

Oral presentation

Spend a penny independent - a multidisciplinary project

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Background

Today children with long-lasting state of illness including children with myelomeningocele (MMC) reach adulthood to an entire larger extent than before and will set an entitled requirement on participation in the society. A mapping of treatment regimes for children with neurogenic bladder - and bowel disturbances shows that independence in the toilet situation is quite rare despite intensive actions at the hospital and that incontinence is common. A multidisciplinary project to evaluate the obstacles to independence in the toilet situation has been running. The general aim was to develop a strategy, based on the outcome of four of altogether nine studies, to give a possibility for the growing child to gradually take responsibility for itself that may create improvement in quality of life, decrease in costs for continence aids, assistance and healthcare.

Materials and methods

A pilot study has been performed including 16 children, 5-17 years (mean 11 years) with MMC. After consent a visit at the child's home was performed by an urotherapist and occupational therapist together. After observation of the toilet visit the child was asked to choose to train either the bladder - or the bowel emptying and to set step by step goals to increase independence

Evaluation

Observation of toilet activity by a standardized manual, COPM (Scale 0 very bad to 10 excellent), CICOPA (Cards with additional pictures showing the CIC) and GAS (goal

setting). A timetable for growing up <http://www.rbu.se> was given to the family together with some questions about the child's own knowledge about his/hers disability. The child's time perception ability was observed.

Results

After a median of two visits, 8 children reached their goals (+2) and another 5 more than the agreement (+3). The goals were not reached by two children. Participating families emphasized the difference in focussing on the situation at home compared with discussing it in hospital environment.

Conclusion

Actions with an urotherapist and occupational therapist working together in a home setting to reach independence for the child with MMC had better outcome than traditionally performed in the hospital setting. Further children will be included in the study.