**48**

Wilde M[1], Brasch J[1], Getliffe K[2], McMahon J[1], Anson E[1], Tu X[1]
***1.*** *University of Rochester (NY),* ***2.*** *University of Southampton (UK)*

# A NEW CATHETER-RELATED QUALITY OF LIFE INSTRUMENT FOR LONG-TERM URINARY CATHETER USERS.

Hypothesis / aims of study

A catheter-related quality of life (C-IQoL) instrument was developed and tested in two studies to support research with long-term urinary catheter users, using indwelling urethral or suprapubic catheters indefinitely.

Study design, materials and methods

The initial instrument, which was modified after each study, was based on an ICS validated generic continence quality of life tool [1]. ICS guidelines were used to develop content, including descriptive and qualitative literature, subjective measures (e.g., knowledge about self care, working with others in catheter management, effects on sexual activity) and objective measures (e.g., blockage, catheter associated urinary tract infection, unplanned changes). Additional content was based on a review of literature and described in the 4th International Consultation on Incontinence, (pp. 228-9).[2] This involved concerns related to: sexuality (compounded by effects of illness or injury), shame and stigma associated with a catheter, embarrassment (including male/female sensitivities), loss of control or bodily function, reminders of illness/mortality, inconvenience/worries of catheter related problems, drainage bag impact on daily life (e.g., concealing the bag, odor, emptying), the role of education on acceptance of catheter, autonomic dysreflexia and the lack of knowledge about it by caregivers. C-IQoL consisted of 29 items scored on a 1-5-point scale, with agreement from 1 extremely, 2 quite a bit, 3 moderately, 4 a little, and 5 not at all.

The new measure performed adequately in a pilot study of an intervention to teach self-monitoring skills to 11 long-term urinary catheter users over a six month period of time. The measure was used at six months. Face validity was assessed by an incontinence researcher, specializing in long-term catheter care studies. Four additional items were added as a result of this assessment. Cronbach's alpha for internal consistency reliability was .85. Based on feedback from the study participants, who were interviewed on the phone, the response items were simplified to terms that were easier to interpret, i.e., a five point Likert type scale of strongly agree, agree, neutral, disagree, and strongly disagree. In addition, stems of "I feel worried" were changed to "I am concerned about" to more accurately reflect study participants views.

After revision, the tool was tested in a second study at intake, six months, and one week later (test-retest). In this prospective study of long-term catheter use, catheter related problems and complications were reported by 43 individuals with long-term catheters at intake, 2, 4, and 6 months. Reliabilities were assessed at baseline and 6 months, and then a week later for test retest (see Table 1). Factor analysis was conducted using principal axis factoring with Promax rotation, comparing the factors at baseline and 6 months. We found that 7 items did not show consistency in the pattern matrices over time; therefore, those items were removed and when rerun (forcing three and four factor solutions), all items loaded on the same three factors at baseline and 6 months. (See items listed below.) As a result of this analysis, the instrument was shortened to 22 items (from 29).

Several additional changes were made prior to using this tool in a current randomized trial in a population of long-term catheter users, adding 4 items. One item, which had been removed after the factor analysis, was returned to the scale after a modification, based on a recent study [3]. The item "I feel depressed" was replaced with "I feel depressed about my catheter". In addition, based on recent consultation with others at ICS who have developed continence related quality of life instruments, three more items about common catheter related problems were added: I am concerned about catheter leakage, I am concerned about the catheter getting pulled out by accident, and I am concerned about difficult or painful catheter changes.

Results

Reliabilities are reported below (Table 1) for each of the factors and the entire instrument, as well as mean scores for the scales.

Table 1. C-IQoL Reliabilities and means from Prospective Study on Long-term Catheter Use

| | INTAKE Mean | INTAKE Reliability | 6 MONTH Mean | 6 MONTH Reliability | Follow Up Mean | Follow Up Reliability |
|---|---|---|---|---|---|---|
| TOTAL Scale | 3.27 | 0.90 | 3.31 | 0.93 | 3.70 | 0.86 |
| Management subscale | 3.01 | 0.86 | 3.10 | 0.91 | 2.67 | 0.89 |
| Interpersonal subscale | 3.34 | 0.83 | 3.27 | 0.88 | 2.89 | 0.83 |
| Psychosocial subscale | 3.68 | 0.81 | 3.77 | 0.81 | 3.70 | 0.86 |
| Test-retest between 6 month & Follow Up | | | | | | .897 |

22 questionnaire items are listed by factors below:

Factor 1- Catheter management/problems (Management)

I am concerned about getting wet because of the catheter leaking.
I am concerned about where toilets are in new places.
I am concerned about whether the toilets are accessible and private for emptying the drainage bag.
I am concerned about catheter blockage.
I am concerned about others smelling urine on me.
I am concerned about my catheter causing more problems as I grow older.
I have to watch what I drink.
I am concerned about getting a urinary tract infection.
I am concerned about not being able to empty my drainage bag before it gets too full.
I am concerned about being embarrassed or humiliated because of my catheter.

Factor 2. Interpersonal
I am concerned having to instruct my care attendants about how to care for the catheter properly.
I am concerned about doctors and nurses not knowing about autonomic dysreflexia.
I am concerned about conflicts in care management with my doctors and/or nurses.
I have a hard time because of catheter pain.
I am concerned about how the catheter might affect my having sex.
I am concerned about getting supplies for my catheter.
My catheter limits my choice of clothing.

Factor 3. Psychosocial
My catheter makes me feel like I'm not a healthy person.
I get less enjoyment out of life because of my catheter.
I feel frustrated because my catheter prevents me from doing what I want.
My catheter makes me feel helpless.
I don't feel free to leave my home for long periods of time.

Interpretation of results
This catheter-specific quality of life instrument is the first known measure of its kind, and psychometric testing for reliability and identifiable factors indicated that the tool performed adequately. The measure has been used by colleagues developing a similar quality of life tool in a larger sample of people with long-term urinary catheters, and it should be particularly useful for tests of construct validity.

Concluding message
Quality of life instruments need to be device-specific to address appropriate and critical issues in randomized trials. For further development of a valid and reliable measure, continued collaboration is needed among researchers working with this population.

## References


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| ***Specify source of funding or grant*** | **Wound, Ostomy, and Continence Nursing Foundation** |
| ***Is this a clinical trial?*** | **No** |
| ***What were the subjects in the study?*** | **HUMAN** |
| ***Was this study approved by an ethics committee?*** | **Yes** |
| ***Specify Name of Ethics Committee*** | **University of Rochester (NY) Research Subjects Review Board** |
| ***Was the Declaration of Helsinki followed?*** | **Yes** |
| ***Was informed consent obtained from the patients?*** | **Yes** |