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REGULAR ARTICLE

Independence in the toilet activity in children and adolescents with myelomeningocele – managing clean intermittent catheterization in a hospital setting

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Abstract

Aim: The aim of this study was to identify and describe gross motor, fine motor, executive and time-processing obstacles for independence in children with myelomeningocele who are treated with Clean Intermittent Catheterization and to relate their opinions about their performance in the toilet activity, and their medical records, to the observed outcome.

Methods: In a hospital setting, 22 children with myelomeningocele were observed using a structured information form while performing their toilet activity, and tested for time processing ability with the Ka-Tid instrument.

Results: Only five children were independent, despite the fact that 12 of 22 children were completely satisfied with their toilet activity. Neither the degree of motor impairment, nor sex or age had any significant impact on performing the toilet activity. The ability to remain focused on the toilet activity proved to have no relation to age or learning disabilities. The medical records for the children were only able to classify approximately three quarters correctly with respect to independence. The only measurement that could suggest anything in relation to a maintained focus was time processing ability.

Conclusion: The children were unaware of their abilities and limitations. Time processing ability and observations are important factors to assess independence.

INTRODUCTION

With advances in medical treatments, children with myelomeningocele (MMC) nowadays survive to adulthood (1,2). In Sweden, a nation with approximately 9 million inhabitants, the incidence figure of children born with MMC was estimated to be about 25 per annum, yielding a crude prevalence of some 600 children in total. This figure has decreased significantly over the last decades. Approximately 30% of these children are currently 15–18 years old (2). These figures, in turn, imply that about 40–50 children with MMC will turn 18 per annum. Studies on adults with MMC point to the need for lifelong medical services (3–7).

One frequently reported problem sustained into adulthood is urinary incontinence (1). This incontinence is a consequence of the lesion with subsequent reduced sensory function, as well as reduced gross motor functions. In fact, despite the lesion being typically in the lumbar section of the spine, fine motor functions in the upper extremities have also been shown to be affected (8).

In addition, cognitive impairments have frequently been reported (1–6), typical problems being planning and initiations of task oriented actions, as well as sustained focus on the task. As pointed out by Lezak (9), cognition and execution of tasks are inherently united, which implies that cognitive impairments may be reflected in activities of daily life (ADL). Children with MMC have been reported to manage their toilet activities later on in life than other ADL (10). Since the late 1970s, most children with MMC utilize Clean Intermittent Catheterization (CIC) since early childhood, and the toilet activity becomes more complicated than for children without MMC. CIC requires the child to prepare the equipment, make necessary moves to undress and access the urethral orifice, prepare and insert the catheter into the urethra, empty the bladder and, finally, to clean up afterwards. These procedures have to be repeated every third or fourth hour during daytime in CIC treatment. The present study focuses on management of the toilet activity related to CIC, as opposed to the toilet activity of emptying the bowel. For simplicity reasons, however, the toilet activity related to CIC will hereafter be referred to as the toilet activity.

Most often, children with MMC are assessed before school start with respect to their independence in their toilet activity; some 86% of them have hydrocephalus (2), but in many cases these activities are assessed verbally through an interview by a physician, rather than in practice. As children with hydrocephalus are known to have better verbal IQ than performance IQ, as measured by intelligence tests

(11), it can be assumed that these children claim to perform differently than they actually do. Children with MMC and hydrocephalus with low to average IQ have been shown to have deficits in short- and long-term memory, as well as in planning and organization (11), whereas this pattern has not been found in children with MMC without hydrocephalus and learning disabilities.

At present, persons with MMC need life-long check-ups and support with respect to toilet activities (1,12). Actually, older children and adults with MMC have reported deficits in cognition and toilet activities to be the most significant ones in ADL (13). To become independent in adulthood, problems in childhood with the toilet activities must be identified more in detail, and penetrated with respect to possible future interventions. However, no such investigation has been reported and, hence, the aim of this study was to identify and describe gross motor, fine motor, focus and time-processing obstacles for independence in children with MMC who are treated with CIC. Furthermore, an additional aim was to relate their opinions about their performance in the toilet activity, and their medical records, to the observed outcome.

METHODS

Participants

All 32 children with MMC reporting to their annual check-up at the regional hospital were asked to participate in the study over a 5-month period. Nine of them declined. Another child was occupied in a concurrent study and was not asked to participate for this reason. The background facts of these 32 children are presented in Table 1

As shown in Table 1, there were no significant differences between participants and nonparticipants.

Procedures

The procedures used to gather the data were the following: First, the medical records of the 32 children were scrutinized with respect to age, sex, the prevalence of hydrocephalus, learning disabilities, i.e. IQ assessed by formal psychological tests at the Habilitation Centres to find proper schooling for each individual, wheelchair usage, independence in the toilet activity according to the child and/or the child's parents as stated in these medical records and, finally, whether or not the child had personal assistance. The child's independence in the toilet activity was double checked for in the separate urotherapists' records. No disagreements between these and the medical records were found. It should, however, be noted that at this hospital, no urotherapists perform home or school visits. Second, the 22 children who participated were assessed with Canadian Occupational Performance Measurement (COPM)(14). Third, the children were observed during the toilet activity in one of the hospital toilets, 19 of them with some personal assistant chosen by them. Finally, immediately after the observation, the KaTid (15) test was performed.

Table 1 Background facts for the 32 children who were potential participants

	The participants (n = 22)	The nonparticipants (n = 10)
Age (range)	13.1 (6.1–18.7 years)	13.9 (7.2–17.3 years)
Gender ♂♀	11♂, 11♀	6♂, 4♀
Wheelchair users	18/22 = 82%	9/10 = 90%
Hydrocephalus	20/22 = 91%	8/10 = 80%
IQ learning disabilities* (l.d.)	16 of 22 = 73% no l.d.	9 of 10 = 90% no l.d.
Personal assistance (PA) in school	17 yes/22 = 77% had PA	8 yes/10 = 80% had PA

All data were taken from their medical records.

*As reported in their medical records. IQ is usually assessed before school start by formal psychological tests at the Habilitation Centres.

Instruments

A structured observation form was developed and tested for inter-rater reliability (88%), using a video clip among 15 independent raters, four of them being urotherapists and the other 11 being occupational therapists. The observation form allowed the observer, i.e. the first author, during the toilet activity at the hospital, to continuously assess:

- verbal and/or physical assistance from parents or a personal assistant
- gross and fine motor skills and their impact on the performance of the toilet activity
- time for a completed toilet activity
- technical aids used while performing the toilet activity
- undressing and dressing, plus pros and cons with the clothes they wore
- the children's focus on the activity, measured as maintained (M), partly maintained (PM) and lost (L) with respect to the efficiency of the toilet activity
- independence in the toilet activity, broken down into subactivities; each rated from 5 = totally independent to 1 = the parents or the personal assistant completed the entire subactivity without any involvement of the child. Children who scored 5 on all subtasks performed were judged as independent.

COPM (14) was used in a slightly modified version, as the toilet activity was pre-chosen. The rating scale from 1 (*'I never do/I am not satisfied at all'*) to 10 (*'I do extremely well/extremely satisfied')* was used for the children to answer the questions on their performance and satisfaction with their performances in the toilet activity.

To assess the children's time-processing skills, the instrument KaTid (15) was used. It comprises tasks regarding time perception, time concept, time orientation, time management and questions about everyday functioning. This instrument was developed for children aged 6–10 years without disabilities and tested for validity and reliability. Children with good time processing ability also show a higher degree of autonomy (15).

Statistical analysis

Data were analysed using SPSS 14.1 (SPSS Inc., Chicago, IL, USA). Spearman's rank correlation was used for all

correlation analyses, Mann–Whitney *U*-test for comparisons of ordinal data between independent groups, One-Way ANOVA using Tukey's HSD post hoc analysis for comparison of normally distributed interval data as assessed by Kolmogorov–Smirnov test (i.e. time to complete the toilet task) between independent groups and Kruskal–Wallis test for multiple comparisons of ordinal data. In all analyses, the α-level was set to 0.05 and, consequently, only p-values below that pre-set level are reported.

The present study was approved by a Regional Ethical Committee according to Swedish law. Informed consent was given by all the children and their parents.

RESULTS

The results from the medical records, the COPM performance and satisfaction measurements, as well as the observation and KaTid are presented in Table 2.

In total, 12 of 22 children were completely satisfied with their toilet activity performance, all but two assessing their performance as good as possible when asked with the COPM. However, one-third of them were not assessed as independent in their medical record, and only two of them were, in fact, observed to be independent. Despite the fact that four children rated their satisfaction lower than their performance, as shown in Table 2, there was a significant positive correlation between self-rated performance and satisfaction according to the children's own assessments, as measured by COPM (Spearman's rho = 0.574, p = 0.005).

The five children who were assessed as independent in the observations were all assessed similarly in their medical records. Furthermore, the nine children who were assessed to be dependent in their medical records had these assessments corroborated by the observations. However, eight children were stated to be independent in their medical records but were not in the observations. These figures, however small, give a sensitivity of the medical records of 100% to detect those who are independent also when observed, whereas the specificity of these records turned out to be 53%, providing a screening score of 153. In other words, the medical records were able to classify 77% correctly, with respect to independence in the toilet activity.

The participants used a variety of methods for the toilet activity, with no systematic patterns found with respect to wheelchair or technical aids usage. The median time they took to complete the toilet activity was 10.5 min (25th percentile 6.0 and 75th percentile 12.8), ranging from 3 to 19 min (mean 10.1 min, SD 4.8). No significant differences were found between boys and girls, or between wheelchair users and ambulant children. Gross and fine motor skills

Table 2 Results from the medical records, the COPM performance and satisfaction measurements, KaTid, focus and time, for each of the 22 participants

				Child's own assessment		External assessment		Measurements		
				COPM		Independent according to:		KaTid	Focus	Time*
Participant sex	Age (years. months)	Wheelchair (yes/no)	Recorded IQ (N/<N)	Per-formance	Satis-faction	Medical record	Observation	KaTid range 0–50†	M/PM/L	min
♀	15.11	Yes	<N	10	10	Yes	No	38	PM	12
♂	12.11	Yes	N	6	8	Yes	No	50	PM	17
♀	9.1	No	N	10	10	Yes	No	39	PM	12
♂	14.10	Yes	N	10	10	Yes	Yes	48	M	19
♀	8.10	Yes	N	10	10	No	No	31	PM	7
♀	16.1	Yes	<N	10	10	Yes	No	38	PM	12
♂	6.9	Yes	N	5	8	No	No	16	L	17
♀	9.1	No‡	N	10	10	Yes	Yes	37	M	4
♂	14.6	Yes‡	N	9	9	Yes	Yes	48	M	5
♂	8.2	Yes	<N	2	10	No	No	1	L	11
♂	9.5	Yes	N	5	4	No	No	36	PM	11
♂	18.3	Yes‡	N	10	10	Yes	Yes	49	M	3
♀	18.7	Yes	N	10	10	Yes	No	48	M	8
♀	14.0	Yes	N	6	8	Yes	No	50	PM	11
♂	7.2	Yes	N	1	5	No	No	19	L	15
♂	6.1	Yes	N	10	10	No	No	21	L	10
♀	13.2	No	N	10	5	Yes	Yes	47	M	6
♀	15.1	Yes	<N	10	7	No	No	27	L	7
♀	15.4	Yes	<N	7	10	Yes	No	37	M	6
♀	10.11	No	N	10	10	No	No	32	PM	8
♂	13.11	Yes	<N	4	5	No	No	45	M	4
♂	8.4	Yes	N	7	3	Yes	No	45	PM	18

N = normal or above; <N = below normal as stated in their medical record, as assessed by formal psychological tests at the Habilitation Centres; M = maintained, PM = partly maintained, L = lost focus; COPM = Canadian Occupational Performance Measurement.

*Time to complete the toilet activity.

†High values are better.

‡Performed the observation with no personal assistant or relative attending.

were observed and assessed during the toilet activity. Only three of 22 children had no motor impairments affecting their performance. Eight of the participants had impaired upper torso balance, in four of them in combination with impaired gross and fine motor functions in the upper and lower extremities. Impaired fine motor functions in the upper extremity affected four children, whereas the remaining participants were observed to have problems with either spasticity (five children) or lack of range in the torso and the upper extremities, combined with visual occlusion problems (two children).

The participants' capability to maintain focused on the toilet activity was assessed, as shown in Table 2. No significant differences in this variable were found with respect to the age of the participants or with respect to whether the participant had learning disabilities or not. However, significant differences were found between the three foci groups, with respect to the time they took to complete the toilet task. The comparison of those who maintained focus (M, $n = 8$) with the other two groups (PM, $n = 9$ and L, $n = 5$) showed that the M-group completed the task on average in 5.9 min (95% CI 3.7–8.0) compared with the PM-group (12.1 min, 95% CI 8.6–15.5) and the L-group (13.4 min, 95% CI 9.2–17.6), $p = 0.002$. No significant difference was found between the PM- and the L-groups.

Total independence in the toilet activity was assessed to be present for five participants, as shown in Table 2. No correlation was found between age of the participants and independence. Two participants scored top scores on the KaTid, and there was a significant positive correlation between age and KaTid score (Spearman's rho = 0.597, $p = 0.03$). Furthermore, a positive correlation was found between KaTid score and observed independence (Spearman's rho = 0.508, $p = 0.016$), and between KaTid and the child's own performance assessment of the toilet activity (Spearman's rho = 0.730, $p < 0.001$). In addition, children who assessed their performance as good were also observed as more independent (Spearman's rho = 0.675, $p < 0.001$).

DISCUSSION

This study highlights the differences in assessments of the children's performance in the toilet activities between assessors. The medical records were only able to classify approximately three of four children's independence correctly, based on observed behaviour in this study. This finding advocates that medical records should, to a greater extent, be based on observations rather than interviews. However, children who assessed their performance as good were also observed as more independent, which in turn implies that this reasoning does not make complete sense. However, this finding was supported only by a moderate correlation and thus observations – preferably combined with interviews – will probably constitute an optimal foundation for the assessment in the medical records.

Neither the degree of motor impairment, nor sex had significant impact on performing the toilet procedures. Remaining focused on the toilet activity proved to have no relation to age or learning disabilities, as assessed by the psychological tests at the Habilitation Centres. The only measurement that could suggest anything about a sustained focus was the time processing ability, as measured by KaTid. The better the children scored in the test, the shorter time it took to finish. Actually, children who had a good time processing ability were more independent in the toilet activity.

Independence showed no correlation to age, but KaTid did, a finding that is somewhat puzzling. Moreover, children who scored high on KaTid also assessed their toilet activity performance as better. It is possible that time processing ability is more sensitive to the issue of maintaining focus on the toilet activity than traditional indicators, such as degree of motor impairment, sex, age, learning disabilities, etc. KaTid is developed for children in lower ages than the participants in this study. Despite this fact, only two participants scored maximum points. Is impaired time processing ability a facet closely related MMC? Future research should focus on this.

All findings from this study are based on data gathered in a hospital setting, which should be taken into account as a confounding factor. When performing such a close observation, it is possible that the observation itself added attention and thereby the children may have over performed. On the other hand, performing the toilet activity in an unknown environment while observed may have worsened their performance. Hence, future research should replicate this study in the children's home or their school environment, as the children may very well be independent at home and in school, but not in a hospital setting. Nevertheless, the finding that regardless of age, only five of 22 (i.e. 23%) were independent is staggering, especially as 12 children rated their performance and satisfaction to be at maximum.

The findings of the present study should, however, be viewed upon the fact that statistical analyses are made on a limited number of participants. In the comparisons where we failed to find significant differences between subgroups of the participants, based on for example age, sex, wheelchair usage and learning disabilities, failure may be because of lack of power of the study. Furthermore, the significant correlations found were all moderate, which should be kept in mind when considering the conclusions drawn from the present study.

The present study had its focus on the urinary toilet activity. However, bowel emptying is often hard for children with MMC to manage by themselves, and constitute yet another crucial obstacle for independence. As a matter of fact, irrigation procedures are even more time consuming than urinary toilet activities and need more support to manage. However, CIC has to be performed more frequently than bowel emptying, and was chosen to be studied as a first step. Nevertheless, future research should include different treatment methods of bowel emptying, as the goal for these children is to achieve maximal independence as they become older. In fact, the research group involving the first author has launched a clinical programme addressing the entire toilet activity including bowel emptying.

CONCLUSIONS

The children were unaware of their abilities and limitations. Only five children were independent, despite the fact that 12 of 22 children top rated their performance in – and were completely satisfied with – their toilet activity. Their medical records were only able to classify approximately three quarters correctly with respect to independence. The only measurement that could suggest anything in relation to a maintained focus was time processing ability. Actually, children who had a good time processing ability were more independent in the toilet activity. Time processing ability and observations are important factors to assess independence.

References

1. Mattsson S, Gladh G. Barn med ryggmärgsbråck blir vuxna (Children with spina bifida grow old). *Läkartidningen (Swed Med Soc J)* 2005; 102: 2566–70.
2. Olsson I, Dahl M, Mattson S, Wendelius M, Åstöm E, Westbom L. MMC in Swedish adolescents. *Acta Paediatr* 2007; 96: 446–9.
3. Verhoef M, Barf HA, Post M, van Asbeck F, Gooskens R, Prevo A. Secondary impairments in young adults with spina bifida. *Dev Med Child Neurol* 2004; 46: 420–7.
4. Hunt G, Oakeshott P. Link between CSF shunt and achievement in adult with Spina Bifida. *J Neurol Neurosurg Psychiatry* 1999; 67: 591–5.
5. Hunt G, Oakeshott P. Outcome in people with open Spina Bifida at age 35: prospective community based cohort studie. *BMJ* 2003; 326: 365–6.
6. Hetherington R, Dennis M, Barnes M, Drake J, Gentili F. Functional outcome in young adults with Spina Bifida and hydrocephalus. *Childs Nerv Syst* 2006; 22: 117–24.
7. Padua L, Rendeli C, Rabini A, Girardi E, Tomali P, Salvaggio E. Health-related quality of life and disability in young people with spina bifida. *Arch Phys Med Rehabil* 2002; 83: 1384–8.
8. Gölge M, Schultz C, Dreesmann M, Kuhtz- Buschbeck J, Hoppe B, Wezelburger R, et al. Gripforce parameters in precision grip of individuals with meningocele. *Dev Med Child Neurol* 2003; 45: 249–56.
9. Lezak M. Neuropsychological Assessment. 3rd ed. New York: Oxford University Press, 1995.
10. Börjesson M-C, Lagergren J. Life conditions of adolescents with myelomeningocele. *Dev Med Child Neurol* 1990; 32: 698–706.
11. Lindqvist B. Hydrocephalus in Children. Cognition and Behaviour. PhD Thesis, Gothenburg: Göteborg University, 2007.
12. Borzyskovski M, Cox A, Edwards M, Owen A. Neuropathic bladder and intermittent catheterization: social and psychological impacts on families. *Dev Med Child Neurol* 2004; 46: 160–7.
13. Lollar DJ. Secondary conditions: concepts, identifications, and interventions. *Eur J Pediatr Surg* 1997; 7 Suppl 1: 57–8.
14. Law M, Baptiste S, Carswell A, McColl MA, Polatajko H, Pollock N. Canadian Occupational Performance Measure (Swedish Version). Nacka: FSA, 1999.
15. Janeslätt G, Granlund M, Alderman I, Kottorp A. Development of a new assessment of time processing ability in children, using Rasch analysis. *Child Care Health Dev* 2008; 34: 771–80.

