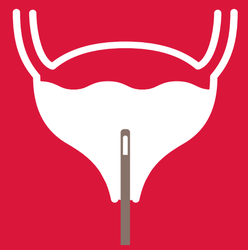
Understanding the Lived Experience of Intermittent Self-Catheterization: Quality of Life and Health Status from a Multinational Continence Care Registry

Background:

Intermittent self-catheterization (ISC) is recommended for bladder emptying in individuals with chronic urinary retention, but long-term adherence and quality of life may be affected by usability, convenience, and psychosocial factors.



Real-world data on daily ISC experiences remain limited. Patient-reported outcomes can provide insight into lived experiences and catheterization practices and support more patient-centered care.

References:

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Aims:

To evaluate self-reported quality of life, ease of use, convenience, discreetness, psychological wellbeing, and perceived health status among individuals performing intermittent self-catheterization using data from the Continence Care Registry (ConCaRe™).

Methodology:

Baseline self-reported data from the ConCaRe™ Continence Care Registry, a multinational longitudinal registry of individuals performing intermittent self-catheterization (ISC), were analyzed descriptively.

Electronic questionnaires included the Intermittent Self-Catheterization Questionnaire (ISC-Q) and EuroQoL-5D visual analogue scale (EQ-5D VAS.) Outcomes included ISC-related quality of life, ISC-Q domain scores, and general health status. Results were summarized for the United States (n=178), United Kingdom (n=87), and Canada (n=61), with additional analyses by gender.

United States n=178

119 males **59** females

United Kindom n=87

45 males **42** females

Canada n=61

33 males **28** females

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Table 1

ISC-Q measure	US	UK	Canada	US Female	US Male	UK Female	UK Male	Canada Female	Canada Male
Average of ISC-Q QoL Score 100	67.50	65.11	59.51	67.76	67.40	66.93	63.43	64.03	55.79
Ease of use	80.77	81.43	76.56	80.63	80.83	82.41	80.52	82.29	71.84
Convenience	53.72	44.25	46.47	57.91	52.01	46.98	41.73	49.26	44.18
Discreetness	68.86	69.52	57.73	70.21	68.31	73.68	65.68	67.38	49.78
Psychological well-being	57.64	52.85	47.26	54.70	58.84	52.82	52.87	46.18	48.16

Average scores on a scale of 0-100.

Table 2

EQ5D VAS	US	UK	Canada	US Female	US Male	UK Female	UK Male	Canada Female	Canada Male
Average of VAS Score	73.70	65.39	73.48	74.54	73.36	63.13	67.47	68.73	77.38

Average scores on a 0-100 (Worst-Best) scale

Presented at ICS 2026 Maastricht, NE

Results:

Across regions, mean ISC-related quality-of-life scores were highest in the US, followed by the UK and Canada. Ease-of-use scores were consistently high across all regions, indicating generally favorable experiences with catheter handling.

Not drawn to scale

Discreetness scores were high, particularly in the US and UK, indicating that participants generally perceived ISC as discreet in daily life. These findings are consistent with the PRICE study, which reported low difficulty with catheterization and favorable perceptions of discreet catheter use.[1]

In contrast, convenience scores were lower across countries, reflecting challenges with carrying, storing, and disposing of catheters during daily activities. EAUN guidelines emphasize convenience and speed of use as important to adherence,[2] highlighting opportunities to improve catheter and packaging design to better meet patient needs.

Psychological wellbeing scores were moderate overall, indicating a persistent emotional and psychosocial burden associated with ISC. Prior studies have identified fear, embarrassment, and reduced self-esteem as barriers to catheter use and confidence,[3] underscoring the importance of addressing these concerns in clinical practice.

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Gender-based patterns were similar across regions, with females generally reporting slightly higher discreetness and convenience scores than males, while ease of use remained relatively high across genders. EQ-5D VAS scores varied by region and were highest in the US and Canada.

Despite relatively favorable general health ratings, Canadian participants reported lower ISC-related QoL, suggesting that ISC-related burden may persist independently of perceived overall health status.

Conclusion:

Baseline ConCaRe™ continence care registry data indicate generally favorable ease of use and discreetness among individuals performing ISC, while convenience and psychological wellbeing remain areas for improvement.

Regional and gender-based variations underscore the value of individualized assessment and patient-centered catheter selection. Real-world patient-reported outcomes can further inform strategies to improve adherence, satisfaction, and quality of life.