ORIGINAL ARTICLE

Children with myelomeningocele and independence in the toilet activity: A pilot study

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Abstract
Objective: Regarding adult life and independence the most common obstacles for young adults with myelomeningocele (MMC) are cognitive dysfunction and difficulties in performing toilet activities. A step-by-step method with goal setting for the training of self-care in toilet activities for children with MMC was evaluated. Method: Twenty-two children with MMC and bladder and bowel dysfunction (12 girls, 10 boys) aged 3–17.2 (m 9.1) were included. The toilet activities were observed at home jointly by an occupational therapist and urotherapist. Goal-setting procedures of self-training were promoted. Observation scores before and after intervention were compared, the goal setting being evaluated on a Goal Attainment Scale (GAS). Results: Fifteen children who trained in self-catheterization had a median observation score of 22 before and 37 after the training period (p = 0.002). Another seven trained in trans-rectal irrigation with a median score of 30 before and 49 after (p = 0.02). As a result of GAS all children improved, of whom 17 reached the goal or even more so than expected. Conclusions: In this pilot study mutual goal setting in a step-by-step training programme based on professional observation of the toilet activity at home showed a better outcome than traditionally performed training in a hospital setting or with traditional habilitation support.

Key words: toilet training, spina bifida, self-care, neurogenic bladder and bowel dysfunction

Introduction

Previously people with myelomeningocele (MMC) were not expected to live very long but today they do. However, shortcomings in participation in adult life are reported (1,2). The young ones are not prepared to take responsibility for their adult life and self-care (3,4). Nor are the medical services prepared to meet the special needs of care and expectations concerning adults with MMC. Children with MMC have difficulties getting things done due to the deficient quality of task performance. It is therefore crucial for occupational therapists to access, understand, and support the development of performance skills in children in order to enhance their autonomy and active participation in everyday life, school, and society (5). Cognitive dysfunction and difficulties in the toilet activity are the most common obstacles for people with MMC (2). Fortunately there is a growing physiological and clinical knowledge of how cognitive obstacles present themselves (6,7). Performance skills are the way the body functions are used and organized into actions in task performance. They depend on the person’s motor, cognitive and communicative functions and are presented in three different types as motor skills, process skills, and interactive skills (8). In the habilitation context participation should be considered in terms of not just the goal but also the process of reaching the goal (9).

An observational study of children and adolescents with MMC performing clean intermittent catheterization (CIC) as part of their annual medical control in a hospital setting demonstrated unawareness of abilities and limitations in performing the toilet activity.
Even time-processing ability was impaired (10). Children and adolescents with MMC also find it difficult to describe their own condition in general and cause and effect especially (11).

Another observational study of the toilet activity was performed in 50 children, but in an environmental setting familiar to the child. Half of the children were independent but far from what might be expected in relation to age and cognitive and physical status of the child (12). It is shown that time perception influences the possibility for independence and participation (13). The observation of 50 children with MMC also showed that time orientation was most often normal but time perception and time management lowered compared with peers of the same ages (12). It is obvious that toilet procedures with CIC and TRI (trans-rectal irrigation) are more time-consuming compared with how long healthy children spend at the toilet. In a running project concerning children with MMC and independence at the toilet an extra finding was that children using CIC and TRI are spending approximately 7.5 hours more per week at the toilet (unpublished data). Time perception in general and time to perform the toilet activity proved predictive of the child's independence (12).

The present study will deal with acquired knowledge about how the disabled child can be given support in order to increase control of his/her own life by a higher degree of participation (3,12,14). The knowledge of various factors that influence independence in the toilet activity will also be considered (10,14,15). The process of doing should be seen and analysed both in general and in a specific sense. Peny-Dahlstrand et al. concluded that persons with MMC need particular guidance to learn not only how to do things but also “how to get things done” (16). The aim is to evaluate the effects of a step-by-step method with goal setting, based on common agreement between child and parents, along with distinct documentation and feedback when training self-care in the toilet activity.

Material and methods

Participants

The study has an open, prospective design including children with MMC with bladder and bowel dysfunction living in the nearby area of a tertiary centre of a paediatric clinic at a university hospital. At that time a total of 36 children (<18 years) lived in the county. Three children were excluded due to severe mental challenges and incapacity to make their own decisions. Thirty-three children and their parents were asked to participate in a project of self-care training in the toilet situation with a focus on independence. It was crucial that all children, even the very young ones, had the possibility to express themselves. Eleven children declined to participate (six girls and five boys) mean age 14.5 (SD 3.5).

In total 22 children, 12 girls and 10 boys, mean age 9.1 (SD 5.5) agreed to participate and informed consent was given by all children and their parents. All children involved had a shunted hydrocephalus. Fifteen (15/22) were wheelchair bound while seven could walk with splints or crutches. Sixteen attended a regular school and one a special class for disabled children. Another five were too young to attend regular school. Eleven children had a personal assistant at school. All used clean intermittent catheterization (CIC) for bladder emptying and all but one regularly used trans-rectal irrigation (TRI) for bowel emptying. All 22 children depended on helpers during the toilet activity. The studied children were followed up at least once a year for control of bladder and kidney function at the paediatric hospital (17) and all had been attended to in traditional habilitation care since birth.

Fifteen of the children (mean age 11.5 years) had before start of this study trained in toilet activities once or twice in a hospital setting (two to five days’ training and follow-up) without lasting effects on independence. For seven children (mean age five) home-based training was their first step to becoming independent in the toilet activity.

Procedure

Altogether four urotherapists and four occupational therapists were engaged in the study. One urotherapist and one occupational therapist jointly made a house call observing the child during toilet activities. Afterwards advice was given based on what had been observed. The toilet environment was adjusted when needed, with the focus on independence. Recorded observations made it possible for professionals and parents to make sure that the same message was given to the child about how to perform the task but also to increase the awareness of the support they received during the toilet activity. Individual goals were set after discussion by the child and parents together with the purpose of performing this new goal at every toilet visit, thus gradually making it an automatic habit. Also of great importance was adjusting goals and training to the individual child’s potential. In order to increase insights into their own needs and conveying hope to reach independence the following activities were added:

- The observers asked: “Do you know why you empty the bladder and bowel in a different way?” The question was a prompt to communicate regarding facts to take into consideration and be aware of in relation to the disability and its consequences.
The children were offered the opportunity to see their back and discuss scars and consequences. This intervention may cause discussion of the influence of the disability on daily living and participation.

The children were asked if they wanted to see the doctor without the presence of parents. This offer is to emphasize that the intervention concerns the child him/herself, not a parental matter, and underlines their rights of autonomy.

Attention was given to the time-processing ability of the child and if required assistive technology was suggested as a time-aid, to improve sense of time, or a procedural scheme of the different actions when performing the toilet activity to keep the process going.

A worksheet with an individually adjusted performance of the toilet activity was given to each child. The actions independently performed by the child were written in black, the actions performed with support in red, and the training actions in green. This worksheet gives conditions for joint notions on how the activity should be performed.

Self-rating of own performance and satisfaction was also recorded by using the instrument Canadian Occupational Performance Measure (COPM) (18).

Ethical issue

In daily life almost all children and many adults with MMC need support from another person when urinating or emptying the bowel, as was the situation for all the children involved in our study. For a human being one of the most private situations is to perform toilet activities. Two persons with different fields of knowledge do observe the children during the toilet situation to try to elucidate the barriers to independent toilet visits and to create tools for independent living. To be professional and able to give adequate support when handling the problems encountered during toilet activities, both observed as well as theoretical knowledge is needed. The children and their parents accepted observation of the toilet activity in the hope that the child would be independent in the future. The study was approved by the regional ethical committee in agreement with Swedish law.

Evaluation

The observation of toilet activities was made at the start and at follow-up in a structured manual. The manual had been developed earlier with an interrater reliability of 88% (7). For evaluation of the toilet activity with CIC or TRI, 12 or 13 variables respectively were used (Table I). The tasks performed were ranked from 1 to 5 (from dependent to independent) by the observers. The ranking was as follows: (1) don’t perform, (2) perform with physical and verbal support, (3) perform with physical support, (4) perform with verbal support, (5) perform by oneself (see Table I). The maximum score for CIC performance was 60 and for TRI 65. The scores before and after the intervention were then compared.

Table I. Observed and evaluated tasks during the observations of the toilet activities.

<table>
<thead>
<tr>
<th>CIC performance</th>
<th>TRI performance</th>
<th>5</th>
<th>4</th>
<th>3</th>
<th>2</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pick up equipment</td>
<td>Pick up equipment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prepare catheter</td>
<td>Prepare enema device</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Move to toilet seat</td>
<td>Prepare water filling</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Remove pad</td>
<td>Hang up the bag</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wash hands</td>
<td>Move to toilet seat</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Put in catheter</td>
<td>Undress</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Take out catheter</td>
<td>Remove pad</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Put on pad</td>
<td>Put in cone</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dress</td>
<td>Adhere/put out cone</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Flush the toilet</td>
<td>Clean bottom</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wash the hands</td>
<td>Wash the hands</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clean up</td>
<td>Move back</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

Note: "Different sheets were used for clean intermittent catheterization (CIC) and transrectal irrigation (TRI) performance."
A Goal Attainment Scale (GAS) was used with negotiated practical goals providing an individualized, criterion-referenced measure of change (19, 20). The scale is ranked as follows: –2 (baseline), –1 (outcome less than expected), 0 (expected outcome), +1 (outcome greater than expected), +2 (outcome much greater than expected). To avoid subjective rating a distinct goal setting was emphasized. The worksheet, indicating observation (the starting position), goal, and different steps, was subsequently given to the family. Important was describing “who was expected to do what”. 

The Canadian Occupational Performance Measure (COPM) allowed self-rating of own performance and satisfaction (18). The COPM was modified as the toilet activity was pre-chosen. The rating scales range from 1 to 10 relating to own performance: “I never do it by myself” to “I manage the toilet activity extremely well” and to own satisfaction: “I am not satisfied at all” to “I am extremely satisfied with my way to wee/poo”. The COPM was performed by both children and parents at start and last follow-up.

Statistical analysis

For statistical analysis SPSS 18.0 was used. Descriptive statistics (mean, median, range, SD) and Wilcoxon’s pairs test with p < 0.05 indicated significant differences.

Results

General

The joint work by the urotherapist and occupational therapist performed in the children’s home environment provided a substantially complete picture of the toilet activity. It was noticed that some children needed changes in their toilet environment such as storing the equipment near the toilet seat (a shelf, cupboard, or bag), adjusting the basin site and/or installing a wastebasket. Advice was also given regarding changing technical aids, inserting or excluding different toilet devices, changing size of catheters, reaching an adequate position, and improving the techniques of CIC and TRI, as well as tips on hygiene, hand washing, and cleaning. However, in this study the modification of the toilet environment and technical adjustments for better physical function were not decisive to reach the goals.

Two home visits were performed with 16 families, three with six families, with a median of 40 days (m 60 days, range 20–191) between first and last visit. Three visits were needed because of different unforeseen events like surgical treatment for one, a fracture of the lower limb in one, the need for aids to facilitate the toilet procedure for three. One family wanted to postpone the training due to the summer break.

Ten children had never seen their back and the scars after the closure of the cele in the neonatal period. Most parents had told the children why they had to “wee and poo” in a different way from their peers, but it could not be taken for granted that they had fully understood. Two children were equipped with special aids to facilitate time-processing ability. So far none of the children had seen a doctor without parents present, even if a few wanted to think it over.

Observations

All 22 children were at first visit observed in the toilet activity during the CIC procedure and 16 in the TRI procedure as well. In 15 children the chosen goal was related to CIC (CIC group) and in seven it was related to TRI (TRI group). The CIC group at the start had a median observation score of 22 (m 25, range 9–52) and after training 37 (m 36.3, range 17–56), which indicates improved independence (p = 0.002). The TRI group at the start had a median score of 30 (m 32.1, range 28–41) and after training 49 (m 44.6, range 32–54), thus also showing a significant improvement (compared means p = 0.02; Figure 1).

Figure 1. Observation scores at baseline (before the training period) and at follow-up (the last visit) during the toilet activity performing clean intermittent catheterization (CIC) (A) and trans-rectal irrigation (TRI) (B).
Goal Attainment Scale

Negotiated (children and parents) goals were set from a step-by-step strategy working on individual skills (the goals varied greatly from child to child and could be to take the catheter out of the package as well as to manage the whole toilet procedure by themselves). All children improved and 17 reached their individual goal or did more than expected (Figure 2). The other five improved one step (–)1 but did less than expected. Three of them were quite young (aged 4.5 to 5.3 years). The other two (17 and 14.2 respectively) needed both special arrangements and more visits. There was no difference between CIC and TRI regarding GAS outcome, either in respect of ranking, or of days between, or number of visits (p = 0.3, p = 0.9, p = 0.6).

Canadian Occupational Performance Measure

The children’s (n = 16) own COPM scoring of performance showed a significant negative difference between the first and last home visit (at start m 5.6, after training m 3.5; p = 0.008), implying that the children judged their performance in the toilet activities to be less good after training. There was no difference in the children’s satisfaction with the method of emptying the bladder or bowel (p = 0.2) or the parent’s (n = 19) outcome of performance and satisfaction (0.9 and 0.9 respectively). However, the COPM evaluation at the last home visit exposed that the children scored their performance of CIC and TRI lower than the parents did (m 3.5 compared with m 6.2; p = 0.005) and the same with satisfaction (m 4.6 compared with m 6.8; p = 0.04).

Discussion

To reach independence in self-care in toilet activities for a child with MMC, a urotherapist and an occupational therapist working together with the child and parents in a home setting implements a wide range of know-how and common ground to start from. A step-by-step training programme with distinct goal setting based on observation of the toilet activity at home seems to give a better outcome (15/22 children) than...
training in the traditionally performed hospital setting or with traditional habilitation support.

To be independent in the toilet situation is looked upon as a matter of course and should be the same obvious and self-evident basis in the care of children and young adults with bladder and bowel disturbances. By using the strategy of a step-by-step programme with goal setting and training of the mutually agreed actions at every toilet visit, all reached a higher level of independence. Our study shows just one step but many more steps are needed. One example when using further steps is a 17-year-old boy not managing the TRI by himself. He was very active with several hobbies and had been highly motivated to achieve independence for a long time. The parents and staff from both a habilitation centre and a tertiary paediatric hospital had been trying to solve the problem for years. After four months with further goal setting in four steps the person in question became fully independent.

In fact everyone (n = 22) participating in the study made some progress. The outcome in the long run is not known from this study but it is not unrealistic to believe that an ongoing process with this strategy will help the growing child with MMC to become more aware of both self-care and how to manage it on his/her own. After 54 home visits it was found that despite rational and well-functioning parents it was common that families had adhered to old, outdated habits and irrational methods suggesting that they will benefit from support during the child’s entire growth period (12).

The observation of the toilet activity enables a realistic view of the child’s performance, supporting adequate goal setting. When measuring changes over time, GAS is useful for the individual to take control of the process and to see clearly the goal reached. This also makes it possible for the individual and others involved to work from common ground on how to perform the activity, with every step clearly described. Steenbeek et al. concluded that the use of GAS alone was dubious as an outcome measure and recommended adding another programme of evaluation (20). In the present study GAS was used alongside recording the observations of the activity before and after training. The improvement after training was significant as was the GAS outcome, which implies that the children improved in their self-management.

It is reasonable to believe that by particular guidance and everyday training in a familiar environment a specific task might be managed automatically. To help oneself will thus become self-evident.

Children with MMC reach autonomy skills later than their peers and the cognitive problems form the greatest barriers (21). In addition to problems with memory, planning, and execution (2,6), young persons with MMC do not always have a realistic view of either skills or obstacles (10,12,14). This may be the reason why the COPM outcome of performance as judged by the children scored better performance of the task before training than after, despite the fact that they managed better. During the training process they apparently became aware of how the task should be performed.

This is a pilot study with a rather short follow-up and shows just one step of a complete activity but there are many steps left to reach independence. The positive effects towards independence in the toilet activity using the strategy described have to be proved in a controlled fashion in a larger group of children. Nevertheless, the study describes one concept promoting a joint picture of what has to be done and how, viewing a motivated child as being part of the goal-setting and planning of the training. The youngest children were not yet expected to be independent but our concept offers the growing child one tool to become so. In our group of children the strategies also produced rapid effects, altogether contributing to better self-confidence and quality of life (22).

Acknowledgements

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