

## Pro and Cons of Transurethral Self-Catheterization in Boys: A Long-Term Teaching Experience in a Pediatric Rehabilitation Centre

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**Purpose:** To describe the acceptance and efficacy of clean intermittent catheterization (CIC) in the management of lower urinary tract (LUT) dysfunction regardless of the age of the children and their degree of urethral sensation.

**Materials and Methods:** We retrospectively evaluated boys managed with CIC at a pediatric teaching hospital between 1992 and 2014. Age, urethral sensation, acceptance, efficacy in terms of continence and preserving upper urinary tract and genitourinary complications were reviewed in the medical records.

**Results:** Sixty boys managed with CIC for LUT dysfunction due to neurological or urological disorders were identified. The median age at CIC initiation was 8.2 years (range, 1.4-18). With regard to age, CIC was well tolerated in younger boys and without genital sensation. Failure in the CIC protocol occurred within the first six months (n = 9). More boys with genital sensation were socially continent with CIC (91% versus 83%,  $P = .05$ ). Vesicoureteral reflux was resolved in 69% of boys ( $P = .03$ ), and hydronephrosis in 54% ( $P = .07$ ).

**Conclusion:** CIC was effective in terms of continence and renal protection. The procedure was feasible even in boys with preserved urethral sensation. Therapeutic education by a dedicated urotherapy nurse is the key factor in ensuring long-term CIC compliance and acceptability.

**Keywords:** patient education as topic; self-care; urinary catheterization; nursing; community health nursing; male; child; urinary tract infection.

### INTRODUCTION

The introduction of clean intermittent transurethral catheterization (CIC) by Lapedes and colleagues in 1972 radically changed the management of lower urinary tract (LUT) dysfunction in patients with congenital or acquired neurogenic bladder.<sup>(1)</sup> Other methods to manage LUT dysfunction include anticholinergic agents, chronic indwelling suprapubic or urethral catheters, continent catheterizable channels (CCC) or incontinent reservoirs. The therapeutic objective is to increase complete bladder emptying at regular intervals, thus maintaining a low level of intravesical pressure, which prevents vesicoureteral reflux (VUR) and decreases the risk of urinary tract infection (UTI).<sup>(2)</sup> CIC is commonly used in the management of neurogenic LUT dysfunction. Long-term follow-up studies in the adult population reported that the technique is effective, well tolerated and associated with minimal complications. The indications for CIC have been extended to boys with neurogenic LUT dysfunction and normal urethral

sensation. CIC has a reputation for causing discomfort, and consequently catheterization may not be as easily tolerated by individuals with preserved urethral sensation as those without sensation.<sup>(3)</sup>

The purpose of this study was to evaluate the acceptance and efficacy of CIC for LUT dysfunction in boys as a function of their age and degree of urethral sensation.

### MATERIALS AND METHODS

#### Study Population

Medical charts of all boys with LUT dysfunction managed with CIC between October 1992 and May 2014 were retrospectively reviewed, following approval by our Institutional Research Ethics Board. The main evaluation criteria were acceptance and long-term effectiveness in terms of urinary continence and prevention of upper urinary tract dilation.

#### Procedures

All of the boys underwent the following investigations

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**Table 1.** Patient characteristics before clean intermittent catheterization initiation.

Characteristics	Number
Total number of boys	60
Median serum creatinine level, $\mu\text{mol/L}$ (range)	32.1 (23-62)
VUR at baseline, no (%)	13 (22)
Unilateral	9
Bilateral	4
Upper urinary tract dilation at baseline, no (%)	13 (22)
Unilateral	1
Bilateral	12
History of febrile UTI, no (%)	12 (20)
Urinary incontinence, no (%)	57 (95)
Fecal incontinence, no (%)	18 (30)
Prior neurosurgery for spinal cord decompression, no (%)	28 (46.7)
Prior urological surgery, no (%)	23 (38)

**Abbreviations:** VUR, vesicoureteral reflux; UTI, urinary tract infection.

before CIC initiation: plasma creatinine assay, voiding cystourethrography (VCUG), and urinary tract ultrasonography (US) to look for upper urinary tract dilation. The decision to offer CIC to the patients and families was based on the bladder diary findings interpreted in accordance with the recommendations of the International Children's Continence Society (ICCS).<sup>(4)</sup> Initiating CIC was considered for boys who had LUT voiding dysfunction with or without hydronephrosis, impaired renal function and recurrent UTIs. The indications and modalities of CIC were explained to the patients and their parents during a physician visit.

An urotherapy nurse provided therapeutic education and practical hands-on instructions in CIC. The educational materials used included anatomical drawings, information booklets, and dolls. The nurse provided practical tips aimed at facilitating the procedure as much as possible. The first catheterizations were performed at the outpatient clinic. The nurse listened carefully to the concerns voiced by the boys and parents to minimize the level of anxiety. The family's lifestyle was evaluated to determine the optimal times for CIC. Finally, the cooperation of the school physician was enlisted.

The technique was demonstrated to the parents, who then performed CIC on their child under the supervision of the urotherapy nurse. During the learning phase, the parents could contact the nurse by telephone in the event of problems or questions. When the acceptance of the procedure by the child was in doubt, the educational sessions were postponed. No child was forced to accept

CIC.

The same CIC technique with a regular coated (pre-lubricated) catheter was used in all age groups since 1992. In patients with urodynamic evidence of detrusor overactivity, oral anticholinergic drug therapy (oxybutynin) was started as soon as regular CIC was achieved. In boys with detrusor overactivity that was inadequately controlled by anticholinergic therapy, a second-line therapy with a detrusor injection of botulinum-A toxin was proposed.<sup>(5)</sup>

### Evaluations

The study data were abstracted from the medical charts. The following data were recorded for each patient: age, cause of the LUT dysfunction, prior neurosurgical procedures for spinal cord decompression or release, prior urological surgical procedures, history of UTIs (with or without fever), and whether the patient had anal incontinence.

Boys and families who had been lost to follow-up were contacted by telephone and were asked to return for a new in-person clinic visit. If there was no answer to the telephone call, they were excluded from the study. Long-term acceptance, defined as agreeing to perform CIC routinely, and efficacy of CIC defined as achieving continence and protecting the urinary tract, were assessed. The following data were collected routinely in a standardized manner at 6-month intervals: difficulties or complications such as pain, discomfort, gross hematuria, febrile or afebrile UTIs, epididymitis, urinary incontinence assessed using the Schulte-Baukloh score.<sup>(6)</sup> Plasma creatinine level, urinary tract US (appearance of the upper urinary tract, bladder wall thickness, and post-voiding residual urine) and VCUG was performed only in boys with VUR and/or febrile UTIs.

### Inclusion and Exclusion Criteria

All boys with LUT dysfunction managed by CIC per urethra were included. The urethral sensation in children with neurogenic bladder was defined by the feeling of burning or tingling when performing CIC. The exclusion criteria were incomplete medical files or boys using a catheterizable channel such as a Mitrofanoff continent urinary diversion.

### Statistical Analysis

The data are presented as the number and percentage or as the means  $\pm$  standard deviation (SD) or median and range, as appropriate. Nonparametric tests were used. Stochastic variables were compared using nonparametric chi-square, Pearson, and Fisher tests and continuous variables using the Mann-Whitney *U* test. A Cox regression model was built for the univariate analysis. *P* values  $\leq .05$  were considered significant.

**Table 2.** Acceptance and effectiveness of CIC in terms of urinary continence for boys as a function of their age at CIC initiation.

Variables	Group 1, 1-8 Years (n = 28)	Group 2, 9-13 Years (n = 14)	Group 3, 14-18 Years (n = 18)	P Value
Median age at CIC initiation, years (range)	5.6 (1-7.8)	9.2 (8-11.3)	15.7 (13.5-18.3)	NS
Mean age, years $\pm$ SD at CIC initiation	4.9 $\pm$ 2.05	9.4 $\pm$ 1.23	15.7 $\pm$ 1.33	NS
Percentage of patients doing Hetero/self CIC	92 / 8	21 / 79	6 / 94	NS
Patients with failure in the CIC protocol, % (no)	17.8 (5)	14 (2)	11 (2)	NS
Patients with initial difficulties, % (no)	21 (6)	28.5 (4)	33 (6)	NS
Patients with persistent difficulties, % (no)	14 (4)	14 (2)	11 (2)	NS
Patients socially continent with CIC*	71 (20)	92 (13)	88 (16)	NS

**Abbreviations:** CIC, clean intermittent transurethral catheterization; SD, standard deviation; NS, not significant.

\*Refers to the Schulte-Baukloh incontinence scale score.

## RESULTS

### Patient Population

Between 1992 and 2014, 73 boys who met the criteria for CIC were identified. Sixty boys agreed to start CIC for LUT dysfunction during the study period. The median age at CIC initiation was 8.2 years (range from 1.2 to 18 years). The other 13 boys did not start catheterizing because parents refused CIC (n = 11), and two patients had urethral strictures after valve ablation.

Before CIC initiation, 57 (95%) of the 60 boys who agreed to start CIC had socially unacceptable incontinence according to ICCS and Schulte Baukloh scale. The remaining three boys (5%) were continent, but were at risk for upper urinary tract dilation. Underlying diagnoses included congenital neurogenic LUT dysfunction (78.4%, n = 47), bladder exstrophy (8.3%, n = 5), underactive bladder (3.3%, n = 2), bladder tumor resection (3.3%, n = 2) and epispadias (1.6%, n = 1).

**Table 1** demonstrates the main patient characteristics. Of the 60 boys, 30 (50%) had the catheterizations initially performed by another person (at a median age of 5.6 years (range from 1 to 15.3 years). Twelve of these thirty boys subsequently performed self-catheterization. Thus, 42 boys were self-catheterizing at a median age of 10.8 years (range from 5.9 to 18.4 years). The

switch from hetero- to self-catheterization occurred after a median of 2.1 years (range from 2 months to 7.8 years). Mean follow-up time was 9.9 years ( $\pm$  4.3). At the end of the study, 11 of the 60 boys (18%) failed to remain on CIC.

### Acceptance

With regard to age, CIC was well accepted in younger boys (**Table 2**). Boys older than 13 years reported more difficulties during the learning period than the younger boys (33% in the 13-18 years group versus 21% in the group 1-8 years,  $P = .06$ ). The usual cause was the child's fear of potential pain and harm to bodily parts. However, more young boys stopped CIC (n = 5/9, 17.8%). Most parents (n = 4) reported too much anxiety in performing hetero-catheterization and the absence of immediate benefits. Discontinuation of CIC occurred within the first 6 months. In one case of a 7-year-old boy, the protocol failed after 8 months because he could not tolerate CIC after a urethral false passage. Two boys who were completely incontinent were lost to follow-up after stopping CIC because of family difficulties.

During subsequent follow-ups, fewer boys reported difficulties performing CIC in each age group. One of them had fibrous phimosis hindering foreskin retraction, three had genitourinary complications, two experi-

**Table 3.** Acceptance and effectiveness of CIC in terms of urinary continence for boys as a function of their urethral sensation.

Variables	Normal Urethral Sensation (n = 24)	No Genital Sensation (n = 36)	P Value
Median age at CIC initiation, years (range)	12.5 (7.4-18.2)	5.9 (1-18.4)	NS
Mean age (years) $\pm$ SD at CIC initiation	12.2 $\pm$ 0.4	7.2 $\pm$ 0.79	NS
Percentage of patients doing hetero/self CIC	65 / 35	40 / 60	NS
Patients with failure in the CIC protocol, % (no)	16.7 (4)	13.8 (5)	NS
Patients with initial difficulties, % (no)	29 (7)	25 (9)	NS
Patients with persistent difficulties, % (no)	12.5 (3)	13.8 (5)	NS
Patients socially continent with CIC*	91 (22)	83 (30)	.05

**Abbreviations:** CIC, clean intermittent transurethral catheterization; SD, standard deviation; NS, not significant.

\*Refers to the Schulte-Baukloh incontinence scale score.

enced difficulties switching from hetero- to self-catheterization, and two had poor compliance due to a limited understanding of the risks and benefits. With regard to urethral sensation, CIC was well accepted in boys without genital sensation ( $n = 25$ , **Table 3**). Boys with normal urethral sensation reported more difficulties during the learning period (29% versus 25% for boys without sensation,  $P = .06$ ). They reported urethral pain ( $n = 2$ ) or anxiety ( $n = 5$ ) during the introduction of CIC. More boys with normal genital sensation stopped CIC (16.7%,  $n = 4$ ) at the median time of five months after starting CIC (range from 1 to 8 months). The protocol failed in three boys because they had anatomical difficulties due to bladder exstrophy and were not able to succeed in CIC. The other boy did not experience benefits from CIC. During the follow-up, an equivalently low number of boys ( $n = 6$ ) had persistent difficulties performing CIC.

### **Continence**

Of the 57 boys who started CIC for unacceptable incontinence, 53 (93%) became socially continent (totally dry or wet only once a day, usually at night) according to the Schulte-Baukloh score, with no statistically significant difference between the hetero- and self-catheterization groups. Among them, 21 boys (36.8%) required anticholinergic therapy. The three remaining boys who started CIC because they were at risk for upper urinary tract dilation remained continent with CIC.

Fifteen boys (26.3%) required bladder augmentation in addition to CIC to achieve continence. Furthermore, Young-Dees-Leadbetter and Pippi-Salle bladder neck reconstruction were performed in nine and six cases, respectively. One patient underwent bladder augmentation, bladder neck reconstruction and a Mitrofanoff procedure. Of these 15 patients, 13 (86.7%) were continent after surgery and CIC. The two remaining patients with persistent unacceptable incontinence complied poorly with treatment recommendations (discontinuation of CIC and refusal of additional bladder neck reconstruction) and were lost to follow-up.

In five boys with CIC who were taking anticholinergic therapy, social continence was achieved with a botulinum-A toxin detrusor injection for detrusor overactivity as examined by urodynamic studies. An endoscopic periurethral bulking agent injection was performed in three patients. The goal of the bulking agent injection was to increase the urethral closing pressure after increasing bladder capacity by injecting botulinum-A toxin. Two boys with considerable sphincter deficiency, despite dextranomer treatment, are currently waiting for a second surgery.

With regard to age, 92% of teenagers were socially continent with CIC. The five boys with persistent incontinence were younger than eight years old. Among them, three had insufficient urethral closing pressure, and two complied poorly with the CIC protocol. Three boys (5%) had a malignant tumor in regression after irradiation. They stopped CIC because of the disappearance of voiding problems and spontaneous complete micturition. With regard to urethral sensation, more boys with normal urethral sensation were socially continent with CIC (91% versus 83% with neurogenic bladder,  $P = .05$ ).

### **Protection of the Upper Urinary Tract**

Before CIC initiation, 13 (21.7%) boys had VUR including four with bilateral VUR. Early in the study period, ureteral re-implantation, in addition to CIC, was performed in three boys with high grade VUR. At last follow-up, the reflux had disappeared in 69% ( $n = 9$ ) of cases.

Before CIC initiation, 13 boys (21.7%) had upper urinary tract dilation on US including 12 with bilateral dilation. Hydronephrosis without VUR was observed in 4 boys. At last follow-up, dilation had resolved in 54% of cases ( $n = 7$ ). No patient experienced worsening of pre-existing dilation or de novo development of dilation. The two boys with persistent bilateral ureteral hydronephrosis had caudal regression syndrome with obstructive megaureters. In two boys (3.3%) in whom CIC provided insufficient protection of the upper urinary tract, urinary diversion was required (one case each of incontinent cystostomy and ureterostomy).

The three boys (5%) with baseline renal failure experienced improvements in kidney function with CIC. Plasma creatinine levels (mean,  $30.8 \mu\text{mol/L} \pm 1.7$ ) remained normal for their age throughout the follow-up in the remaining 57 boys (95%). No patient experienced a decline in renal function during follow-up. No kidney transplantation was required. No differences were observed in protecting the upper urinary tract as a function of age or urethral sensation.

### **Genitourinary Complications**

A single episode of gross hematuria occurred in three boys during the learning phase. In four boys, catheterization became impossible at some point, and cystoscopy showed urethral false passage in two boys, urethral stricture in one patient, and bladder neck hypertrophy in one patient. Those complications occurred after the learning period at the median time of ten months (range from 1 to 14 months). The two boys (3.3%) with false passages were 6.2 and 8.3 years without genital sensation. They were managed for a few days with in-

dwelling catheterization. Once their symptoms abated, CIC was resumed with no further difficulties for one boy. The family of the other boy stopped CIC because of anxiety. One patient (1.6%) who was 9.3 years old with urethral strictures required multiple dilatations. Finally, the patient who had difficulty with abutment of the catheter against a bladder neck hypertrophy was managed with continent cystostomy. The incidence of urethral lesions did not increase at puberty and showed a non-significant decrease in the group performing self-catheterization.

Epididymitis occurred in four boys (6.7%) including three with bladder exstrophy requiring bladder neck reconstruction, and one with immunosuppression due to chemotherapy for an iliac Ewing sarcoma. This complication did not lead to further non-acceptance in the CIC protocol.

Before CIC initiation 12 (20%) boys had a history of febrile UTIs. The number of patients with febrile UTIs decreased to four with CIC ( $P = .05$ ). Factors significantly associated with febrile UTIs during CIC were hydronephrosis, VUR, and prior febrile UTI ( $P = .05$ ). Neither the continence status ( $P = .33$ ) nor the catheterization method ( $P = .25$ ) influenced the risk of febrile UTIs.

## DISCUSSION

We present a large series of CIC procedures with a mean follow-up of 10 years, and an examination of the procedure's acceptance and efficacy. CIC used to treat LUT dysfunction in boys was well accepted regardless of age and of the degree of urethral sensation.<sup>(7)</sup> Our study showed that CIC could be successfully started and continued in older children even if they expressed more difficulties during the first six months than the younger boys. Nevertheless after the learning period, a small proportion of patients reported persistent difficulties in every age group. Special attention was required for adolescents when changes occurred in their life habits, which may play a role the decreasing motivation to continue performing CIC. Young adults needed specialized care, especially when they were transferred from pediatric to adult practices. Our findings provide a reassuring long-term outcome of well-accepted CIC in the neonatal period or in infancy despite the need for a learning period.

With regard to the degree of urethral sensation, boys with normal sensation expressed more difficulties starting CIC, but after a learning period, the rate of persistent difficulties was equivalent in all groups. Our study showed that CIC could be successfully started in chil-

dren with genital sensation, regardless of their age in the beginning. The oldest boys started CIC at 17 years old. The success rate for CIC in those patients was 83.3%. In limited series, the success rates for children genitally sensate who performed CIC have been reported to be between 65% and 70%.<sup>(8)</sup> We believe that our high success rate was due to the heavy involvement of an experienced nurse who was directly available to assist in the teaching and maintenance of the CIC technique. Compliance with the CIC program correlated significantly ( $P < .05$ ) with urinary continence outcomes. This study showed that CIC is effective in achieving urinary continence in boys with sufficient bladder capacity (92% of patients were socially continent with CIC). Of the 24 boys with normal urethral sensation, 91% were continent with CIC. Only 8% ( $n = 2$ ) were incontinent at the last follow-up. Concurrent procedures, such as CCC (Mitrofanoff or Monti channels), that provide an alternative drainage access to the bladder are often debated in children with difficult access through the native urethra. Focusing on long-term outcomes (greater than five years), incontinence was one of the most frequent complications with CCC.<sup>(9)</sup> In a large series of 189 patients, Leslie et al. reported a 65% rate of incontinence in the first three years after the initial operation ( $P = .7$ ). Surgical revision was performed in 10% of patients for incontinence. In that study, they concluded that incontinence arose during the long-term evaluation. As many interventions are carried out in children with bladder voiding dysfunction, it is important to evaluate patients for issues that may arise over a long period of time. In our experience, despite an initial trial period, CIC provide a reassuring long-term outcome, regardless of the age of initiation and the degree of urethral sensation. Because of the development of late problems with CCC upon long-term evaluation, we promote the use of non-invasive procedures as long as possible.

In our center, we have established an effective infrastructure to support education and training in CIC, as well as satisfactory social support. In a real world experience, however, long-term compliance with CIC is a main concern. To re-engage children and parents who were initially successful but subsequently became non-compliant, we introduced an individualized educational care plan involving the boy and the urotherapist. We offered the child the opportunity to speak face-to-face with the dedicated nurse to review anatomy, evaluate appropriate catheter material and catheterization technique, and also to discuss any concerns that they encountered in daily life and with the family. In addition, each patient was systematically asked to attend

clinic every 6 months. Thus, any obvious recurrent episodes of incontinence episode or urinary tract infections could be detected.

There was an important finding regarding urethral safety during CIC. During the learning phase, 16 boys reported difficulties with catheter insertion, especially in the non-neurogenic population and in boys with hetero-catheterization. Most complications occurred within the first two years and were followed by a relatively complication-free period. Our results are in line with the previous literature,<sup>(10)</sup> although we observed that complications did not lead to non-compliance.

We also compared our data to those of other studies of boys using Mitrofanoff or Monti channels for CIC.<sup>(9-11)</sup> As depicted, an initial peak in the number of events (including surgical revision, redo operation, bulking agent injection and prolapse correction) was followed by a relatively stable complication-free period. Nevertheless, long-term follow up problems were detected that were related to wear and tear of the conduits. Even with a learning period, the healing process of CIC by the native urethra was well performed by boys or their family members with a low rate of complications. In boys with normal urethral sensation, CCC and CIC are both associated with a high morbidity rate.

We also focused on the rates of stenosis. In our study, urethral stenosis developed in a single patient (1.7%), as a probable result of an inflammatory response to repeated catheter-induced trauma. Recently, administration of triamcinolone ointment for lubrication of the catheter following internal urethrotomy has been shown to decrease the stricture recurrence rate.<sup>(12)</sup> In pediatric studies, the urethral stenosis rate has ranged from 0%<sup>(13)</sup> to 25%.<sup>(14)</sup> Our incidence of epididymitis was commensurate with those found in the literature, which ranged from 3.6%<sup>(14)</sup> to 19%<sup>(13)</sup> and was not correlated with the number of years of CIC ( $P = .05$ ).

CIC may constitute the most effective means of preventing febrile UTIs by achieving sufficient bladder capacity with low intravesical pressures and regular voiding. UTIs appear to be the main cause of morbidity and upper urinary tract alterations in pediatric patients with bladder dysfunction. In our study, regular CIC was associated with a low incidence of febrile UTIs ( $P = .05$ ). VUR that was present at baseline resolved in 69% of patients, and upper urinary tract dilation improved in 54%. Thus, CIC is very effective in protecting the upper urinary tract.

Our study has several limitations that warrant mention aside from its retrospective design. In the absence of validated anxiety assessment tool, the evaluation

of tolerance was difficult. Patients did report fear of pain and injury to the body as well as general anxiety. Furthermore in many cases, a variety of additional procedures, such as urethral bulking agent injections, bladder augmentation, Mitrofanoff channel creation, bladder neck surgery or intradetrusor botulinum toxin injections, were required to achieve continence, thus challenging the assessment of CIC efficacy. Despite the relative small number of children and these limitations, our study highlights a high rate of long-term acceptance of CIC, although promoting non-invasive procedures as long as possible is still advisable.

## CONCLUSIONS

CIC used to treat LUT dysfunction in boys is well accepted and effective in ensuring urinary continence and protecting the upper urinary tract for most children with or without genital sensation. Despite initial difficulties performing CIC during the learning period, high long-term success and compliant rates were observed. CIC exhibited low rates of genitourinary complications regardless of the presence of urethral sensation. Particular attention is needed for the initiation of CIC in young children and boys with non-neurogenic bladder to optimize acceptance. An individually tailored education program delivered by an urotherapy nurse is crucial.

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## CONFLICT OF INTEREST

None declared.

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