Acceptance and compliance of clean intermittent catheterization among Saudi patients

Khalid Fouda Neel, MD, FRCSI, Mahmoud A. Salem, MSc, MRCS, Sherif M. Soliman, MD, FRCSed, Hamdan Al-Hazmi MD, SBU, Abdulmonem B. Gomha, MBBS, MSc, Amenah A. Khatab, BSN.

ABSTRACT

الأهداف: تحديد مدى إمكانية، وتقبل، واستمرارية مرضى المثانة العصبية في تفريغ المثانة بواسطة قساطر نظيفة متكررة (CIC) عند الحاجة.

الطريقة: تمت مراجعة ملفات المرضى اللذين تطلب علاجهم استخدام القساطر النظيفة المتكررة (CIC) بين عام 1998م وحتى 2006م في كلاً من مستشفى الملك خالد الجامعي ومستشفى قوى الأمن – الرياض – المملكة العربية السعودية. ركزت تحاليلنا على تشخيص المرض، وسبب لجوئنا إلى استخدام القساطر النظيفة المتكررة (CIC)، السن الذي بدء استخدام القساطر النظيفة المتكررة (CIC) فيه، الشخص الذي يقوم بعمل هذا النوع من القساطر، مستوى تقبل الفكرة لدى المرضى وذويهم، وأيضاً مدى استمرارية المرضى على هذا النوع من العلاج.

النتائج: شملت الدراسة 280 مريضا، 118 أنثى (42%) و 162 ذكر (58%)، متوسط أعمارهم 6 سنوات. كان 196 (70%) طفلاً يعانون من مرض المثانة العصبية وذلك لوجود عيب خلقي بالحبل الشوكي، و84 طفلا يعانون من أمراض أخرى تستدعي استخدام القساطر النظيفة المتكررة (CIC)، مثل: (صمام بقناة مجرى البول الخلفي، أو اختلال وظيفي بين المثانة والعضلة التحكمية بقناة مجرى البول). كان متوسط العمر 4.25±6.49 عاماً. وجدنا أن 257 (91%) من المرضى يتقبلون فكرة العلاج، و 248 (88.5%) يستمرون باستخدام القساطر بنجاح. كانت الأمهات هن المسئولات عن القيام بعمل القساطر لأطفالهن في الغالبية العظمى من الحالات 204 (72.9%)، في حين إن 76 (27.1%) مريضا كانوا هم اللذين يقومون بعمل القساطر لأنفسهم. كان متوسط أعمار الأطفال اللذين يتقنون عمل القساطر بأنفسهم بدون مساعدة هو 8 سنوات. كان تعليم المرضى وذويهم على استخدام القساطر يتم في العيادات الخارجية من قبل معلمة الصحية وذلك خلال الثلاث سنوات الأخيرة.

خاتمة: يعد استخدام القساطر النظيفة المتكررة (CIC) لإفراغ البول طريقة علاجية مناسبة للمرضى، حيث أنهم اظهروا تقبل واستمرارية عالية وممتازة لهذا النوع من العلاج. وللحصول على أفضل النتائج، نقترح أن يتم تعليم المرضى على كيفية استخدام القساطر بطريقة سليمة وكذلك متابعة المرضى بشكل دوري.

Objectives: To determine the applicability, acceptance, and compliance of the option of clean intermittent catheterization (CIC) when needed by patients in our society.

Methods: We retrospectively reviewed the files of all patients for whom CIC was conducted at King Khalid University Hospital and Security Forces Hospital, Riyadh, Saudi Arabia, between 1998, and 2006. We considered primary pathology, indication of CIC, age at CIC initiation, and who administered the CIC. We also documented the acceptance and compliance levels of the procedure by the patient over time.

Results: We included 280 patients, of which 118 (42%) were female and 162 (58%) were male in this study. The main pathology was myelodysplasia in 196 (70%) patients, posterior urethral valve in 52 (18.6%) patients, and non-neuropathic bladder sphincter dysfunction in 32 (11.4%) patients. The mean age was 6.49 ± 4.25 years. Two hundred and fifty-seven (91.7%) families and their children accepted the idea of CIC, and 248 (88.6%) continued with the CIC program. Mothers were responsible for carrying out the procedure in 204 (72.9%) patients. However, in 76 (27.1%) cases, the patient was doing the procedure independently and the average age for a child to master the technique was 8 years. During the last 3 years, an urotherapist took over the educational services and performed outpatient education instead of our previous inpatient education.

Conclusion: Clean intermittent catheterization is an appropriate method of treatment for our group of patients. They showed excellent acceptance of and compliance with the procedure, however, we suggest that for complete success, proper education, teaching, and follow-up should be conducted.

Saudi Med J 2008; Vol. 29 (7): 1014-1017

From the Division of Urology, Department of Surgery, King Khalid University Hospital, Riyadh, Kingdom of Saudi Arabia.

Received 22nd February 2008. Accepted 2nd June 2008.

Address correspondence and reprint request to: Dr. Khalid Fouda Neel, Associate Professor, and Consultant Pediatric Urologist, Urology Division, Department of Surgery (37), King Khalid University Hospital, PO Box 7805, Riyadh 11472, Kingdom of Saudi Arabia. Tel. +966 (1) 4671575/4672561. Fax. +966 (1) 4679493. E-mail: kfouda@ksu.edu.sa

Clean (non-sterile) intermittent catheterization (CIC) was introduced by Lapides et al[1] (1972) when they reported experiences with non-sterile frequent self-catheterization of the bladder in 14 patients with neuropathic bladder dysfunction. They concluded that this technique was safe when performed properly and on schedule.[1] This practice revolutionized the care of patients with bladder dysfunction (with or without neuropathic cause). Several studies have shown that the success of CIC in the pediatric population ranges from 94-100%, primarily for children with neuropathic bladder resulting from myelomeningocele or spinal cord injury.[2] A limited number of studies have investigated CIC in children with normal genital sensation and have reported success rates of 65-70% overall.[3-5] In this study, we determined the applicability, acceptance, and compliance of our group of patients to the option of CIC when needed, as there was a general belief (even among medical personnel) that our group of patients would have difficulty in accepting this method of neuropathic bladder management. We faced this belief during local conferences and teaching courses in different cities in Saudi Arabia, and it was based on the wrong concept that the cultural background of many families in Saudi Arabia cannot cope with this modality of intervention.

Methods. We retrospectively reviewed the medical records of all patients (for whom CIC was required) who presented themselves to 2 referral institutes (King Khalid University Hospital and Security Forces Hospital) between 1998, and 2006. The following variables were recorded and analyzed: primary pathology, age at initiation of CIC, who performed the CIC, acceptance of the idea of CIC by parents and patients, compliance of parents and patients with time, causes of failure, and degree of difficulty either during learning or through the course of the procedure. All patients in whom CIC was indicated either for voiding disorders with large residual urine or at bladder risk (poor compliance, high intravesical pressure) with or without hydronephrosis were included in the study. None of those patients were excluded primarily from a trial of CIC teaching. Initially, when it was determined that there was a need for a CIC program, the concept of the CIC technique was introduced and discussed with the family in our outpatient clinic. The necessity of performing CIC was explained to the family, and at the same time other alternative solutions were discussed. A full explanation of the technique and a complete demonstration of how it should be carried out was presented, and time was given to allow any questions. In this setting we attempted to minimize the anxiety level for the family and the child. We next scheduled an appointment for hospital admission so that they could learn the technique. For the last 3 years of the study, an urotherapist educated patients during an outpatient appointment rather than the previous inpatient admission. Both parents and other family members who may be asked to perform CIC were involved in the teaching sessions. We start by verbal review to describe the technique, elaborate any fear and answering any concerns about the procedure. Then full demonstration of the procedure was explained on simulated manikins (**Figure 1**). Then the urotherapist performed CIC on the child, and then one, or both parents (or the child himself if old enough) performed CIC in the urotherapy clinic. Follow up telephone call from the urotherapist within 2 days is essential to ensure that the family is carrying out CIC comfortably in the correct way, and a scheduled appointment is given in 2 weeks to meet the parents again and re discuss the process again. Enough supplies are given to the family, and they are assured that the team will be available for any concerns, and all contact details are given to them. Approval was obtained for the local ethics committee in the College of Medicine, King Saud University, and informed consent was obtained from all patient's.

Results. The files of 280 patients for whom CIC was required were reviewed. Of these, 118 (42%) were female and 162 (58%) were male patients. The mean age was 6.49 ± 4.25 years (ranging from 3 months to 16 years). Principle diagnoses of the patients included neuropathic bladder due to myelodysplasia in 196 (70%) patients, posterior urethral valve (PUV) in 52 (18.6%), patients and non-neuropathic bladder sphincter dysfunction (NNBSD) in 32 (11.4%) patients (**Table 1**).The average number of catheterizations was 4-5 per day. The most common catheter size used was 8F in 136 (48.6%) of our patients. However, different sizes were used according to age as follows: size 6F in 40 (14.3%), 10F in 76 (27.1%), 12F in 24 (8.6%), and 14F in 4 (1.4%) patients. Of 280 patients, 257 (91.7%) families, and their children accepted the idea of CIC when it was first presented and discussed and 248 (88.6%) began and continued the CIC protocol at a mean follow-up of 4.38 ± 2.39 years (ranged from 3 months to 7.5 years). Those patients that were not compliant to the CIC protocol were shifted to another line of management according to their original pathology, such as augmentation ileocystoplasty with continent stoma or incontinent diversion. The main cause of failure of compliance for patients of neuropathic bladder was lack of cooperation by the families in 6 patients. However, pain, anxiety, and discomfort were the main causes of failure of CIC acceptance in patients with sensate urethra (23 patients) and lack of family support was the cause of failure of CIC compliance in the other 3 patients. Mothers, with some help from other family personnel, were responsible

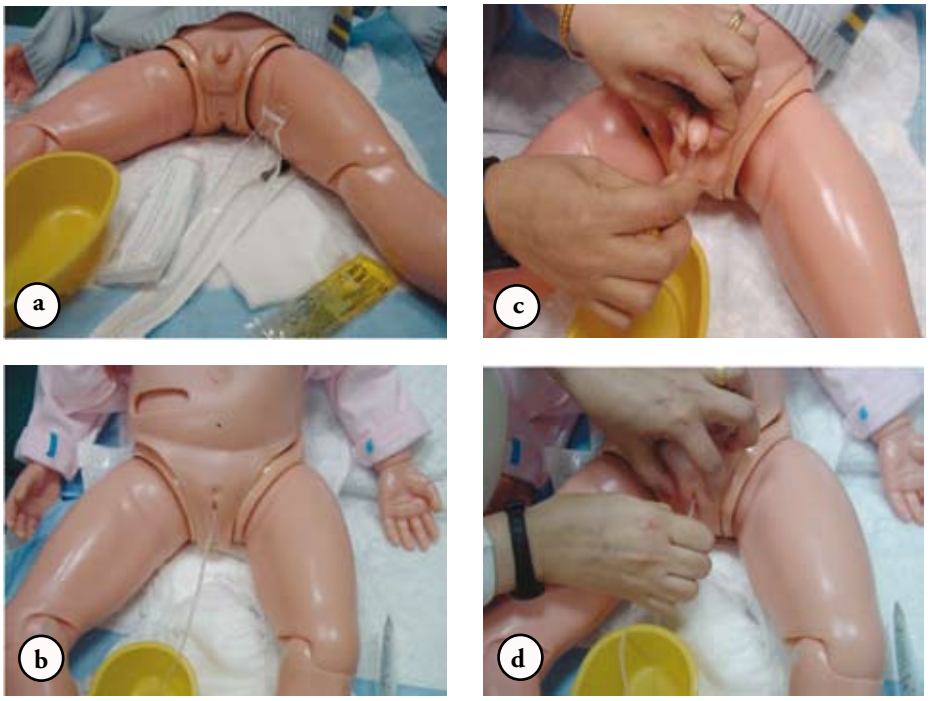

Figure 1- Use of simulated **a**) & **b**) male, and **c**) & **d**) female manikins in patient's education by the Urotherapist.

Table 1- Total number of patients, and final outcome of CIC training.

Diagnosis	No. of patients (%)	Acceptance to start CIC	Compliance post training
Neuropathic bladder (myelodysplasia)	196 (70)	196/196 (100)	190/196 (96.9)
Sensate urethra (PUV & NNBSD)	84 (30)	61 /84 (72.6)	58/61 (95)

CIC - clean intermittent catheterization, PUV - posterior urethral valve, NNDSD - non-neuropathic detrusor sphincter dyssynergia.

for carrying out the procedure in 204 (72.9%) patients. However, in 76 (27.1%) cases, the patient was doing the procedure independently and the average age for the child to master the technique independently was 8 years. In the last 3 years of the study, all patients and their parents could learn the CIC technique in one outpatient clinic visit of one hour or less with the help of an urotherapist who was experienced in teaching CIC.

Discussion. Clean intermittent catheterization (CIC) is now a well established technique for the management of neuropathic bladder and/or dysfunctional voiding.[6] Since its introduction in the early 1970s it has already transformed the lives of many patients with this condition, not only due to improving continence and assisting in complete evacuation of the bladder, but also due to protecting the kidneys for those at risk of damage to the upper urinary tract.[7-9] The CIC was popularized in Saudi Arabia over the last 10 years by the pediatric urology group,[10] where a common protocol was suggested, and applied by the contributing hospitals. Studies have suggested that urinary incontinence is one of the most stressful aspects for patients with myelodysplasia as well as for their parents. It is rated even more difficult than other challenges such as impaired motor function.[11,12] This symptom becomes more stressful when the patient has a non-neuropathic condition such as PUV or NNBSD and his incontinence is the major apparent complaint. When the clinical situation calls

for it, the decision to begin CIC in a patient without genital sensation is usually straightforward. Conversely, the perceived sentiment regarding instituting CIC in genitally sensate individuals, especially children, is that genital discomfort limits the practical use of CIC. However, recent studies have shown better success with instituting CIC in populations of genitally sensate children, however, the success rates are much lower than those seen for patients with diseases that eliminate genital sensation (for example, myelodysplasia, spinal cord injury, or sacral agenesis). While the success rates for CIC in patients with myelodysplasia ranges from 94-100%, Pohl et al[3] showed a 70% success rate in 24 pediatric patients with high post-void residuals but no identifiable anatomic or neurological abnormalities.[3] Similarly, Van Savage et al[4] demonstrated a 65% success rate in a group of children with a variety of diagnoses who required CIC for bladder management.[4]

In our group of patients, 100% and 96.9% without genital sensation and 72.6% and 95% with intact genital sensation, accepted and were compliant with the CIC protocol, which is comparable to the international published literature.[3,4] The majority of failures to accept the protocol was in the first 2 weeks, mainly due to pain and anxiety, however, once the patients and families accepted the protocol they showed excellent compliance. These high success rates refute the commonly held belief that our group of patients has difficulty accepting this method of bladder management. Although the mothers were mainly, but not only, responsible for carrying out the procedure in 73% of our patient population, our policy was that both parents should master the technique, but it would be quite understandable that mothers will be more available, particularly for younger children. As expected, our success rate increased during the last 3 years of the study due to the intensive involvement of an experienced urotherapist. Our urotherapist worked closely with the patients and their families, using hands-on demonstrations, anatomical drawings, and graphs and photos. They were available to assist in the teaching and maintenance of the CIC technique. Establishing a trusting relationship between the urotherapist and the family from the beginning is crucial for reinforcing the importance of maintaining CIC as well as providing emotional and technical support.

In conclusion, CIC is an appropriate method of treatment for bladder dysfunction, when indicated, and our patients showed excellent acceptance and compliance, and the belief that some social background restrictions might prevent its use in our community is not true. The procedure can be taught to children and their parents in a short time period with high long-term success rates among Saudi children.

References

1. Lapides J, Diokno AC, Silber SM, Lowe BS. Clean, intermittent self-catheterization in the treatment of urinary tract disease. 1972. ***J Urol*** 2002; 167: 1584-1586.
2. Plunkett, JM, Braren, V. Clean intermittent catheterization in children. ***J Urol*** 1979; 121: 469-471.
3. Pohl HG, Bauer SB, Borer JG, Diamond DA, Kelly MD, Grant R, et al. The outcome of voiding dysfunction managed with clean intermittent catheterization in neurologically and anatomically normal children. ***BJU Int*** 2002; 89: 923-927.
4. Van Savage JG, Sackett CK, Wilhelm CL, Sessions RP, Mesrobian HG. Indications for and outcomes of clean intermittent catheterization in children with normal genital sensation. ***J Urol*** 1997; 157: 1866-1868.
5. Alpert SA, Cheng EY, Zebold KF, Kaplan WE. Clean intermittent catheterization on genitally sensate children: patient experience and health related quality of life. ***J Urol*** 2005; 174: 1616-1619. discussion 1619.
6. Kass EJ, McHugh T, Diokno AC. Intermittent catheterization in children less than 6 years old. ***J Urol*** 1979; 121: 792-793.
7. Borzyskowski M, Mundy AR, Neville BG, Park L, Kinder CH, Joyce MR, et al. Neuropathic vesicourethral dysfunction in children. A trail comparing clean intermittent catheterization with manual expression combined with drug treatment. ***Br J Urol*** 1982; 54: 641-644.
8. Geraniotis E, Koff SA, Enrile B. The prophylactic use of clean intermittent catheterization in the treatment of infants and young children with myelomingocele and neurogenic bladder dysfunction. ***J Urol*** 1988; 139: 85-86.
9. Boemers TM, de Jong TP, van Gool JD, Bax KM. Urologic problems in anorectal malformations. Part 2: functional urologic sequelae. ***J Pediatr Surg*** 1996; 31: 634-637.
10. De Castro R, Fouda Neel KA, Alshammari AM, Abu Daia JM, Abd Al-Aaly MA. Clean intermittent catheterization in Saudi Arabia; suggestion for a common protocol. ***Saudi Med J*** 2000; 21: 1016-1023.
11. Altshuler A, Meyer J, Butz MK. Even children can learn to do clean self catheterization. ***Am J Nurs*** 1977; 77: 97-101.
12. Lie HR, Lagergren J, Rasmussen F, Lagerkvist B, Hagelsteen J, Borjeson MC, et al. Bowel and bladder control of children with myelomeningocele: a Nordic study. ***Dev Med Child Neurol*** 1991; 33: 1053-1061.