

Clean intermittent catheterisation—performing abilities, aversive experiences and distress

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A total of 407 patients participated in a one year follow up study concerning their personal experiences and attitudes towards clean intermittent catheterisation (CIC). Most patients (90%) were able to perform CIC themselves, approximately 70% having no problems with the procedure. However, one third of the patients experienced CIC as aversive with significantly higher distress scores on the general health questionnaire (GHQ-28). Aversion and distress were more often reported by younger patients and females, and by patients with non neuropathic bladders. The patients' physical disabilities and their length of previous CIC experiences did not seem to influence the feelings of aversion. These findings demonstrate the importance of considering the psychological implications of CIC, and the emotional needs of these patients in order to improve compliance and quality of life.

Keywords: clean intermittent catheterisation (CIC); disability; discomfort; distress; experience.

Introduction

Due to certain congenital conditions, acquired diseases or injuries, urinary tract problems, including retention, incontinence, infections and, in some patients, renal failure can develop. Since the introduction of clean intermittent catheterisation (CIC),¹ these problems have been reduced or indeed solved for many patients. Several authors have reported on the beneficial effects of this treatment.^{2–7} However, patients treated with CIC constitute a heterogeneous group with different degrees of disability⁸ and it may be asked to what degree the physical disability influences the performance of CIC.

Furthermore, there is a close connection, both physically and emotionally, between the sexual organs and the urinary tract. Catheterisation is in many ways a disturbing procedure, and some patients experience

the procedure as a form of trauma. Therefore, we may ask to what degree there may be aversion to the CIC procedure, and also the possible significance of such attitudes.

Apparently, there has been little in the way of study to identify the patients' own opinions and feelings concerning the performance of CIC, particularly with reference to their physical disability. Information regarding the patients' ability to perform CIC has also been scarce. The aim of the present study is to clarify these problems on the basis of an investigation which includes all CIC patients in a given population in Norway.

Materials and methods

On the basis of a nationwide catheter delivery programme, and the reception of information from physicians working in this field, nearly all outpatients using CIC in

Norway (population 3.2 million over 16 years) were identified. In the period from February to August 1988, they were asked to participate in a one year follow up study concerning possible physical and psychological complications related to CIC. Four hundred and seven from a total of 493 patients (206 men and 201 women), consented to participate. These patients had used CIC for a mean period of 18 months, range 0–126. Their mean age was 51.7 years (16–84). The females were younger than the males ($p < 0.01$).⁸

All patients performed catheterisation as a clean procedure. Disposable sterile PVC catheters were used only once. Most patients (95.8%) used PVC catheters coated with polyvinylpyrrolidone (PVP) to obtain a low friction catheterisation (LoFric (R)—Astra Tech AB, Mölndal, Sweden). The remainder used other PVC catheters.

Initially all patients underwent urological and neurological examinations. According to the diagnosis and the examinations, patients were divided into five diagnostic groups. A total of 106 patients with a lesion of the spinal cord above the conus (UMN bladder), constituted group I; 141 had lesions of the conus or peripheral nerves (LMN bladder), (group II); 136 had bladder dysfunction of unknown etiology (detruser myopathy), (group III); 19 had infravesical obstruction with normal detrusor (group IV); and group V consisted of 5 patients with suprapontine lesions.

In the initial examination, the patients completed questionnaires concerning physical functions, complaints and problems regarding the urinary tract, CIC performance and their personal experience with CIC. The revised physical battery (RPB)⁹ was also included in the patients' questionnaires. Each patient was given a disability score ranging from 15 (normal) to 46 (grave disability), based on RPB and three other questions concerning the functions of hands and legs.⁸

Examinations performed by physicians, focusing especially on complications and complaints, were repeated every 3 months during the following year, with a total of five studies. Each patient was given a clinical infection score depending on the frequency

and severity of urinary tract infection (UTI) in the previous three month period.¹⁰ The mean score was 0.6 for each time period with a range 0–6.

In examinations 1–5 psychological distress was measured by the general health questionnaire—28 item version (GHQ-28).¹¹ This is a very well validated self-report method of assessing distress and wellbeing in physically ill patients. In the present study likert (eg 0-1-2-3) scoring was used to analyse GHQ-28 (range 0–84).

Pain and discomfort were assessed by the self constructed CIC pain and discomfort self rating scale (PDS). A factor analysis of the PDS (Chronbachs alfa = 0.86) indicated no difference between pain and discomfort; and for further analyses the total score was used, called the discomfort score. The scale had a range from 0 (no discomfort/painless) to 18 (intolerable pain and discomfort). PDS focused exclusively on pain and discomfort in relation to the catheterisation procedure.

In examinations 2–5, the patients completed questionnaires concerning possible difficulties with CIC. In the fifth examination questions were included regarding the patients' possible aversions to the procedure and whether or not they considered the CIC treatment an advantage. GHQ-28 and the questions regarding performance of CIC, advantage of CIC and aversion to CIC were answered properly by 98%, 85% and 96% of the 302 patients respectively at the end of the study, while the corresponding values for discomfort were 100%, 88% and 97%.

A total of 83 patients (20.4%) stopped using CIC during the study, and 22 (5.4%) could or would not participate throughout the whole study. No differences were found between these 105 patients and the remaining 302 regarding age, sex and length of use of CIC. The 302 patients had, at the end of the study, been observed for a mean period of 13 months, with a mean CIC use of 33 months.

Standard statistical methods were used throughout. A two-sided p value of 0.05 or less was considered significant. Multivariate analyses were carried out to assess factors related to the patient's attitude towards, judgement of, and adjustment to the CIC

therapy. In the analyses, the dependent variable was coded 0 if the patient never reported aversion, if the CIC procedure was easy, or if the patient judged CIC to be an advantage; otherwise the variable was coded 1. In the models considered, age was categorised in four groups, disability in three groups, and the diagnostic groups as described above. The clinical infection score was categorised in three groups: patients having no sign of infection, patients having one or two minor bladder infections, and patients having more or serious UTI. SPSS (PC+ version 3.0)¹² was applied throughout except for logistic regression in which BMDP (PC version 88.2) was used.¹³

Results

The mean disability score was 23.3 (range 15–45). The patients with UMN bladders (group I) had the highest disability score and those in group III (detrusor myopathy) the lowest. The differences between group I (mean 28.9), II (mean 23.4) and III (mean 18.8) were significant ($p < 0.01$).

In the first examination, 89.5% of the patients performed CIC themselves while the remaining 10.5% needed help from others, either sometimes or always. These

proportions remained almost stable throughout the observation period. No differences were observed in the various age and sex groups. A higher proportion of patients in group I (21.7%) needed help compared to group II (9.9%) ($p < 0.05$) and group III (4.4%) ($p < 0.01$). A higher disability score was observed among patients who needed help versus those who did not ($p < 0.001$).

A total of 67.2% reported no problems with the CIC procedure in the second examination, 30.0% had some difficulties, and 2.8% found the procedure difficult. In the subsequent three examinations, the percentage of patients without problems varied from 70.2 to 73.3. The questions on difficulties in performing CIC were answered by 299 patients in each of the four last examinations (Table I). The percentage of men who reported the procedure to be easy was higher than that of women ($p < 0.05$). On the other hand, no significant differences were observed regarding age, disability, diagnostic groups and length of use.

In examination 5, 263 (87.1% of the remaining patients) reported whether or not the CIC therapy had been an advantage (Table II). A majority (86.3%) reported that CIC had been advantageous to them.

Table I CIC patients by type of experience and according to whether CIC was performed by themselves or by others

Type of experience	CIC performed by the patients themselves				CIC performed by others
	N	%	Male (%)	Female (%)	
No difficulties at all	144	53.7	A	71.0*	16
Initial difficulties—became easy during the study	31	11.6			
Some kind of difficulties reported every time	42	15.7	B	17.6*	6
Initially easy—became difficult during study	18	6.7			
Varied between easy and difficult during study	33	12.3	11.4	13.1	3
Total	268	100	100	100	31

*Male patients reporting A or B versus females reporting A or B.
 $\chi^2 = 3.92$; $p < 0.05$.

Table II CIC patients by type of statement as to advantage of the procedure and according to whether CIC was performed by themselves or by others

Statement as to advantage	CIC performed by the patients themselves		CIC performed by others	
	N	%	N	%
CIC has been a major advantage	160	66.4	18	81.8
CIC has been some advantage	48	19.9	4	18.2
The urinary tract problems have been unchanged	27	11.2	0	
CIC has been a disadvantage	6	2.5	0	
Subtotal	241	100	22	100
None or no conclusive answers	33		6	

No differences were observed regarding age, sex, disability and length of use of CIC between the patients reporting an advantage versus those reporting none. The patients who required assistance in practising CIC all stated that CIC had been an advantage.

Among the patients who performed CIC themselves, 68.2% were never averse to the catheterisation procedure, 25.8% were sometimes averse and 6.0% were always averse. A similar distribution was found among those needing help in performing CIC.

A significant difference was observed with respect to age and sex. In both sexes, the older were least averse and the younger most. There were no statistically significant differences in aversion regarding diagnostic groups, disability, length of use, and the need to obtain help in performing CIC. Logistic regression was used to assess the association of aversion to CIC to age and gender, adjusted for disability, diagnostic group, duration of CIC treatment and who performed it. Patients younger than 30 years were more averse to CIC than patients older than 60 years. The young patients had an odds ratio of 5.0 (95% confidence intervals: 1.9–12.8) compared to patients older than 60 years. The age groups between 30 and 60 years fell in between. Females were 1.9 (confidence intervals: 1.1–3.3) times more often averse compared to males.

The mean GHQ-28 distress score at the start of the study was 25.5 in the patients starting simultaneously CIC ($n = 91$) and 24.5 in those previously using CIC. In

examination 2 the mean score was 25.2 with a range from 5 to 77. The mean PDS score (discomfort) was 2.9 (0–18). Candidate predictor variables of GHQ-28 and PDS were sex, age, diagnostic groups, disability, duration of CIC, clinical UTI score in the previous 3 months period, and opinion of performing CIC. Opinion of performing CIC turned out to be the statistically strongest predictor of distress, but clinical UTI score was also a major predictor (Table III). Discomfort was also predicted by the patient's opinion of performing CIC as well as by clinical UTI and sex (Table III). No statistical differences were found in the GHQ-28 scores or the PDS scores in examinations 2–5. The same trend with regard to predictive variables was found throughout, even though clinical UTI did not reach significant values in examination 3.

To the predictive variables of distress and discomfort listed above, the patient's feelings of advantage of CIC and aversion to CIC were added in examination 5. The variables which showed statistically significant distress, were the patients' opinions of performing CIC and their aversions to the procedure (Table IV). The same variables were predictors of discomfort in addition to the patients' feelings of advantageous CIC (Table IV).

Of the 105 patients who did not participate throughout the study, 29 stopped CIC because they could not manage the procedure. Apart from the patients quitting within the first 3 months of the study, all who could not manage CIC had significantly

Table III CIC-treated patients. Mean distress (GHQ-28) and discomfort (PDS) in examination 2 by opinion of performing CIC, sex and clinical infections in the previous 3 months period

Predictive variable	Distress				Discomfort					
	<i>N</i>	Mean GHQ-28 score	SD	<i>p</i> value ^a	ANOVA ^b <i>p</i> value	<i>N</i>	Mean PDS score	SD	<i>p</i> value ^a	ANOVA ^b <i>p</i> value
Opinion of performing CIC					< 0.001					< 0.001
Easy	237	22.5	12.2			238	2.0	2.4		
Sometimes or always difficult	115	30.7	15.4	< 0.001		115	4.6	3.4	< 0.001	
Sex					0.714					0.04
Male	176	23.9	12.7			176	2.1	2.5		
Female	177	26.5	14.8	0.07		178	3.6	3.4	< 0.001	
Clinical UTI					0.01					< 0.001
None	191	24.3	12.9			191	2.5	2.7		
Some	119	24.4	12.8			119	2.9	3.2		
More ^c	43	31.7	18.2	< 0.01		44	4.5	3.5	< 0.001	

^aBy one-way analysis of variance; ^bthe results are adjusted for age, diagnostic groups and disability; ^cmore than two lower UTI in the previous 3 month period.

Table IV CIC-treated patients. Mean distress (GHQ-28) and discomfort (PDS) in examination 5 by experience of performing CIC, feeling advantage of CIC and feeling aversion to CIC

Predictive variable	Distress					Discomfort				
	<i>N</i>	Mean GHQ-28 score	SD	<i>p</i> value ^a	ANOVA ^b <i>p</i> value	<i>N</i>	Mean PDS score	SD	<i>p</i> value ^a	ANOVA ^b <i>p</i> value
Opinion of performing CIC					0.003					< 0.001
Easy	206	20.6	11.4			212	1.8	2.0		
Sometimes or always difficult	90	31.3	16.1	< 0.001		90	4.6	3.2	< 0.001	
Advantages					0.663					0.003
Yes	225	23.2	13.8			230	2.3	2.3		
No	33	27.8	16.0	0.08		33	4.5	3.3	< 0.001	
Aversion					< 0.001					< 0.001
Never	199	20.4	11.3			202	1.7	1.9		
Sometimes or always	90	31.5	16.0	< 0.001		91	4.9	3.0	< 0.001	

^aBy one-way analysis of variance; ^bthe results are adjusted for age, sex, diagnostic groups, clinical infections and disability.

higher mean GHQ scores than those who continued.

A comparison of GHQ distress scores between patients just starting CIC with those who had some previous experience with the procedure at the inclusion in the study, demonstrated an association between high distress score in the beginning and subsequent aversion measured one year later (Table V).

In 298 of the 302 patients, the physicians evaluated the patients' adaptations to CIC and possible changes in their urinary problems. The physicians claimed that 64.1% were well adjusted, 29.9% fairly well and 6.0% were poorly adjusted to CIC. No differences were observed with respect to age, sex, disability or length of use. The reasons why the patients were poorly adjusted to CIC were related to 'nervous problems' in 6 cases; 7 patients had frequent UTIs; 5 patients worried a lot about CIC; and 3 patients gave other reasons. Regarding urinary problems, the physicians claimed that 36.3% had improved substantially, and 29.6% had become a little better. The urinary problems were unchanged in 28.5% and had become worse in 5.6%.

When analysing only the patients performing CIC themselves, their judgement of the possible advantage of, as well as aversion to CIC were also related to diagnostic groups using group I as a reference. Group II and group III reported less advantage and more aversion to CIC than the reference group.

Discussion

As far as we know, this is the first non selected population-based study where nearly all adult outpatients using CIC have been included. About 10% required some assistance in practising CIC, but even patients with high disability scores were able to perform CIC themselves.

The majority of the patients in the present study considered CIC an advantage, and they were not averse to the procedure which they found easy to perform. However, approximately one third of the patients had periodical or permanent aversion to CIC. Aversive reactions were associated with higher psychological distress, and were more frequently reported by females and younger subjects. Patients dropping out later on during the study because they could not manage the CIC procedure also had higher mean distress scores.

As opposed to the findings in the present study, where more women than men reported practical difficulties and aversions in connection with the CIC procedure, Murray *et al*¹⁴ found that only one out of 37 women was dissatisfied with the treatment. The variance might be explained by different ways of obtaining the information: all patients studied by Murray *et al* gave their answers during interviews. Answers to sensitive personal questions are generally considered more valid when obtained by questionnaires.

Age was also found to be a strong

Table V Patients starting CIC and patients using CIC previously. Mean distress score (GHQ-28) at the start of a one year prospective study by aversion to and advantage of the treatment one year later

Opinion about CIC after one year	New patients			Patients using CIC previously		
	N	Mean	p value ^a	N	Mean	p value ^a
No aversion	36	24.0	0.16	161	21.1	< 0.001
Aversion	13	30.1		77	31.0	
CIC has had advantages	41	23.4	0.03	182	23.4	0.06
CIC has had no advantages	3	39.0		30	28.3	

^aBy one-way analysis of variance

predictor regarding aversion. Whether this is related to age per se or represents a cohort effect cannot be clarified in the present study. The fact that patients over 60 years of age reported less aversion to the procedure is in accordance with other studies which also report that CIC in general is well accepted and performed by the elderly.^{15,16} Apparently, there has been no earlier report showing patients under 30 years to be as averse to the procedure as the present study has shown.

The reasons for being averse or reporting difficulties and disadvantages with the treatment could be aggravation of problems in the urinary tract caused by CIC per se. However, this can hardly be the full explanation, as according to the physicians' statements only a few were considered worse. Is it likely that the reason for aversion and difficulties being reported could to some extent be of a psychological nature?

Psychologically, urination has many conscious and unconscious meanings, such as erotic and aggressive components.¹⁷ Difficulties in urinating with subsequent use of self catheterisation procedures may therefore provoke strong feelings often related to shame and weakness. Manipulation of the meatus area is most often related to sexual activity, particularly in females, and may give rise to further emotional distress. These feelings and thoughts are regularly associated with low esteem and cause anxiety and depression.

The marked relationship between bladder function and emotions has been demonstrated in empirical studies. In a study of 211 female patients attending a urodynamic unit, roughly a quarter of all the patients reported that their urinary symptoms rendered life intolerable and they were anxious, depressed and phobic as psychiatric inpatients.¹⁸ Irrespective of etiology, patients with detrusor instability or urgency were distressed. This corresponds to the present findings.

A psychological explanation of the gender differences in the experience of aversion is further supported by studies of adjustment to other medical treatment procedures. Most studies on chronic disabling or life threatening illness state that women report

more psychosexual dysfunction than men. This has been reported in leukaemia patients treated with bone marrow transplantation or chemotherapy¹⁹ as well as in subjects seen after major surgery for intra-oral cancer.²⁰ The latter study also reported higher level of distress in younger patients.

However, despite these findings, it is not likely that the performance of CIC per se is the only explanation of the aversive experiences. Most studies state that about 20–30% of the patients report negative emotions and distress related to chronic disorders and treatments. This is almost independent of the specific nature of the treatment or condition.^{21,22} Some of the aversive reactions and distress may thus reflect general mental problems in relation to urinary functions²³ and possibly also the medical disorder or personality variables.

The finding that a high distress score at the start of the study predicted both aversion and lack of satisfaction with the procedure one year later, among new CIC patients as well as among those who had previous experience, supports this assumption (Table V). Nevertheless, according to other studies of adjustment to medical procedures and illness, personality variables are likely to play a significant role in early distress responses.^{24,25} This will be addressed in a forthcoming paper.

The importance of psychological aspects is further stressed by the findings that aversive reactions were not related to degree of disability. In fact, patients belonging to group I (UMN bladders) seemed better adapted while patients belonging to group III (detrusor myopathy) were less pleased with CIC compared to the other groups.

The acquisition of valid information of the patients' reactions and attitudes towards CIC is a difficult and methodologically controversial task. The issue was evaluated in this study by questionnaires. The patients were asked to what degree they found CIC to be difficult, how advantageous they found it and how averse they were to carrying out the procedure. In our opinion such statements give a reasonable indication of the acceptance of CIC. This is supported by the fact that the physicians reported similar relative distribution of well, fairly

well and poorly adjusted patients. These findings are supported by the answers from the questionnaires concerning difficulties and aversion.

Conclusions

The clinical implications of this study are that not many problems can be expected in accepting CIC in elderly, not very disabled persons. The good acceptance by most patients is in agreement with the report by

Maynard *et al*⁵ who stated that almost 80% of the patients accepted the procedure readily. Furthermore, the present study shows that problems with CIC should be anticipated in younger people and especially in young females. Therefore more support and perhaps a closer follow up should be given to younger patients and females needing CIC. One has to bear in mind that many of these patients have superimposed non-organic problems and may benefit from a follow up in which psychological aspects are given due consideration.

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