIRGINIA OF
VIRGINIA COMMONWEALTH UNIVERSITY

The Estimated Incidence of Normal Pressure Hydrocephalus in Assisted Living and Extended Care Facilities for the Senior Virginia Residents

TO THE GOVERNOR AND THE GENERAL ASSEMBLY OF VIRGINIA



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# The Estimated Incidence of Normal Pressure Hydrocephalus in Assisted Living and Extended Care Facilities for the Senior Virginia Residents

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Executive Summary: A study of potential risk for Normal Pressure Hydrocephalus (NPH) among the elderly housed in extended care or assisted living facilities within the State of Virginia was completed. In addition, 20,000 brochures describing the symptoms of NPH targeted to our senior citizen population was completed and distributed throughout the state. Medical records from a total of 235 residents within 4 facilities, one extended care and three assisted living were analyzed and queried for risk factors coincident with NPH. Of the 235 residents, 115 (48.9 %) were over the age of 85 and were excluded from analysis leaving 147 residents in the study cohort. The three major symptoms, difficulty in walking, dementia and incontinence were identified and classified as to the degree of risk category ranging from no risk (0) to maximum risk (10). 19.5 % of residents were associated with a degree of risk of 6 or greater. Residents with all three symptoms of the triad are among the greatest risk for NPH. A total of 8.7 % of residents had all three symptoms: gait disturbance, incontinence and dementia. Only 10/147 residents had a brain image (computerized tomography or magnetic resonance) which is necessary to confirm the diagnosis. We conclude, based on symptoms, the estimated incidence of suspected NPH among our senior citizens is high and ranges from 9 to 14 % of all admissions. Other medical problems developing over time may overshadow the complications brought on by NPH and it is important that diagnosis and treatment be instituted early. An NPH screen is proposed which can take the form of a one-page query of symptoms specific to Normal Pressure Hydrocephalus. This would include the presence of one or more of the elements of the NPH triad of gait disturbance, incontinence and dementia. Excluding other pathology, the physician can then request a CT scan to determine if ventricles (cavities within the brain) are enlarged and consistent with the diagnosis of NPH. With the combination of symptoms and enlarged ventricle, the patient may be referred to specialists for additional tests to determine if the patient would benefit from surgical treatment leading to an improved quality of life.

#### Introduction

The goal of this study is to improve the overall health and quality of life of Virginia's adult population by increasing awareness of the potential benefits of screening and treatment for Normal Pressure Hydrocephalus. Normal Pressure Hydrocephalus (NPH) is a clinical syndrome that typically occurs in late adulthood and is characterized by the gradual onset of worsening gait apraxia or difficulty in walking, dementia and incontinence. The gait apraxia may be characterized by either a shuffling, wide-based or ataxic gait. Incontinence may be complete or simply frequent urination. Dementia may be either faltering short or long-term memory. Due to its typical presentation, the diagnosis of this complex condition can be quite difficult. Unfortunately, NPH is frequently misdiagnosed or undiagnosed and is, therefore, left untreated. Delegate Frank Hargrove, after seeing how his wife, Orianna, benefited with treatment for NPH questioned how many other patients in care facilities might have benefited with proper diagnosis. In light of this, and after discussions with Dr. Harold Young, Chairman of Neurosurgery at Virginia Commonwealth University Medical Center and Dr. Marmarou, Vice Chairman of Research, we proposed two major objectives: First, to develop a brochure and a Web page targeted to our senior citizens of Virginia, which would explain NPH and how to get help. Second, to conduct a survey of incidence and un-diagnosis of NPH among nursing home residents in the state of Virginia. All of these objectives were completed.

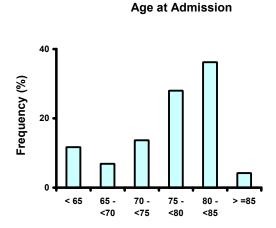
#### Methods

All procedures were approved by our internal review board. In cooperation with Drs. Boling and Penczak and the nurse coordinator Laura Finch, we began by identifying nursing homes and assisted living facilities from which to derive our patient sample. As confidentiality of patient medical records was a key issue, Dr. Marmarou and staff members visited each of the 4 facilities and provided a lecture describing NPH to the medical staff which helped enormously in gaining the confidence of the administrator and director at each site in allowing access to their resident's medical records. More importantly, it provided the facility with the procedure as to the medical chart review and how confidentiality would be maintained. As a result, all of the sites agreed to join the study and cooperation was outstanding. Medical records from 4 sites, two extended care and two assisted living were reviewed for a total of 245 charts screened. A trained nurse traveled to each site to perform these on-site chart reviews, which were coordinated with the site staff. The goal of the chart review was to identify patients who fit the typical NPH risk profile and assign them a "risk grade", as specified by a strict screening protocol. These data were entered into an NPH database that was used for subsequent statistical analysis of estimated incidence of potential NPH patients.

#### **Results**

#### **Age and Gender of the Study Cohort**

Residents 85 years and older were excluded from the study as it was decided that the risk/benefit of treatment at this age range and beyond was not favorable for the patient. Of the 245 patients 38% were over the age of 85 leaving 147 patients for the study group. The distribution of age among the study cohort is shown in Figure 1.0.



The numbers of residents increase with age and the greatest number of patients are within the 75 to 85 year range which is well within the age range expected for NPH. There was considerable gender difference between men and women suggestive of the longer life expectancy of women. The ratio of women to men was approximately 4 to 1.

# **Symptoms of Normal Pressure Hydrocephalus**

As stated earlier, the three major symptoms of NPH referred to as the "triad" are gait disturbance, dementia and incontinence. The number of patients with the complete triad equaled 11 of 126 or 8.7 %. Gait is considered the predominant component of the triad and it is unlikely that the patient has NPH without some form of gait disturbance. The number of patients with gait problems alone equaled 28 of 132 or 21.2 %. The number of residents with gait difficulty/dizziness equaled 31 of 131 residents (23.7%). The number of residents with gait difficulty and incontinence equaled 19 of 128 or 14.8 %.

Table 2.0 Components of the NPH Triad among Residents of the Study Group

Components of the NPH Triad	Percentage of Study Group
Residents with gait, incontinence and dementia	8.7%
Residents with gait difficulty or dizziness	23.7%
Residents with gait difficulty and incontinence	14.8%
Residents with gait difficulty only	21.2%

#### **Estimation of the Incidence of NPH**

In summary, the estimate of NPH based on records of residents with the complete NPH "triad" is 8.7 % of patients. If we consider gait and incontinence, the number of residents with two components of the triad equal 14.8 %. Similarly, if we consider the combination of gait and dementia, the number of residents having both symptoms equal 9.5 %. Therefore, we estimate the incidence of NPH based on symptoms alone to range from 9.0 to 14.8 % of the resident cohort.

# **Co-Morbidity among the Senior Residents**

The residents within the study group have several additional medical problems (co-morbidity) that can co-exist with the suspected NPH incidence. The major problems are summarized in table 3.0 below.

Table 3.0 Medical Problems within the Study Group - N=147

Depression	51.4%
Parkinsons	8.8%
Seizures	10.3%
Hypertension	38.4%
Cardiovascular	16.5%
Back Pain	17.9%
Respiratory	12.3%
Short Term Memory	75%
Long Term Memory	65.8%

These other problems certainly play a role in deciding the optimal management of those residents with suspected NPH. A more detailed analysis of problems and medical conditions associated with the resident group is contained in Section II of this report.

#### **Survey of Assisted Living Compared to Extended Care**

It was interesting to review the survey data from assisted living in comparison to the extended-care facilities. Of the 245 residents surveyed, 139 were housed in assisted living

facilities. Of the 139 residents, 45 were over the age of 85 leaving 94 residents in the assisted living study group.

# **Age and Gender of the Assisted Living Cohort**

The comparison of age distribution in assisted living and extended care is shown in Table 2.0. We were under the impression that assisted living residents would be younger than those in extended care. However, this was not the case. For example, 69 % of residents in assisted living were within the age range of 75 to 85. This compares with 55 % of residents in extended care facilities in the same age range. Therefore, residents within

extended care facilities cannot be excluded from more thorough diagnositic procedures for NPH based on the premise that these residents would be much older and as a result at higher risk for surgical intervention. Other factors would have to be considered.

Table 4.0 Comparison of Resident Age between Assisted Living and Extended Care Facilities

Age Range	Assisted Living	Extended Care
Less than 65	7.5	18.9
65-70	3.2	13.2
70-75	15.9	9.4
75-80	28.7	26.4
80-85	40.3	28.3
>85	4.3	3.8

# **Incidence of Suspected NPH in Extended Care and Assisted Living Facilities.**

Although it may seem, based on age, that the resident profiles are similar, this is not the case when comparing symptoms which are characteristic of Normal Pressure Hydrocephalus. These differences are listed in table 5.0

Table 5.0 Components of the NPH Triad Among Residents of the Study Group

Components of the NPH Triad	Assisted	Extended Care
	Living	
Residents with gait, incontinence and dementia	1.3%	19.2%
Residents with gait difficulty or dizziness	19.0%	30.8%
Residents with gait difficulty and incontinence	6.5%	26.9%
Residents with gait difficulty only	17.7%	26.4%

Clearly, the residents in extended care facilities are at proportionately higher risk when comparing the frequency of elements within the NPH triad. The greatest difference lies in the residents with the complete triad. In extended care, the percentage equals 19.2 and only 1.3 % in assisted living. In summary, the percentages of all elements of the triad appear at greater frequency in the extended care facilities.

#### Co-Morbidity among Senior Residents in Assisted Living vs Extended Care

The residents within the study group had several additional medical problems that were coincident with the suspected NPH incidence. The major problems are summarized in table 1.0 below. It is also evident from Table 1.0 that the co-morbidity is higher in the extended care

facilities, which is not unexpected as the residents with more problems require a greater amount of care. It reinforces the notion that attention must be paid to the co-morbidity of the residents in regard to potential for surgical intervention for relief of NPH symptoms.

**Table 6.0 Comparison of Co-morbidity in Assisted Living and Extended Care Facilities** 

	Assisted Living	Extended Care
Depression	50.5%	52.8%
Parkinsons	8.8%	7.5%
Seizures	5.6%	18.9%
Hypertension	29.7%	52.8%
Heart Disease	22.5%	32.7%
Diabetes	15.7%	32.7%
Short Term Memory	76.0%	74.5%
Long Term Memory	72.0%	62.7%
Stroke	11.2%	25.0%
Cancer	13.5%	17.3%

## **Comparison of ADL Scores in Assisted Living and Extended Care Facilities**

Perhaps the most telling statistics are in the activities of daily living (ADL) scores. These describe the degree of independence in various daily tasks. The ADL score ranges from A to G and are defined as follows.

- A. Independent in feeding, continence, transferring, toileting, dressing and bathing
- B. Independent in all but one of these functions
- C. Independent in bathing and one additional function
- D. Independent in all but bathing, dressing and one additional function
- E. Independent in all but bathing, dressing, toileting, transferring and one additional function.
- G. Dependent in all six functions.

The comparison of ADL scores among assisted living and extended care residents are listed in Table 7.0.

**Table 7.0 Comparison of ADL Scores in Assisted Living and Extended Care Facilities** 

ADL score	Assisted Living	Extended Care
A	9%	0%
В	23%	9.4%
С	13%	7.6%
D	7%	5.7%
Е	4%	9.4%
F	6%	3.8%
G	28%	62.2%

From Table 7.0, as expected, the proportion of residents dependent in all six functions (G) in assisted living facilities equals 28 % compared to 62.2 % in extended care. This emphasizes the notion that patients at high risk for NPH must be diagnosed and treated early before other medical problems become so overwhelming that residents who may have benefited become refractory to treatment.

#### Recommendations

This study was primarily a chart review and our findings, based on clinical symptoms. suggest that 9 to 14 % of residents are at risk for Normal Pressure Hydrocephalus. It is important that an "NPH Screen" be instituted by the attending physician prior to admission either to an assisted living or extended care facility. This NPH screen can take the form of a one-page query of symptoms specific to Normal Pressure Hydrocephalus which would include the presence of one or more of the elements of the NPH triad of gait disturbance, incontinence and dementia. Excluding other pathology, the physician can then request a CT scan to determine if ventricles (cavities within the brain) are enlarged and consistent with the diagnosis of NPH. With the combination of symptoms and enlarged ventricles, the patient may be referred to specialists for additional tests to determine if the patient would benefit from surgical treatment leading to an improved quality of life.