

Poster presentation

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## Independence and perceived quality of life in young adults with myelomeningocele. Function, needs and recommendations for what to do

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### Background

Adults with myelomeningocele (MMC) mainly have the same type of problems, as do children with MMC, implying a chronic disability and need for medical care and rehabilitation services throughout their lives. The aim of this study was to investigate function and needs in relation to independence and perceived health-related quality of life in young adults with MMC. We also propose recommendations for what to do to promote independence and quality of life.

### Materials and methods

The population consisted of fourteen adults with MMC (md = 20 years). Six of them have been investigated till now. Two were community ambulators and four wheelchair users. The participants were investigated regarding medical needs, neuropsychological function, motor function, communication and learning skills. Independence and perceived quality of life were estimated from structured interviews (FIM, HRQOL and SF-36). The study was performed at Folke Bernadottehemmet, the regional rehabilitation unit of the Uppsala University Hospital.

### Results

The results from six investigations are presented here. All six participants had shunt-treated hydrocephalus, bladder and bowel dysfunction and at least four medical problems

each (mean = 8.3). One person was severely and one slightly mentally retarded. All had problem with executive functions, visuospatial function, memory and self-awareness. Some of them had problem with reading comprehension in spite of good understanding of single words and good spelling skills. Muscle strength of shoulders and hands was generally below average and motor performance was slow. The inability to initiate and organise activities seemed to be a clear hindrance for independence. The lowest independence was classified in the fields of memory and problem solving, toileting and bladder and bowel continence. Health-related quality of life was classified as rather positive despite the fact that the participants reported pain and low vitality. Recommendations: A first step was to increase individual awareness of specific difficulties. Our method was then to: • inform and teach about executive impairment • make the environment obvious by clear structure, sequencing strategies, a lot of preparation and feedback • have fixed routines and time/activity schedules • use clear, concrete verbal language and related questions to support communication • use visual support in school education and learning.

### Conclusion

Medical and executive problems are common in young adults with MMC and together with low self-awareness they constitute a clear hindrance in daily life. Strategies to

facilitate daily activities are available and should be applied so that independence and health-related quality of life is promoted.

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