Cerebrospinal Fluid Research



Oral presentation Open Access

Cognitive and psychological sequelae of hydrocephalus and spina bifida: correlating subjective data and objective neuropsychological data to establish insight and inform clinical intervention and guidelines

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from 53rd Annual Meeting of the Society for Research into Hydrocephalus and Spina Bifida Belfast, UK. 24-27 June 2009

Published: 27 November 2009

Cerebrospinal Fluid Research 2009, 6(Suppl 2):S7 doi:10.1186/1743-8454-6-S2-S7

This abstract is available from: http://www.cerebrospinalfluidresearch.com/content/6/S2/S7

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Background

Despite significant advances in treating and improving the prognosis of individuals with hydrocephalus and spina bifida, many of these individuals continue to experience specific cognitive difficulties in the areas of memory, language, attention and executive function and these can often have a significant negative impact on everyday functioning [1-3].

Materials and methods

A comprehensive questionnaire was designed, based on known cognitive and emotional sequelae, to assess patient and caregiver perceptions of the specific difficulties experienced by people with hydrocephalus and spina bifida and the extent to which these are being addressed. In order to establish levels of insight, this questionnaire was correlated with detailed neuropsychological data to triangulate actual cognitive performance with subjective self-assessment obtained from patients and the objective view of caregivers.

Results

Questionnaire data will be presented that will highlight specific areas of discrepancy and concordance between patients and their caregivers (n = 60) and will be discussed in relation to actual performance on a range of cognitive tasks and the subsequent implications for strategic advice and intervention.

Conclusion

The data is being used to tailor specific cognitive strategies based on enhanced self-awareness, as part of small group and individual cognitive training interventions, within a multidisciplinary setting. It is hoped that the dissemination of the materials and methods designed for this study will inform best practice guidelines for these individuals and their caregivers and provide measurable outcomes for cognitive performance discrepancy, meta-awareness, strategy implementation and evaluation.

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