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Editorial

Long-term outcomes of hydrocephalus

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The consequences of chronic illness that originates in childhood are of interest to all physicians, especially to those who treat these conditions. Surgeons sometimes focus on the physical aspects of the patient's condition and may not give sufficient attention to the individual's social and emotional needs. These nonphysical aspects of the problem may very well dominate the patient's thoughts. Focusing on the physical aspects of the disease by the surgeon is understandable, especially when the condition is associated with significant long-term mortality rates.

The authors of this study help us return our focus to some of the long-term social and emotional problems seen in patients with hydrocephalus. They do this by asking the patient or his/her guardian to complete a survey discussing their functional outcome. As is mentioned in the article, such studies are inherently seriously flawed. Looking at my own practice and knowing the very small percentage of patients who are involved with the national Hydrocephalus Association and realizing that those involved families tend to be more affluent and have less physically affected patients underscores our inability to generalize the results of this survey.

Despite this limited ability to generalize the information, findings like depression; dependence on others for financial, emotional, and physical needs; and a lack of independence surely ring true for the many patients in this group.

As mentioned by the authors of this study, the comorbidities seen with hydrocephalus may very likely play a significant role in determining the patients' outcome. Neural tube defects, cerebral palsy with Grade III and IV intraventricular hemorrhage, serious head injury, meningitis, seizures, and congenital hydrocephalus with major brain developmental anomalies would all seriously lower performance scores and probably dominate the course of the functional outcome of patients who also happened to have hydrocephalus. If I were guessing, I would think that the comorbidities are much more important in determining outcome than the hydrocephalus itself. However, the surgeon can seldom alter the comorbidity and is left simply treating the hydrocephalus.

Lowering the infection rate and extending the interval between shunt revisions are appropriate and admirable goals. Helping these patients achieve a more useful life is ideal. Focusing on the factors we can influence and improve rather than those we cannot seems helpful and appropriate.

RESPONSE: We thank Dr. Oakes for his thoughtful comments. In many ways, the information obtained through the

Hydrocephalus Association database should be viewed as a beginning rather than an end. For parents of children with hydrocephalus many questions are raised when diagnosis and treatment are first discussed. Some of the questions, such as the risk of shunt infection in the postoperative period, are relatively well understood. Other important questions relating to the long-term consequences of hydrocephalus remain poorly defined. As Dr. Oakes suggests based on experience with his own patients, the families involved with the Hydrocephalus Association were more affluent and had children who were less affected by their disease. Despite this, we were struck by the profound impact of hydrocephalus on the activities of daily living of this highly selected population. It is our suspicion that the disease burden demonstrated by the results of this survey is almost certainly an underestimate. It should be noted that deaths related to hydrocephalus could not be captured by this type of survey.

The results obtained from this analysis of the Hydrocephalus Association database clearly identify how future studies should be structured. First, the study must be population based to allow the results to be generalized. Second, associated diagnoses must be clearly defined. Dr. Oakes is correct to point out that the primary diagnosis may have a dominant effect on patient outcome. Understanding the contribution of comorbidities will greatly improve our ability to counsel patients and their families. Third, the disease burden must be identified in terms that reflect the actual functional impact on the affected patient population. Although we have traditionally presented disease and treatment outcomes in terms of number of procedures, complications, and rough estimates of functional capacity, it is clear that in the majority of previous studies, measures that could have been used to assess the integration of the individual as a functioning member of society were not examined. This will be our challenge in the future as we attempt to understand how early interventions affect our patients for many years to come.

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