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REGULAR ARTICLE

Children and youth with myelomeningocele's independence in managing clean intermittent catheterization in familiar settings

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ABSTRACT

Aim: To examine the ability of children and youth with myelomeningocele to independently manage clean intermittent catheterization.

Methods: There were 50 participants with myelomeningocele (5–18 years); 13 of them had also participated in a previous hospital-based study. Their abilities and interest in completing the toilet activity were examined at home or in school using an interview and the Canadian Occupational Performance Measure (COPM). Actual performance was observed and rated. Background variables were collected from medical records and KatAD+E tests.

Results: In total, 48% were observed to perform the toilet activity independently, in comparison with 74% who self-reported independence. Univariate analyses found KatAD+E could predict who was independent. COPM failed to do so. Ability to remain focused and ambulation were predictors of independence, but age, sex and IQ were not. Multivariable analysis found time to completion to be the strongest predictor of independence. Four children were independent in their familiar environment, but not in the hospital setting, and six of 13 children maintained focus only in their familiar environment.

Conclusions: Interviews were not sufficiently accurate to assess independence in the toilet activity. Instead, observations including time to completion are recommended. The execution of the toilet activity is influenced by the environmental context.

INTRODUCTION

Most children with myelomeningocele (MMC) have neurogenic bladder dysfunction, mainly with emptying difficulties resulting in incontinence and recurrent urinary tract infections. These difficulties are usually combined with neurogenic bowel dysfunction (1,2). The bladder dysfunction is a threat to kidney function compelling a majority of children with MMC to use clean intermittent catheterization (CIC) for bladder emptying, usually from birth (3,4). During the first years of life, CIC is managed by parents with the goal that children will manage the task themselves before beginning school. CIC was introduced in the late 1970s (5) and requires the child to: (i) prepare the equipment; (ii) undress to access the urethral orifice; (iii) hand washing; (iv) prepare and insert the catheter into the urethra; (v) empty the bladder and (vi) clean up afterwards.

These procedures must be repeated every third or fourth hour during daytime. This lifelong, regular, low pressure bladder emptying self-care treatment is now a standard procedure for children with MMC. However, the rationale behind it is not always apparent to the children (6,7). A review of treatment regimes for children with neurogenic bladder and bowel dysfunction shows that independence in the toilet activity is quite rare (8,9) despite varying and intensive interventions from habilitation centres and paediatric clinics (9). For many children with MMC, anticholinergic drugs are also required, usually administrated intravesically several times per day (3). Some children have undergone different surgical procedures aimed to improve bladder emptying and continence. Incontinence, however, remains common and is for many individuals the largest obstacle to independence (10,11). The often lifelong need for specific neurogenic bladder and bowel interventions make many children with MMC dependent in the toilet situation into adulthood (12). This study focuses on management of the toilet activity related to CIC, as opposed to bowel emptying. For simplicity, the activities related to CIC will hereafter be referred to as the toilet activity.

There are important implications of being dependent in managing toileting tasks for children and adolescents with MMC. The need for specific equipment, designated spaces and additional time can impose a considerable barrier to participation in productive and leisure activities in the community (13). Any subsequent reduction in participation in social and community-based activities may lead to isolation and reduced health and well-being (14–16).

An observational study of children and youth with MMC performing CIC in a hospital setting as part of their annual review demonstrated that the they were unaware of their abilities and limitations in performing the toilet activity (8). One key outcome was that their time processing abilities were related to their independence. Time processing abilities include mental functions of ordering events in chronological sequence, allocating amounts of time to events and activities and relate to children's time management (17). ICF-CY (18) defines time management[1] as part of the higher-level cognitive functions, commonly referred to as executive functions. Cognitive impairments in children with MMC have frequently been reported as including planning and initiation of task-oriented actions, as well as sustaining focus on the task. Timing, attention and task-related movement are inter-related. Therefore, these executive cognitive functions will be reflected in the performance of activities of daily life (19). In addition to findings related to the effect of time processing on managing the toilet activity, Donlau and Falkmer (8) found that to accurately assess the children's independence, they must be observed performing the task. However, in that study, the hospital setting may have influenced the outcome, affecting both the children's focus when performing the toilet activity and their time processing ability.

This study aimed to extend our knowledge of the toilet activity abilities of children with MMC who are treated with CIC by evaluating their performance in a familiar environment, either at home or in school. The specific aims were to:

(i) Examine the consistency in determining independence in the toilet activity between self-reported and direct observation of performance.
(ii) Identify and describe the influence of locomotor, focus and time processing abilities on independence in, and time taken to complete, the toilet activity.
(iii) Determine which variables are the strongest predictors of independence in the toilet activity.
(iv) Evaluate whether independence in the toilet activity was different when performed in a well-known environment compared with the hospital setting.

METHODS

Informed consent was given by all the participating children and their parents. The study was approved by a Regional Ethical Committee in Linköping. The study design and procedures conformed to the declaration of Helsinki.

Participant eligibility and recruitment

Eligible participants were sought from the regional hospital, and through occupational therapists in four counties outside the Linköping region. Inclusion criteria included ages 5–18 years, diagnosis of MMC and treatment using CIC. In total, 76 children with MMC were asked to participate in the study. Twenty-six of them declined but allowed access to their medical records.

Procedures and instruments

Data were gathered on the background characteristics of the participants, their self-reported independence, their time processing ability and whether they demonstrated independence in the toilet activity in a self-nominated familiar environment. The procedures used to gather these data are described in the following sections.

Background data

The medical records of the 76 children were scrutinized to extract data on the child's age, sex, the presence of hydrocephalus, walking ability according to the HOFFER classification (20) scoliosis/kyphosis, learning disabilities as determined by IQ assessed by formal psychological tests at the habilitation centres, and whether the child required a personal assistant (PA) at home and/or in school. The background characteristics of these 76 children are presented in Table 1.

There were no significant differences between participants and nonparticipants on any of the variables. Of the 50

Table 1 Background characteristics of the 76 children who were potential participants, divided into participants and nonparticipants

	The participants (n = 50)	The nonparticipants (n = 26)
Age mean/median (range)	12.5/12.1 (5.8–18.3 years)	12.8/14.2 (6.4–17.3 years)
Sex ♂♀ (n)	25 = 50%♂, 25 = 50%♀	16 = 62%♂, 10 = 38%♀
Hydrocephalus (%)	45 = 90	23 = 83
Hoffer 1 (%)	19 = 38	9 = 35
Hoffer 2 (%)	3 = 6	5 = 19
Hoffer 3 (%)	1 = 2	0 = 0
Hoffer 4 (%)	27 = 54	12 = 46
Operated for scoliosis/kyphosis (%)	18 = 36	6 = 23
IQ normal (%)	38 = 76	22 = 85
IQ mild learning disabilities (%)	9 = 18	1 = 4
IQ moderate learning disabilities (%)	3 = 6	3 = 11
PA in school (%)	33 = 66	17 = 66
PA in school and at home (%)	2 = 4	1 = 4

♂ = male ♀ = female; Ambulation according to Hoffer: Hoffer 1 (community ambulator), Hoffer 2 (household ambulator), Hoffer 3 (nonfunctional ambulator), Hoffer 4 (nonambulator); Hoffer 1–2 were considered ambulant, whereas Hoffer 3–4 were wheelchair users. IQ was assessed by formal psychological tests at the habilitation centres. PA, personal assistant.

[1]b1642.

participants (mean age 12.5), 13 participated in a previous observational study where their toilet activity was observed in a hospital setting (8). Data from these observations are used for comparison to meet aim iv.

Self-reported independence in the toilet activity

The children who participated were assessed with the Canadian Occupational Performance Measurement (COPM) (21), where the child rated their perceived performance of the toilet activity and their satisfaction with their performance. The COPM was slightly modified because the toilet activity was prechosen. The rating scales range from 1 *'I never do/I am not satisfied at all'* to 10 *'I do extremely well/I am extremely satisfied.'* The COPM has been used in a wide variety of paediatric research and has strong evidence supporting its validity and reliability (22,23).

In addition, the children were interviewed to obtain their opinions on whether they independently performed each of 10 identified subtasks of the toilet activity and whether they wanted to perform them. The subtasks were as follows:

1. I keep track of when to perform my toilet activity.
2. I prepare all the equipment I need for the toilet activity.
3. I undress myself as much as needed.
4. Independently I transfer myself to the toilet, if needed.
5. I wash my hands.
6. I prepare and insert the catheter into the urethra.
7. I clean up afterwards.
8. I notify my suppliers of catheters when there are just a few left.
9. I order any material for the toilet activity when needed.
10. I decide myself upon the extent of assistance I want to have.

The classification 'does not want to perform' was applied both when children said they did not want to do the task themselves and when they indicated they were happy to receive assistance. Each child's response was recorded by the following four classifications:

- Does *not* perform and does *not* want to perform.
- Does *not* perform but wants to perform.
- Does perform but does *not* want to perform.
- Does perform and wants to perform.

To summarize the child's response for the whole toilet activity into one of these four categories, the following procedure was undertaken: if the child claimed *not* to perform one or more of the 10 subtasks, their entire toilet activity was classified as 'does *not* perform'. Likewise, if the child indicated *not wanting* to perform one or more of the subtasks, the entire toilet activity was classified as 'does *not* want to perform'.

Observation of performance of the toilet activity

The participant and the family decided where the observation of the toilet activity would take place. Thirty-seven participants chose to do it at home, and the remaining 13 at school. All data were collected by the first author with the exception of four participants, for whom data were collected by a specially assigned occupational therapist in the region. In 20 cases, data were collected together with the participant's local occupational therapist and in one case with the urotherapist.

The participants were observed during the toilet activity using the same observation form as in the hospital-based study (8). This observation form has been shown to have an inter-rater agreement of 88% (8). During the task performance, the observer continuously assessed:

1. time taken to complete the toilet activity.
2. the participant's focus on the activity, measured as maintained or lost, as this relates to the efficiency, i.e. planning and organizing of the toilet activity.
3. independence in each of the 10 subtasks of the toilet activity.

Each subtask was rated from 5 = totally independent to 1 = the parents or the PA completed the entire subtask without any involvement of the participant. Participants who scored 5 on all performed subtasks were judged as independent.

Assessment of time processing abilities

Similar to the previous hospital-based study (8), the KatAD[2] test (17) was administered immediately after the observation of the toilet activity. Preliminary evidence supports the construct validity of this test as a measurement of time processing ability (17). Scores on the KatAD range from 0 to 69, and increasing scores indicate better time processing ability. As an indication, children with no disabilities aged 11–12 achieve an average score of 66.6 on this test (24). In addition, children's scores on the KatAD have been shown to be positively correlated with self-ratings of autonomy ($r = 0.519$), suggesting that children with good time processing ability possess a higher degree of autonomy than children with bad time processing ability (17). Recently, a section called KatE has been added to KatAD. KatE comprises a short self-rating scale derived from a previously validated questionnaire measuring autonomy (25). The KatE scores range from 0 to 42 with high scores, indicating a high degree of self-reported independence and participation in different activities of daily living. A Rasch analysis of the self-rating scale for children with disabilities has provided evidence of internal scale validity and 93.4% goodness of fit person response validity (26). The self-rating scale demonstrated acceptable internal consistency (Cronbach's $\alpha = 0.79$). Altogether, the self-rating scale of autonomy demonstrated acceptable psychometric properties (17,27,28). KatE scores have been found to be significantly correlated with time processing ability (26).

[2]Since then, its originator has renamed it to KaTidY.

Statistical analyses

Data were analysed using SPSS 14.1 (SPSS Inc., Chicago, IL, USA) and in all analyses, the α-level was set to 0.05.

To examine differences in independence in the toilet activity between selected subgroups of children, chi-squared tests were used to compare categorical data, and after checking for normal distribution with the Kolomogorov–Smirnov test, Students *t*-tests were used for normally distributed interval-level variables, and Mann–Whitney *U*-test or Kruskal–Wallis test for non-normally distributed data and ordinal-level data.

To assess the relationships between selected variables and the outcome of interest, Pearson's correlation (r) and Spearman's rank correlation (r_s) were used. Further analyses were carried out using partial least squares (PLS) regression by means of projection to latent structures. PLS regression finds the relations between two matrices (**X** and **Y**), i.e. it finds a linear model describing some predicted variables (the **Y** matrix) in terms of other observable variables (the **X** matrix). One or more principal components are obtained from the analysis, and their significance is tested with a cross-validation method. Variables with high loadings (either positive or negative sign) upon the same component are inter-correlated. The PLS regression was performed to analyse which of the variables could predict whether the child was observed as independent or not in the toilet activity. In this study, a method called PLS discriminant analysis was used to maximize the separation between the independent children and the children who were not independent, based on the **X** variables. The variable influence on projection (VIP) identifies the most prominent variables for the model. Variables with a VIP ≥ 1 were considered most influential for the model (29), implying a strong relationship with independence. The goodness of fit was described by R^2 and Q^2 described the goodness of prediction. PLS regression is the least restrictive of the various multivariate extensions of the multiple linear regression model. This flexibility allows it to be used in situations where the use of traditional multivariate methods is severely limited, such as when there are fewer observations than predictor variables. PLS is a distribution-free approach to regression unlike models using the usual maximum likelihood estimation method, which assumes multivariate normality. The advantages of PLS include ability to handle multicollinearity among the independent variables; robustness in the face of data noise, missing data and violation of the usual statistical assumptions of latent variable modelling.

RESULTS

In addition to the background variables, data describing the observed and self-reported performance of the toilet activity are presented in Table 2 for each of the 50 participants, of whom 24 were observed to be independent.

Accuracy of self-reported independence

The overall agreement between self-reported and observed independence in the toilet activity was 74% (37/50), as shown in Table 3. The sensitivity (percentage of cases correctly reported to be independent) was 75%. Specificity, which is the percentage of cases correctly reported to be dependent, was 73%.

Influence of background variables on independence and time to completion

There was no evidence that observed independence was influenced by sex or age. However, children who had better ambulation abilities according to their Hoffer scores, who maintained focus and had better time processing ability (KatAD scores) were more likely to be observed as independent in their toilet activity, as shown in Table 4. As expected, those who had higher scores on KatE were also more likely to be observed as independent.

Furthermore, no evidence was found that age or IQ had any impact on time to complete the toilet activity. However, girls, children who had better ambulation abilities according to their Hoffer scores, those who maintained focus and those who were observed to be independent were more likely to complete the task faster than their counterparts, with mean times ranging from 5.0 to 7.2 min compared with means ranging from 10.2 to 11.9 min, as shown in Table 5. In addition, the self-reported independence and participation in different activities of daily living, as measured by KatE, were negatively correlated with time to completion ($r_s = -0.52$, $p = 0.001$).

Predictors of independence

The PLS discriminant analysis resulted in a model with one significant component (Eigen value = 3.54), explaining 51% of the group belonging (independent or not as assessed in the observation). Hence, the goodness of fit was $R^2 = 0.514$ and the goodness of prediction was $Q^2 = 0.458$. The strongest predictor of independence, as determined by VIP values, was time to completion, followed by KatE, COPM performance, self-rated independence as defined by the child in the interviews, focus and age (Fig. 1). IQ was the least influential variable on independence in the toilet activity.

Satisfaction with performance of the toileting activity

In total, 24 of 50 children were completely satisfied with their toilet activity, i.e. rating 10 on the COPM satisfaction assessment, and 19 assessed their performance as good as possible, as shown in Table 2. The median COPM rating for both performance and satisfaction was 9 (range 1–10). Seven children rated their satisfaction lower than their performance, all of them being community ambulators, i.e. HOFFER 1. There was a moderate positive correlation between self-rated performance and satisfaction ($r_s = 0.5$, $p = 0.001$). Of the 26 children observed to be dependent in their toilet activity, 38% (10/26) rated their performance using the COPM very high, as either 9 (4 children) or 10 (6 children). The corresponding figures for their satisfaction with their performance, as rated on the COPM, were even higher; i.e. 46% (12/26) assessed their performance as either 9 (2 children) or 10 (10 children).

Table 2 Results for each individual participant. The table presents the data of the participants who were observed to be independent in the toilet activity before those who were not independent

	Background variables				Performance						
	Ambulation		Time processing ability		COPM		Interview			Observation	
Participant number, sex and age (in years. months)	HOFFER* (1–4)	IQ†	KatAD Range 0–69	KatE Range 0–42	Performance‡	Satisfaction‡	Claims to perform§	Wants to perform¶	Performs independently	Focus M/L**	Time to completion Min††
1. ♀, 12.9	1	N	65	37	10	10	No	No	Yes	M	3
2. ♂, 17.10	4	N	65	35	10	10	No	No	Yes	M	7
3. ♂, 14.11	4	N	65	16	7	8	No	Yes	Yes	M	18
4. ♀, 13.7	1	N	65	37	10	10	No	No	Yes	M	3
5. ♂, 16.10	2	N	52	32	9	10	Yes	Yes	Yes	M	1
6. ♂, 14.5	4	M	39	24	6	6	Yes	Yes	Yes	M	5
7. ♀, 11.6	4	N	37	17	10	10	Yes	Yes	Yes	M	5
8. ♂, 15.3	4	N	63	34	10	10	Yes	Yes	Yes	M	5
9. ♂, 14.6	4	N	52	27	9	9	Yes	Yes	Yes	M	6
10. ♀, 18.3	4	Mo	67	41	0	0	Yes	No	Yes	M	9
11. ♀, 11.5	1	N	32	18	10	9	Yes	No	Yes	M	5
12. ♀, 14.1	1	N	59	25	10	10	Yes	No	Yes	M	4
13. ♀, 13.7	2	N	37	26	10	6	No	No	Yes	M	4
14. ♀, 10.4	1	N	43	25	8	5	Yes	No	Yes	M	3
15. ♂, 14.7	1	N	69	29	8	6	No	No	Yes	M	6
16. ♀, 12.7	1	M	52	21	8	10	Yes	No	Yes	M	3
17. ♀, 15.1	4	N	58	25	10	10	Yes	No	Yes	M	8
18. ♀, 16.3	1	N	68	36	9	10	Yes	Yes	Yes	M	3
19. ♂, 13.7	4	N	62	21	7	10	Yes	No	Yes	M	6
20. ♀, 11.2	1	N	60	34	10	5	Yes	No	Yes	M	3
21. ♀, 15.4	4	N	55	26	10	10	Yes	No	Yes	M	3
22. ♀, 16.0	4	M	42	19	8	10	Yes	No	Yes	M	3
23. ♀, 18.0	1	N	55	31	10	10	Yes	No	Yes	M	5
24. ♀, 12.0	1	N	42	26	10	5	Yes	No	Yes	M	5
25. ♂, 10.4	1	N	48	17	9	5	No	No	No	L	17
26. ♂, 10.5	4	N	50	17	5	9	Yes	Yes	No	M	22
27. ♂, 6.9	4	N	42	10	10	10	No	No	No	L	12
28. ♂, 6.6	1	N	15	6	10	10	No	No	No	L	10
29. ♂, 12.11	4	N	49	17	5	10	No	No	No	M	7
30. ♀, 13.3	4	Mo	10	12	10	10	No	No	No	M	14
31. ♀, 18.0	4	Mo	4	4	10	10	No	No	No	L	25
32. ♂, 8.11	4	N	61	22	8	8	Yes	No	No	M	25
33. ♂, 7.0	4	N	23	12	6	6	No	No	No	M	14
34. ♀, 8.8	1	N	32	32	2	2	No	No	No	M	5
35. ♂, 13.9	4	N	64	27	9	9	Yes	Yes	No	M	18
36. ♂, 13.2	4	M	59	26	9	9	Yes	No	No	L	15
37. ♂, 17.0	1	M	52	24	8	8	No	No	No	L	5
38. ♀, 7.3	4	N	27	11	7	10	Yes	No	No	L	15
39. ♂, 7.10	4	N	23	6	10	10	No	No	No	M	9

Table 2 (Continued)

	Background variables				Performance						
	Ambulation		Time processing ability		COPM		Interview			Observation	
Participant number, sex and age (in years. months)	HOFFER* (1–4)	IQ†	KatAD Range 0–69	KatE Range 0–42	Performance‡	Satisfaction‡	Claims to perform§	Wants to perform¶	Performs independently	Focus M/L**	Time to completion Min††
40. ♀, 15.9	2	M	48	26	6	8	Yes	No	No	M	6
41. ♀, 5.10	4	N	29	9	7	8	No	No	No	L	4
42. ♀, 10.5	1	N	63	25	9	10	No	No	No	M	5
43. ♂, 7.5	1	N	29	17	7	10	No	No	No	L	8
44. ♂, 12.1	4	N	57	14	5	7	Yes	Yes	No	M	4
45. ♂, 13.3	4	M	33	22	2	6	No	No	No	M	7
46. ♀, 16.9	4	M	38	22	1	1	No	No	No	L	15
47. ♂, 8.6	4	N	35	11	1	5	No	No	No	L	13
48. ♀, 12.2	4	N	40	13	7	7	No	No	No	M	12
49. ♂, 10.6	1	N	18	17	10	6	No	No	No	L	5
50. ♂, 9.6	4	M	3	3	2	10	No	No	No	L	11
Totals	1 = 18 2 = 3 3 = 0 4 = 29	N = 38 M = 9 Mo = 3	Mean (SD) = 45.1 (17.5)	Mean (SD) = 21.7 (9.3)	Mean (SD) = 7.7 (2.8)	Mean (SD) = 8.1 (2.6)	Yes = 25 No = 25	Yes = 10 No = 40	Yes = 24 No = 26	M = 38 L = 12	Mean (SD) = 8.5 (6.0)

*For definitions, see Table 1.
†N, Normal; M, Mild impairment; Mo, moderate impairment.
‡COPM score range is 1–10.
§Self-rated independence.
¶They accepted to perform the toilet activity with assistance.
**M, maintained focus; L, lost focus.
††Median 6 min, range 1–25.

Table 3 Agreement of self-reported and observed independence in the toilet activity

	Observation		
	Independent	Dependent	Totals
Self-reported			
Independent	18	7	25
Dependent	6	19	25
Totals	24	26	50

Table 4 The impact of selected child characteristics on observed independence in the toilet activity

	Dependent	Independent	Test and p-values
Male (n = 25)	8	17	n.s.
Female (n = 25)	16	9	
Age, mean (SD)	14.1 (2.9)	11.1 (3.7)	n.s.
Hoffer 1 or 2 (n = 21)	8	13	$\chi^2 = 6.41$,
Hoffer 3 or 4 (n = 29)	18	11	$p < 0.001$
Maintained focus (n = 37)	13	24	$\chi^2 = 1.14$,
Lost focus (n = 13)	13	0	$p = 0.001$
KatAD, mean (SD)	38.4 (18.5)	52.1 (13.2)	$Z = -2.8$, $p = 0.04$
KatE, mean (SD)	16.2 (7.8)	27.6 (6.9)	$Z = -4.3$, $p < 0.001$

n.s., not significant.

Table 5 Impact of selected child characteristics on time to completion

	Time to complete the task, mean, (SD)	Test and p-values
Male (n = 25)	10.2 (6.1)	$Z = -2.9$,
Female (n = 25)	6.7 (5.5)	$p = 0.004$
Age	$r_s = 0.176$	n.s.
Hoffer 1 or 2 (n = 21)	5.0 (3.3)	$Z = -4.1$,
Hoffer 3 or 4 (n = 29)	11.2 (6.2)	$p = 0.001$
Maintained focus (n = 37)	7.2 (5.7)	$Z = -2.7$,
Lost focus (n = 13)	11.9 (5.8)	$p = 0.007$
Observed independence (n = 24)	4.5 (1.8)	$Z = -4.8$,
Observed dependence (n = 26)	12.4 (6.2)	$p = 0.001$
IQ normal (n = 38)	10.0 (6.3)	n.s.
IQ mild or moderate impairment (n = 12)	8.0 (5.9)	

n.s., not significant.

The interviews revealed that 24 of the children who rated themselves as dependent were happy to accept assistance in the toilet activity, *'I take all possible assistance, because it takes too much time in the toilet.'* Only one child of these children (child no. 3) wanted to perform the required tasks to become independent. In contrast, 16 of the 25 children who rated themselves as independent did *not* want to perform the required tasks to remain independent. The remaining nine children claimed to be, and wanted to remain, independent.

The nine children who rated themselves as independent and who wanted to have control over all tasks in the toilet activity reported difficulties in doing so:

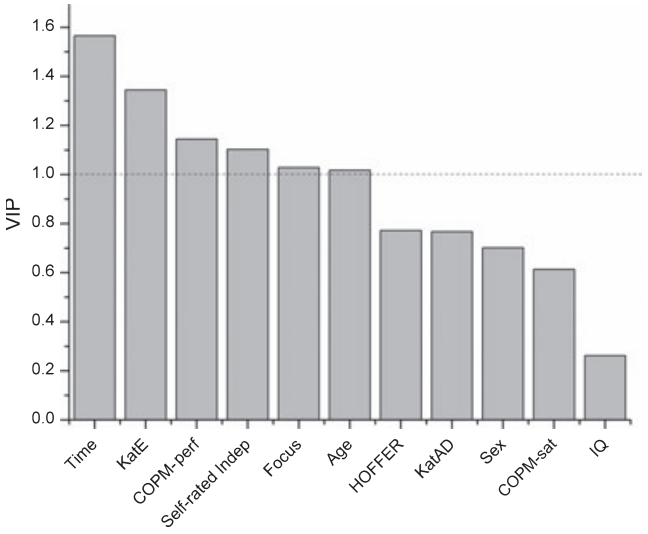

Figure 1 Variable importance on projection (VIP) from the PLS discriminant analysis, explaining 51% of the group belonging. Variables with VIP ≥ 1 were considered important, and high values indicate strong predictors of group belonging (independent or not).

> 'Yeah, I may very well day dream while I'm in the toilet and completely lose track, but eventually someone will knock on the door...'

> 'If I forget to bring fresh catheters, I usually find an old one from last time I was here in the wastebasket…'

> 'Of course I handle all the subtasks myself, except for ordering the products I need…it has not struck me before but, mind you, I'm going to do it next time'

> 'I can definitely do it all by myself but then I have to hurry up before mum enters…'

The subtasks that the children performed independently were also the ones they wanted to be independent in, or at least handle autonomously. To keep track of time when performing the toilet activity was reported as problematic by 20 children. Some ambulant children reported that the more or less fixed time to go to the toilet constituted a barrier to participation with peers in other activities. *'I can't go with my friends after school, because I am not sure I'll find a toilet at the right time'.*

Impact of environment on independence and maintained focus in the toilet activity

Thirteen children participated both in the present study and in a previous study (8), where all data were gathered in a hospital setting when the children attended their annual medical review. The time between occasions of measurement ranged from 1 to 16 months, with the median age of participants on the first occasion being 10.1 and on the second occasion 11.6. A comparison of their performance of the toilet activity within these two settings is presented in

Table 6. Four children who were determined to be dependent in the toilet activity in the hospital setting were found to be independent at home or in school. Each of these children maintained focus in the familiar environment but not in the hospital setting.

DISCUSSION

When asked, a quarter of the participants in the present study incorrectly reported their ability to independently complete the toilet activity. This finding is similar to that reported in a previous study comprising of 22 children that compared observed independence with independence as reported within the medical records (8). This discrepancy is likely due to the fact that the medical records were based on interviews with the children rather than on observations. Hence, an interview is not a sufficiently accurate tool to assess independence in the toilet activity for children and youth with MMC. Neither is the COPM, despite the fact that the performance measurement within it was a strong predictor in the PLS discriminant analysis model. However, it must be kept in mind that this model's explanatory value was only 51%. More than a third of those observed to be dependent reported top performance, and almost half of them were equally satisfied with their performance. The COPM measures perceived performance and, like the interview report of independence, is not sufficiently sensitive or specific to observed independence. Asking participants to rate the level of their perceived performance is, however, not exactly the same as asking them whether they are independent. Nevertheless, our results do raise the question of whether children and youth with MMC are appropriate candidates for self-report instruments that aim to measure capacity.

Table 6 Comparison of performance for n = 13 children in a hospital setting compared with home or school

Child, as numbered in Table 2	Independent in the hospital setting	Independent in home/school setting	Hospital setting; maintained focus	Home/school setting; maintained focus
3	Yes	Yes	Yes	Yes
6		Yes		Yes
7		Yes		Yes
13	Yes	Yes	Yes	Yes
14	Yes	Yes	Yes	Yes
17		Yes		Yes
22		Yes		Yes
26			Yes	Yes
27				
32				Yes
39			Yes	Yes
40				Yes
45			Yes	Yes
Totals	n = 3 Independent	n = 7 Independent	n = 6 Maintained focus	n = 12 Maintained focus

Only half of the participants in the present study, whose ages ranged from 5.8 to 18.3, were observed to be independent in their toilet activity. It has been proposed that adolescents with MMC become autonomous at a later age compared with their healthy peers and that cognitive ability, rather than degree of physical ability, predicts the age at which they achieve autonomy (30). Davis et al. (30) describe older children and youths (12–18 years) in a cohort of 158 patients followed over 10 years and concluded that differences in cognitive ability explained the variance in median ages for skill acquisition more than physical lesion level. In contrast to Davis et al (30) findings, in the present study neither age nor IQ ratings were important predictors of independence or the time taken to complete the task. Our study did not measure fine motor ability, but a general measurement of physical capacity was obtained through the Hoffer ratings. Interestingly, while Hoffer ratings could distinguish between those who were dependent or independent at a bivariate level, when included in the moderately explanatory multivariate analysis, ambulation was no longer an important predictor of independence in the toilet activity. The important predictors for independence in the toilet activity were related to time processing ability, i.e. indirectly to executive functions, confirming previous findings (8). The results from both KatAD, related to time processing ability, and KatE, measuring self-reported independence and participation, could discriminate between those observed to be independent and those not. Unexpectedly, KatAD was not found to be an important variable for independence in the PLS discriminant analysis model in the present study although the independent children scored significantly higher on KatAD than the dependent.

Because of the univariate association between time processing and independence, we would recommend that the entire KatAD+E test is used rather than just the KatE section in clinical practice. Time processing involves many neuropsychological demands, for example memory and executive function, important factors that apparently are necessary to manage the toilet activity. Those participants who remained focused completed the task more quickly, and time to completion was the best predictor of independence in the PLS model. These findings are congruent with Peny-Dahlstrand et al (31) claim that even when children with MMC have the physical skills, their executive dysfunction may affect their performance.

This study included children from 5 years of age up to adulthood with various IQ scores, and despite this variability, neither the present study nor the previous one (8) found that age or IQ was an important predictor of independence in this activity. The differential importance of time processing ability as a measure of executive function and IQ rating supports the notion that IQ rating alone cannot be equated with all aspects of cognitive functioning. In addition, while the girls performed their toilet activity more quickly than the boys, there was no sex difference with respect to independence. Clinicians should not assume that the children's and the youth's reports of their independence are accurate.

For accuracy of assessment, the children and youth must instead be observed doing the activity. However, if there is insufficient time, or they prefer to maintain their privacy, measures of executive functions, using the KatAD +E battery for example, appear to be a useful predictor of independence.

Another interesting finding was that most participants (80%) reported that they did not want to be independent; that is, they were happy to accept assistance to perform the toilet activity. This was even true for 17 of the participants who were observed to be independent. This may be a consequence of cognitive dysfunction that makes it difficult for youth with MMC to comprehend the long-term implications of requiring assistance in this daily activity. Furthermore, it is also possible that there has been no, or reduced, expectations that they should be independent, either from the participants themselves or from their caregivers. As stated by Brislin (32), '*Psychosocial difficulties during development are often not the direct result of congenital abnormalities such as spina bifida; instead, these difficulties arise as a function of ineffective social supports and environmental factors*' (p. 38). Ongoing dependence may, consequently, be related to reduced expectations, or a learned helplessness, because most children with MMC have a large number of people supporting their activities, even in the most private situations.

Some participants performed the toilet activity more independently and were more focused in a familiar environment, compared with the unfamiliar hospital environment. The difference in performance highlights the important impact environmental factors can have on performance and suggests also that these participants had not reached the autonomous level of learning, where the skill performance is flexible and efficient regardless of the environmental context (33). For children and youth with MMC to be independent in their daily life, the CIC activity should be a skill as free from its context as possible. Preferably, they should achieve this skill long before they enter adulthood. The ability to complete this task independently and efficiently, by maintaining their focus, is likely to reduce the participation barriers associated with toileting and subsequently enhance the capacity for youth and adults with MMC to engage in community activities. Helping children and their families to become aware of how the toilet activity is carried out is an important part of treatment, and any cognitive dysfunctions in the child should be addressed as part of an intervention programme. Future research should investigate the effectiveness of interventions aimed at increasing the independence of children and youth with MMC.

The present study focused on the urinary toilet activity, as CIC has to be performed more frequently than bowel emptying. However, children with MMC also find independently managing bowel emptying difficult. This is yet another crucial obstacle for independence (13). Bowel irrigation procedures are even more time-consuming than urinary toilet activities and need more support. Our exclusion of bowel irrigation procedures in the assessment of the participant's independence is a limitation of the present study, because true independence in the toilet activity covers both these procedures. Another limitation of the present study is the low number of children who participated in the hospital-based study, which indeed compromises the comparisons between the two.

CONCLUSIONS

Half of the participants with MMC in this study had the ability to be independent in CIC, indicating that it is possible to achieve independence in this activity. However, this study suggests that the execution of the toilet activity may be influenced by the environmental context. Interviews are not sufficiently accurate to assess independence in the toilet activity for children and youth with MMC. Neither age and sex nor IQ was associated with independence in the toilet activity. Rather, the best predictor for independence was found to be time to completion which may be related to time processing ability in people with MMC. Clinicians therefore may utilize this knowledge to design interventions that support the time management of children and youth with MMC in the toilet and potentially increase the proportion of them who achieve independence well before adulthood.

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