

Determining the variables associated to clean intermittent self-catheterization adherence rate: one-year follow-up Study

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ABSTRACT

Purpose: To determine adherence rate and variables associate with patients' adherence to Clean Intermittent Self Catheterization (CISC).

Materials and Methods: Patients refereed to CISC training program between July 2006 and May 2008, were prospectively evaluated with urodynamic, 3 days bladder diary (BD) and WHOQoL-bref questionnaire. After training to perform CISC, patients were evaluated at 2 weeks, monthly for 6 months and at 12 months with clinical visits and BD. Patients were considered adherent if they were performing at least 80% of the initial recommendation.

Results: Sixty patients (50.4 ± 19.9 years old) were trained to perform CISC (21 female and 39 male). Out of them, 30 (50%) had neurogenic and 30 (50%) had a non-neurogenic voiding dysfunction. The adherence rate at 6 and 12 months was 61.7%, 58%, respectively. Patients < 40 years old had adherence rate of 86%. Women and neurogenic patients had higher adherence rate than their counterparts ($p = 0.024$ and $p = 0.016$, respectively). In the WHOQoL-bref, patients that adhere to the program had a significant higher score on psychological and social relationships domains. There was not difference in pre and post training WHOQoL-bref scores. Educational background, marriage status, detrusor leak point pressure, Bladder Capacity, number of leakage episodes did not play a role on the adherence rate.

Conclusion: Patients in CISC program present a reasonable adherence after one year. Women, neurogenic voiding dysfunction and patients under 40 years old were significantly more adherents. The psychological and social relationship status seems to positively interfere on adherence. CISC did not affect patient's QoL evaluated by WHOQoL-bref.

Key words: Intermittent Urethral Catheterization; quality of life; urinary bladder; neurogenic; urinary retention

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INTRODUCTION

Several conditions associated with incomplete bladder emptying, such as, bladder outlet obstruction without clinical conditions to surgical treatment, under or acontractile bladder and detrusor-sphincter dyssynergia have limited treatment options. One of the main alternatives is to perform clean intermittent self-catheterization (CISC), which has been described by Lapedes in 1972 (1). CISC can be defined as intermittent catheter introduction through the urethral meatus up to the bladder, removing it immediately after urine drainage (2).

When appropriately established, the CISC program reduces bladder over distention, bladder ischemia, and urinary tract complications (3,4). Unfortunately, CISC is not the ideal method to empty the bladder. The main problems are the patient's adherence, the potential impact on quality of life, pain during the procedure, urinary infection, costs, urethral injury and it depend on patient's ability and some degree of cognition (5,6).

The World Health Organization defines adherence as the extent of which a person's behavior corresponds with agreed recommendations from a health care professional (7). There are a variety of

reasons for a patient does not adhere to CISC (8). Some patients report feeling worried, shocked or even depressed, especially those patients with non-neurological conditions, after being offered for the first time to perform CISC. Furthermore, patients that initiate the CISC may not completely follow the physician recommendation reducing the daily number of self-catheterization, similarly to any long-term treatments.

Patients requiring CISC who do not adhere or have a partial adherence may develop major urological complications. Thus, predicting which patient are more likely to adhere to CISC is very important, since it may interfere in the medical treatment decisions in order to prevent future complications. Attempts to determine which factors are associated with patient's adherence to CISC have been done. Age, gender, urethral sensitivity, pain, general health status, mobility and specialized training have been suggested to be predictive of patient's adherence (9). However, there is a lack of studies that clearly demonstrate which of those variables play a role on patient's adherence (10). In the present study, we sought to determine which variables are involved in the patient's acceptance and adherence to a CISC program.

MATERIALS AND METHODS

We performed a prospective study between July 2006 and May 2008. It was included all patients referred to our CISC training program, except those patients with inability to follow the program due to motor, psychiatric or cognitive limitations. All patients were evaluated by means of urological and past medical history, urodynamic study (UDS), 3 days bladder diary and WHOQoL-bref (11). Patients with indwelling catheter had their catheter removed, urinalyses performed and antibiotics introduced as necessary. All patients were individually trained by the same specialized nurse in order to achieve the ability of self catheterization at home. A visual analogical scale (VAS) ranging from 0 to 10, where 0 was no pain at all and 10 was the worst scenario of pain was used to determine pain expectation (before performing the catheterization) and pain experience (after being trained and considered able to perform

the catheterization). Patients were evaluated two weeks after have been trained, then monthly for 6 months and 1 year by means of clinical evaluation and 3 days bladder diary to determine the adherence to the program and the ability to self catheterization.

Patient's training consisted of theoretical explanation with regard to lower urinary tract and how to introduce the urethral catheter by means by means of verbal, visual (at the computer) and written orientations, including explanation regarding the lower urinary tract function and practical training, which was directly guided by a specialized nurse to access if the patient was able to perform the CISC or not. All patients receive the same instructions to perform clean intermittent self-catheterization using a 12 F gel lubricated. All patients were instructed to use the same catheter, which was provided by the hospital. After being trained, patient was sent home to perform the procedure alone and recommended to contact the responsible nurse in case of any difficult. After one week, patients' catheterization ability was evaluated. Those considered skillful were included in the program and those unable to perform the catheterization adequately were re-trained.

The 3 days bladder diary enabled the nurse to evaluate the CISC frequency and to adjust it as necessary based on the urodynamic information regard the bladder compliance and overactive bladder trigger volume. The bladder diary was also used to evaluate adherence to procedure. Patients were considered adherent to the program if they were performing at least 80% of the initial recommendation (10,12,13). The adherence rate was evaluated by patient's report in the 3 days bladder diary. Data were analyzed using mean comparisons (hypothesis tests), ANOVA, tabulation, frequency analysis. We used statistical confidence of 95% and significant level when $p < 0.05$.

RESULTS

Sixty three patients were referred to the CISC program. Out of them 3 (4.3%) were excluded because they refuse to initiate the training after nurse explanation on how to perform CISC. We trained and included 60 patients in the study (Table-1). Of these patients, 21 (35%) were women and 39 (65%)

Table 1 - Distribution of patients by gender and diagnosis.

	Total	Female n = 21	Male n = 39
Neurogenic Bladder	30 (100%)	13 (43.3%)	17 (56.7%)
Bladder Sphincter Dyssynergia	11 (36.7%)	5	6
Under or acontractile Bladder	19 (63.3%)	7	12
Non-Neurogenic Bladder	30 (100%)	8 (24.7%)	22 (73.3%)
Under or acontralite Bladder	26 (86.7%)	5	21
Bladder Outlet Obstruction	4 (13.3%)	3	1

were men, the mean age was 50.4 (range: 15 to 88 years old).

All 60 patients included in the study were able to perform the procedure as instructed. Fifty-five (92%) patients learned how to perform the CISC with only one training session and 5 (8%) patients needed 2 sessions to become skillful.

Out of the 60 patients, 30 (50%) had neurogenic voiding dysfunction and 30 (50%) had a non-neurogenic etiology. The main etiologies for neurogenic dysfunction was Parkinson's disease, cerebral vascular accident, multiple sclerosis, traumatic injury, tumors cerebral, infections with HTLV-1 and neuroschistosomiasis, causing neurological damage. The main etiologies for non-neurogenic dysfunction was diabetes mellitus, benign prostatic hypertrophy, pelvic surgery, and other dysfunction of idiopathic etiology that caused increased post voiding residual, and others dysfunctions (Table-2).

The adherence rate at 1, 6 months was 61.7% and at 12 months was 58%. Table-2 shows the adherence rate according to the gender. Women adhered more to the CISC program than their counterpart. We observed that the younger the patient, the greater the adherence. Patients with neurogenic bladder had a higher adherence rate than non-neurogenic bladder patients ($p = 0.016$) (Table-3).

A multivariate analysis including diagnosis (neurogenic/non-neurogenic), gender and age (≤ 40 y.o.; 41-60 y.o; and ≥ 61 y.o) showed that men ≥ 61 years old with non-neurogenic bladder dysfunction were less adherent to the program ($p = 0.003$) and women ≤ 40 years old with neurogenic bladder dysfunction were the most adherent to the CISC program ($p = 0.040$).

At 12 months follow-up, patients did not present major complications, such as bleeding, urethral traumatic lesion, urethral stenosis/erosion that

Table 2 - Adherence to CISC by gender, age and diagnosis.

	n	Adherent	Non Adherent	
Female	21	17 (81.0%)	4 (19.0%)	p = 0.024
Male	39	20 (51.3%)	19 (48.7%)	
< 40years-old	22	19 (86%)	3 (14%)	p < 0.0001
40-60 years-old	17	11 (64%)	6 (36%)	
> 60 years-old	21	7 (33%)	14 (77%)	
Neurogenic bladder	30	23 (76.7%)	7 (23.3%)	p = 0.016
Non Neurogenic bladder	30	14 (46.7%)	16 (53.3%)	

Table 3 - Pain Visual Analog Scale (VAS) values in adherent and non adherent patients, before and after training.

	Total	Adherent	Non Adherent	p
VAS pre training (Mean ± S.D.)	5.47 ± 2.90	6.49 ± 2.18	3.83 ± 3.19	p < 0.001
VAS post training (Mean ± S.D.)	2.34 ± 1.64	2.38 ± 1.62	2.29 ± 1.71	p = 0.742
p	p < 0.001	p < 0.001	p = 0.031	

Table 4 - The WHOQoL-Bref score between adherent and non adherent patients to the program CISC.

	Total	Adherent (N = 37)	Non adherent (N = 23)	p value
Physical	53.43	54.41	51.59	0.356
Psychological	64.18	66.30	60.18	0.043
Social relationships	61.54	63.73	57.41	0.022
Environment	55.67	54.85	57.71	0.181
Self evaluation quality of life	54.09	56.62	49.31	0.059

difficult CISC. The main complication was symptomatic lower urinary tract infection in 18 patients.

Educational background ($p = 0.246$), marriage status ($p = 0.978$), detrusor leak point pressure ($p = 0.373$), bladder capacity ($p = 0.081$), urinary leakage ($p = 0.362$), superior members limitations ($p = 0.187$) or inferior members limitations ($p = 0.741$), did not play a role on patient's adherence.

Overall, patients anticipated with higher pain expectation before training than they score the pain after experience the catheterization. Adherent patients had higher pain expectation before training, but after experience the catheterization they showed similar values (Table-4). Women reported higher pain expectation than men ($p < 0.000$). Interestingly, patients with neurogenic bladder reported higher pain expectation than non-neurogenic patients ($p = 0.012$). These differences were not observed in the post training VAS evaluation (Table-4).

Table-4 shows the results from WHOQoL-Bref. Higher scores are associated with better quality of life. Patients that adhered to the program had a significant higher score on psychological and social relationships domains.

DISCUSSION

In the present study, we evaluated 63 consecutive patients referred to initiate CISC. Five percent decline to initiate the training at the first visit, even after being previously instructed by their urologist. Sixty patients that concluded the CISC training were evaluated. After being trained, the overall adherence rate was 61.7%. We demonstrated that women, younger patients (≤ 40 years old) and neurogenic voiding dysfunction had the better adherence rate. Educational background, marriage status, bladder capacity, detrusor leak point pressure and daily leakage episodes did not play a role in adherence. Furthermore, pain did not play a role in patients' adherence. Performing CISC did not present any impact on patient's quality of life. However, adherent patients had better scores on social relationships and psychological domains as measured by WHOQoL-bref questionnaire.

It is important to emphasize that performing CISC it is a simple procedure and can be learned even by elderly patients (35% of the patients were older than 60 years old). We found that 55 (92%)

patients were considered able to perform the CISC with only one training session and 5 (8%) patients needed no more than 2 sessions to become skillful. It demonstrates that performing the CISC is not a great technical challenge. On the other hand, some patients (5%) decline to initiate the training, even after being previously instructed by his doctor. It suggests that a small number of patients are greatly scared of passing a urethral catheter and may not even be referred to CISC.

Although all patients were able to perform the urethral catheterization, had understood the importance to perform the treatment due to their clinical condition and had precise indication to CISC, the adherence rate was 61.7%. Interestingly, the adherence rate was similar at 1, 6 months and 12 months follow-up. Demonstrating that once the patient adhere to the procedure and have an adequate instruction, health care support and follow-up, they maintain the CISC at least in the first year. We believe that performing monthly visits in the first 6 months after initiate the CISC was very important providing a positive feedback and re-assuring the importance to perform the procedure.

One possible explanation to patients' adherence to CISC is the possible distress, mostly pain, generated by passing a urethral catheter. To our knowledge, it has never been adequately studied. By assuming that pain is a problem to patients performing CISC, one possibly will believe that it would be less stressful to neurogenic patient with decrease urethral sensitivity and women due to their shorter urethra. Indeed, pain is a great concern to those patients referred to CISC. Just before initiate the CISC training patients had a great pain expectation (score = 5.4 in a scale ranging from 0 to 10). However, after passing the urethral catheter the observed pain was considerably less than what they expected (score = 2.3). Furthermore, our data demonstrates that the pain during urethral catheterization was similar for men and women, adherents and non-adherents and neurogenic and non-neurogenic patients. It demonstrates that pain is not the main factor to determine if a patients will or will not adhere to CISC. Interestingly, those patients with greater pain expectation before initiate training were those who shown higher adherence rate, suggesting that patients with CISC

indication should, at least, undertake an initial trial before decide if they would be able to continue with such therapy.

Patients with better perception of the severity of their disease show higher rates of adherence, even in longer treatments (14). Usually, patients with neurological problems have a chronic health condition that demands more intensive care and, in turn, motivates a better understanding of their pathology. It seems to be a more reasonable explanation to our finding that neurogenic patients had higher adherence rate than their counterparts ($p = 0.016$), rather than thinking that this population had a great adherence because they present less pain during urethral catheterization.

Age seems to be a very important variable to consider when planning a CISC recommendation. Establishing CISC in elderly can be complex, because this group of patients may present little capacity for self-care, lack of motivation, decreased ability to deal with new situations, decreased visual acuity, decreased motor dexterity and preconceptions regarding manipulate their genitals (15). We found that the adherence rate for patients older than 60 years old was only 33%. On the other hand, the adherence rate for patients under 40 years old was 86%.

A major concern with the institution of treatment with CISC is the impact this may have on the daily routine, their social and sexual relationship, economic factors, and the lives of patients who begin the program of CISC (16-20). Performing urethral catheterization four times a day seems to adversely affect QoL, especially for those patients that did not leak urine. In the present study, we search for the CISC impact on QoL by using the WHOQoL-bref questionnaire. We observed that the CISC had neither positive nor negative impact on quality of life. The main difference found on QoL evaluation was between adherent and non-adherent patients. Those patients that adhere to CISC had significant better scores in psychological and social relations domains. It may be associated with a better support and motivation from relatives and friends, which help patients to have a better acceptance and understanding regard their condition.

The adherence rate evaluation is a very important issue. It is a very important variable to de-

termine the treatment success and the health system efficiency. There are few studies aiming to determine the CISC adherence rate and the variables related to it. Van Achterberg et al. (10) performed a study with 20 patients to determine the important factors in patient's long-term adherence. They were not able to find a significant variable to correlate with patient's adherence and concluded that it would be important to perform a more specific study to evaluate the adherence rate to CISC.

CONCLUSIONS

The present study demonstrates that CISC has not a significant impact on the quality of life evaluated by WHOQoL-bref and that gender; age and neurogenic voiding dysfunction play a significant role on patient's adherence. These findings will help physicians to decide which patients would be better candidates to CISC and to define the best treatment strategy for each individual patient with voiding dysfunction.

CONFLICT OF INTEREST

None declared.

ABBREVIATIONS

CISC - Clean intermittent self-catheterization

VAS - Pain visual analogical scale

UDS - Urodynamic study

QoL - Quality of Life

BD - Bladder diary

WHOQoL-brief questionnaire: World Health Organization Quality of Life brief questionnaire

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