

Oral presentation

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How to reach independence in the toilet situation – an update

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Background

At SRHSB in Heidelberg (2007) was shown that for children with myelomeningocele (MMC) the awareness of ability and degree of independence in the toilet activity was too unrealistic. The study is now extended to a larger group of children with observation of the toilet activity in the child's own environment at home or at school. The aim was to evaluate if independence in the toilet situation was different in a well-known home environment compared to a hospital setting.

Materials and methods

Fifty children, 25 girls/25 boys, aged 5.8 – 18.3 years (median 12.8), with MMC and neurogenic bladder dysfunction were observed at a toilet visit at home or at school when performing clean intermittent catheterisation, CIC. Thirteen of them had earlier been observed in a hospital setting. Before visiting the toilet all children rated their experience of how well they perform the toilet activity and how satisfied they were to manage it, using the Canadian Occupational Performance Measurement (COPM). The toilet visit, when performed and documented in a standardised protocol, was followed by a semi-structured interview and an assessment of time-concept perception (KaTid-UNG).

Results

Nineteen children rated their toilet activity as maximally good and 24 were maximally satisfied the way they managed the toilet visit. For the whole group performance and satisfaction were rated at a median value of 9 (range 0 –

10). Performance and satisfaction were strongly related. Twenty-four children (48%) performed the toilet activity independently, 6 of them with some help to take things up and cleaning up afterwards. Twenty-six children were in the need of assistance, significantly related to age. Three children earlier observed in a hospital setting were still independent and so another three, earlier dependent, probably because of an increased focus in the home setting. Time concept perception increased with age but was lower than expected for the actual age group was not related to learning disability but was significantly related to degree of independence.

Conclusion

Children with MMC and neurogenic bladder dysfunction are more independent in the toilet situation in a well-known environment but recent findings of an unrealistic apprehension of abilities and needs for independence are confirmed. A successful tight medical follow up in a standardised national programme, especially for bladder and bowel function (Wide et al 2007), together with the results from other ongoing studies of the child with MMC with focus on independence, provides a scientific basis to create normal kidney function and improved independence in a transition perspective. As independence is a matter of cognitive functions and practical experience, independence starts at infancy!