Epidemiology and Direct Economic Impact of Hydrocephalus: A Community Based Study

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ABSTRACT: ***Background:*** The cost of care for hydrocephalic patients is not well established. ***Methods:*** This retrospective study for the years 1990-1996 analyzed the cost of surgical intervention and hospitalization of hydrocephalic patients in the community-based setting of Manitoba, Canada, with a stable population of 1.138 million. ***Results:*** The number of discharges with a primary diagnosis of hydrocephalus was greater than 200 annually. The mean duration of hospital stay was 12.4 to 21.9 days, depending on the etiology of hydrocephalus. Approximately 80 shunt procedures were performed annually. The total annual cost of care, excluding outpatient costs and chronic non-hospital based costs which could not be determined accurately, was estimated to be CDN$ 3.5 million in this community. ***Conclusions:*** Hydrocephalus is a chronic condition which puts substantial monetary demands on society and therefore deserves greater attention.

RÉSUMÉ: Épidémiologie et impact économique direct de l'hydrocéphalie: une étude de population. ***Introduction:*** Le coût des soins aux patients hydrocéphales n'est pas bien connu. ***Méthodes:*** Il s'agit d'une étude rétrospective des coûts chirurgicaux et hospitaliers du traitement des cas d'hydrocéphalie dans la population du Manitoba, au Canada, une province qui a une population de 1.138 million. ***Résultats:*** Le nombre de congés hospitaliers dont le diagnostic était hydrocéphalie était de plus de 200 par année. La durée d'hospitalisation moyenne était de 12.4 à 21.9 jours, selon l'étiologie de l'hydrocéphalie. Environ 80 dérivations étaient effectuées annuellement. Le coût total annuel des soins, excluant les coûts extrahospitaliers qui ne pouvaient être évalués avec précision, ont été estimés à 3.5 millions ($CDN) dans cette population. ***Conclusions:*** L'hydrocéphalie est une condition chronique qui a un coût monétaire important pour la société et qui mérite donc une plus grande attention.

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The economics of disease and medical disorders are of importance for planning of health care budgets by government and private insurance companies. This was painfully exposed in detail by the 1992 survey, The Cost of Disorders of the Brain, in which the total annual cost of neurologic and psychiatric disorders in the United States was estimated at US$ 401 billion.[1] The authors concluded that if we are to diminish that cost, we must invest resources in brain-related research. One of the recurring themes in the study, however, was that for many disorders there were insufficient data to estimate the real costs.

Hydrocephalus was among the disorders whose cost could not be estimated. It is a neurological condition characterized by dynamic enlargement of the cerebrospinal fluid (CSF) -containing ventricular cavities of the brain. The enlarged ventricles compress and damage the surrounding brain.[2] The natural history of untreated childhood hydrocephalus is poor with only a 20-25% survival to adulthood. Most untreated survivors have severe physical and mental disabilities.[3,4] Childhood handicaps resulting directly from hydrocephalus include disturbances in motor abilities, particularly gait,[5] impaired cognitive development,[6] impaired language abilities,[7] and hypothalamic dysfunction with delayed growth and short stature.[8] In adult-onset hydrocephalus, the disabilities include unsteady gait, urinary incontinence, dementia, and movement disorders.[9,10] Fortunately, the natural history has been altered by intervention. Hydrocephalus can be successfully treated surgically by diversionary shunting of CSF. Currently in Canada, hydrocephalus and spina bifida are the cause of death in only a very small number of children.[11] Unfortunately, treatment by CSF shunting is associated with frequent complications that add to patient morbidity and mortality.[12] Long-term investigations of shunted children indicate that 81% suffer at least one and usually several shunt malfunctions necessitating repeated hospitalization.[13]

Some epidemiologic data are available for hydrocephalus. It is the second most frequent congenital neurological malformation, after spina bifida, in North America, appearing in 5-6/10,000 live births.[14,15] Hydrocephalus also develops secondarily in 80% of patients with spina bifida.[16] Among low birth weight infants, 15% develop hydrocephalus following intraventricular hemorrhage[17] and hydrocephalus can develop later in childhood as a consequence of brain tumors or meningitis.[18] Approximately 2% of institutionalized children with mental

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retardation have hydrocephalus,[19] and hydrocephalus is found to be the primary problem in approximately 1% of adult patients who present with dementia.[20] The annual incidence of newly diagnosed hydrocephalus requiring surgery was approximately 1/10,000 population in 1982-83 in Canada.[21]

Some cost-related data concerning hydrocephalus are also available. A comprehensive survey of the use of CSF shunting devices in Canada for the year 1982-83 revealed that the fee-for-service surgical cost of 3,162 procedures was in excess of CDN$ 21 million.[21] In the United States, based on a random sample of 47,485 households and hospital discharge data from multiple sources, the prevalence of persons with shunts was estimated to be approximately 125,000, i.e., roughly 40 per 100,000 population. The 1991 surgical cost for shunt procedures, excluding hospitalization, was estimated at US$ 94 million, about half of this for shunt revisions.[22] Those cost estimates did not take into account expenses for non-surgical hospital admissions nor the chronic care of handicapped patients who may live for decades. The objective of this study was to assess the cost of caring for hydrocephalic patients by surveying several aspects of the health care system from a community perspective spanning the years 1990-1996.

Materials and Methods

Population

Population statistics were provided by the Manitoba Centre for Health Policy and Evaluation. The population is relatively stable with minimum variation due to migration, and has remained roughly constant during the study period at 1,138,000 ± 1500 persons. The population has equal access to health care facilities through government-sponsored universal health care.[23] Because of the relatively great distances to other major cities, effectively all patients in the province with neurological problems are seen in the city of Winnipeg wherein are located the only two neurosurgical centres in the province.

Survey Method

All neurosurgical admissions in the province go to one of two adult hospitals or the children's hospital. The medical records at the three centres for the years 1990-96 were retrospectively searched for all patient discharges with International Classification of Diseases Clinical Modification (ICD-9-CM) codes: 741.0 (spina bifida with hydrocephalus), 741.9 (spina bifida without hydrocephalus), 742.3 (congenital hydrocephalus) (including aqueduct stenosis in children), 331.3 (communicating hydrocephalus), and 331.4 (obstructive hydrocephalus). No patient was given more than one of these diagnoses. Total length of stay was tabulated for each discharge. A distinction was made between primary and secondary diagnosis where possible. Patients with prolonged hospital stay as a result of other disorders or complications, i.e., in whom hydrocephalus was a secondary diagnosis, were excluded. The daily cost of hospital bed stay was provided by the financial department of the hospitals. This cost reflects the average cost of in-patient care including nursing, drugs, radiologic procedures, etc. The Manitoba Health Services Commission provided procedural billing information for ventricular shunting procedures and cost data for five fiscal years, 1991/92 to 1995/96. Physician fees including those for neurosurgical in-patient care, anesthetic administration, and CT scan interpretation were derived from the Manitoba Health Services Insurance Plan Physicians Manual 1996.

Data were tabulated on the basis of fiscal years and means were calculated. Within each diagnostic category patients were divided in adult and childhood categories, and for each year patients (identified by chart number alone) with multiple admissions were identified. All data were examined for any temporal trends.

Results

Epidemiology

The mean annual number of patient discharges with primary diagnosis of hydrocephalus are shown in Table 1. Many patients, ranging from 10-28% for the different diagnostic categories, were admitted and discharged on several occasions. Most of these patients were admitted 2 or 3 times, although a single patient was admitted 5 times in one year. The approximate number of hydrocephalic patients actively under treatment is 130 per year, yielding a prevalence of 12.2 per 100,000 population.

Table 1: Discharge diagnoses and estimated costs of hospitalization, 1990-96.

Diagnosis (ICD-9-CM code)	Annual number of discharges (a)	Patients with multiple admissions (b)	Proportion of adult patients (c)	Duration of stay (days) (a)	Total annual cost of hospitalization (d)
Spina bifida with hydrocephalus (741.0)	41.6 ± 5.2	28%	15%	12.4 ± 2.6	465,000
Congenital hydrocephalus (742.3)	33.8 ± 8.6	10%	25%	13.1 ± 4.1	399,000
Communicating hydrocephalus (331.3)	23.2 ± 5.7	15%	60%	15.9 ± 4.4	332,000
Obstructive hydrocephalus (331.4)	113.5 ± 15.3	10%	61%	21.9 ± 2.5	2,235,000

a. mean ± SD.

b. Approximation based on number of patients with two or more admissions per year.

c. Adult defined as patient > 18 years age.

d. Estimate includes daily bed charge, admitting physician fees, and one CT scan per admission based on 1996 costs. Expressed in CDN$.

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There were random year to year variations but no indication of any trends. The relative proportion of adults and children differed between the diagnostic categories; the categories of spina bifida with hydrocephalus and congenital hydrocephalus were dominated by children. Communicating, congenital, and spina bifida-associated hydrocephalus were almost always a primary diagnosis. However, obstructive hydrocephalus was diagnosed as a secondary or complicating condition in three times as many cases as it was the primary diagnosis. These patients have not been included in the analysis. In regard to deaths, fewer than one person, usually a child, died each year as a direct result of hydrocephalus or a shunt-related problem. Approximately two persons with a primary neurological diagnosis of hydrocephalus died each year from unrelated causes.

Surgical Procedures

The mean annual number of ventricular shunt procedures for treatment of hydrocephalus was 79.8 ± 12.5 (Table 2). Of these shunt placements, 71% were revisions. In addition, there were 5.4 ± 2.7 lumboperitoneal shunt performed annually, either for adult communicating hydrocephalus or for pseudotumor cerebri. The surgical fee for shunt placement increased from $514 to $673 during the study period. The mean annual fees paid to surgeons for procedures related to hydrocephalus was $55,730. This does not include a small number of procedures reported for simple removal of shunt apparatus; these have not been factored in because it is not clear whether they were followed by a later shunt revision. Using an estimated anesthetic time of 1.5 hours per procedure, fees for anesthesia would be roughly $152 per case or $12,955 per annum.

Table 2: Shunt procedures and surgical fees, 1991-96 (a).

Ventricular shunt placements (revisions)	Surgical fees (CDN$) for ventricular shunts	Shunt removals	Lumbo-peritoneal shunts	Surgical fees (CDN$) for lumbar shunts
79.8 ± 12.5 (56.6 ± 6.4)	$52,812 ± 6,440	9.6 ± 5.7	5.4 ± 2.7	$2,918 ± 1,236

a. annual means ± SD.

In-Hospital Costs

The duration of hospital stay is shown in Table 1. This varied between different diagnostic categories. The duration of hospital stay showed random variations between the years with no evidence of any trends. We were unable to determine whether childhood hydrocephalus had a different duration of hospitalization because our coding system treats patients less than 18 years of age as children, whereas clinically their problems might be more comparable to those of an adult. As noted above, hydrocephalus is frequently a secondary or complicating diagnosis. Whether hydrocephalus contributed to longer stays in patients, with for example head injuries or subarachnoid hemorrhage, is not clear. There was one diagnostic category where this information might be inferred. The mean duration of hospital stay was slightly longer for spina bifida patients with hydrocephalus than for spina bifida patients without hydrocephalus (code 741.90 - .93) (11.7 ± 2.6 days vs. 9.7 ± 3.2 days; not statistically significant by Student's t test).

The 1996 daily cost for an inpatient hospital bed has been determined to be $895. During the study period there was roughly a 5% annual increase in these charges. Fees paid to admitting physicians for inpatient care including history and physical as well as a daily visit were estimated at $50 per hospital stay. A conservative estimate of one CT scan per hospital stay costing $40 per interpretation by a neuroradiologist has been included to determine the total cost of hospitalization of hydrocephalic patients (Table 1). Although MR imaging may be used in the initial diagnosis in some patients, this has not been routine. Furthermore, MR is usually not used for follow-up studies of ventricle size, therefore costs for this procedure have not been included.

For the province of Manitoba, the average total annual cost of caring for hydrocephalic patients, including surgical fees, was calculated to be CDN$ 3.487 million. Because of the lack of specific diagnostic coding, I was unable to get any reliable information concerning the demands of hydrocephalic patients on home care services, special education, pharmacotherapy, chronic care institutionalization, and the like, despite inquiries to providers of these services. Therefore these, undoubtedly significant, costs are not included.

Discussion

Based upon the cost of hospitalization and surgical procedures, the annual cost of caring for patients with hydrocephalus in the province of Manitoba, Canada is roughly CDN$ 3.5 million. Can these data be generalized? The mean duration of hospital stay ranged from 12 to 22 days, depending on the diagnostic category. This was a retrospective study based on ICD-9-CM codes, therefore this estimate may not accurately reflect the time needed for treatment of hydrocephalus because it overlooks complicating factors or additional medical problems. A recent study out of Glasgow, Scotland indicated that hospital stays for shunt procedures averaged 8 days.[24] It is possible that the duration of hospital stay is longer in Manitoba as a consequence of poor operating theater availability. In Manitoba, where remuneration for surgical procedures is relatively low, the actual fee-for-service surgical costs for shunting procedures was a mere 2% of the total costs, considerably lower than the 20% estimated at the British Columbia Children's Hospital.[25] This may be skewed by excessive hospitalization time in Manitoba. However, the British Columbia study was based on a pediatric population whose in-hospital time tends to be lower. Based on local estimates, the average cost of one hospitalization in 1996 for shunt treatment of a hydrocephalic patient was approximately CDN$17,500, including physician fees. A 1985 study in New York determined that an admittedly small number of admissions for treatment of hydrocephalus had an average cost of US$27,600, exclusive of surgeons fees.[26] In Manitoba, the number of hydrocephalic patients under active care was estimated to be 12.2 per 100,000 population. This is lower than a U.S. prevalence estimate of 40 per 100,000, but these data also included hydrocephalic patients with a shunt who are stable and not requiring hospitalization.[22]

The true costs of caring for hydrocephalic patients are certainly higher than estimated here. I was unable to accurately estimate non-hospital direct costs such as chronic care facilities, outpatient follow-up, private nursing, drugs, etc. Furthermore, the estimate does not include the added costs of care when

hydrocephalus complicates another disorder. Nor does it incorporate indirect costs such as loss of productivity by patients and caregivers. This information was not readily available because local chronic care facilities and loss of work data do not use diagnosis codes that are sufficiently specific. There are data from U.S. agencies concerning the pooled diagnostic category of spina bifida/hydrocephalus. In the state of Nebraska for the 15 years prior to 1977, it was estimated that medical care, including non-hospital costs such as nursing and special schooling, for each child was at least US$21,000 annually for the first eight years of life.[27,28] In the state of Washington, each of 190 patients with spina bifida cost the Medicaid program an average of US$11,061 for the year 1993.[29] Fifty-five percent of these costs were hospital and physician-related. The other 45% was due to private nursing, out-patient visits, drugs, special equipment, and miscellaneous expenses.

If the Manitoba data can be extrapolated, the total direct costs of caring for hydrocephalic patients in Canada is probably at least CDN$ 90 million annually and in North America is probably at least US$ 670 million. If the data from spina bifida patients are any guide, this figure could be almost doubled to include non-hospital direct costs and indirect costs. In financial terms, the costs of hydrocephalus rival those associated with epilepsy, brain tumors, or migraine headaches.[1] They may also approach the costs associated with multiple sclerosis which were estimated to be at least CDN$ 160 million in a 1994 Canadian survey that included many presumed non-hospital costs.[30]

The financial burden of hydrocephalus to patients and to society rests in the fact that it is a chronic neurological condition with an imperfect treatment requiring prolonged medical care and repeated hospitalization. What can be done about the costs? It has been estimated that the use of endoscopic third ventriculostomy might be an option in 15% of hydrocephalic patients. The use of this procedure could significantly reduce the in-hospital time and the number of repeat admissions for shunt revision.[24] Improvement of shunt technologies and surgical techniques to reduce infection and shunt failures would reduce the direct costs. This in turn would reduce indirect costs because each episode of ventricular dilatation causes new brain damage[2] which then increases the patient's dependence on care-givers. Clearly, more work is needed to improve the treatment of hydrocephalus.

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Noted added in proof: A 1996 study of childhood hydrocephalus in Boston indicated that admissions for shunt complications averaged 3.0 days duration and US$10,480 in total charges.[1]

[1]Park JK, Frim DM, Schwartz MS, et al. The use of clinical practice guidelines (CPGs) to evaluate practice and control costs in ventriculopeitoneal shunt management. Surg Neurol 1997; 48: 536-541.

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