Can patients independently identify their urinary incontinence symptoms?

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ORIGINAL ARTICLE

Can patients independently identify their urinary incontinence symptoms?

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Abstract

Introduction and hypothesis The objective of our study is to compare patient self-reported urinary incontinence symptoms based on the International Consultation on Incontinence Questionnaire- Short Form (ICIQ-SF) question number 6 (When does urine leak?) with physician-assessed interpretation of the patient's urinary incontinence symptoms.

Methods This trial is a cross-sectional study of patients who presented to a tertiary urogynecology center with symptoms of urinary incontinence between January 2014 and August 2016. We compared patient-reported symptoms on the ICIQ-SF with physician interpretation of urinary complaints during their initial visit. The urinary incontinence symptoms included stress urinary incontinence (SUI), urgency urinary incontinence (UUI), insensible urine loss, nocturnal enuresis, and post-micturition dribbling.

Results A total of 432 patients with a mean age of 61 were included in this evaluation. The most common urinary incontinence symptoms according to the physician were UUI ($n = 357$, 83%), followed by SUI ($n = 308$, 71%). Of the patients who were diagnosed by a physician with the symptom of UUI, only 61% self-identified as having this symptom based on the ICIQ-SF, and for SUI, only 66% self-identified as having SUI symptoms based on the ICIQ-SF. Overall UUI ($\kappa = 0.30$) appears to have poor agreement, as does nocturnal enuresis ($\kappa = 0.39$), when compared with physician historical assessment.

Conclusion There is a discrepancy between patient-reported urinary incontinence symptoms on the ICIQ-SF and physician-assessed symptoms. Symptomatology entered into electronic medical records by patients is often inaccurate. Physician validation is essential in understanding the underlying the precise symptomatology.

Keywords Data self-entry · Electronic medical records · Stress urinary incontinence · Urinary urgency incontinence · Urinary symptoms

Introduction

The International Continence Society defines urinary incontinence (UI) as the "complaint of any involuntary loss of urine" [1]. The prevalence of UI increases with age and is estimated to affect 18% of all adult women and up to 55% of the elderly [1]. UI significantly affects patients' quality of life, including their mental well-being, personal relationships, and work productivity [2]. Despite UI affecting a significant percentage of the population, there is poor patient understanding of UI and pelvic floor disorders. More than 30% of female patients previously treated and presumably educated about UI are noted to have an extremely small amount of knowledge about pelvic floor disorders [3].

The assessment of patient's UI symptoms most commonly includes a review of detailed patient-completed questionnaires and/or a physician interview to confirm and refine this history.

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Geriatric and internal medicine studies have examined patients' medical conditions and the relationship between self-reported diagnoses via questionnaires versus diagnoses based on personal interviews, noting that self-administered questionnaires do not generate the same information as personal interviews. This is particularly true for less severe or transient medical conditions, such as benign tumors, cerebral ischemia, rheumatism, colon polyps, and skin disease. The study concluded that self-administered questionnaires do not generate the same information, especially for less severe or transient disease compared with personal interviews [4]. With the advent of electronic medical records and the availability of direct self-entry of data by patients, it is tempting to use quality of life and other questionnaires to ascertain patient symptoms. However, it is unclear whether these data are accurate. To date, there are no reports comparing the self-reported UI symptoms with in-person physician-based diagnostic interviews.

A commonly used, robust, and validated questionnaire—the International Consultation on Incontinence Questionnaire for Urinary Incontinence—has a self-diagnostic measure focused on patient-perceived causes and occurrences of UI [5]. In order to measure the impact of UI on an individual's life, a number of self-completed quality-of-life questionnaires have been developed. The International Consultation on Incontinence (ICI) in 2002 developed a short-form ICI questionnaire for urinary incontinence (ICIQ-SF) to provide a simple, brief, and robust questionnaire for the assessment of UI symptoms. This questionnaire has been validated in various populations, across nationalities, and translated into 35 languages.

In this study, our objective was to compare patient perceptions of UI symptoms, based on ICIQ-SF question number 6 ("When does urine leak?"), to the symptoms assigned during the physician-based interview at the patient's first office visit.

Materials and methods

We carried out a cross-sectional study of female patients who presented to a single provider at a tertiary Female Pelvic Medicine and Reconstructive Surgery center with complaints of urinary incontinence between January 2014 and August 2016. The Institutional Review Board of NorthShore University HealthSystem determined this study to be exempt. A total of 432 new patient visits in the electronic medical record were reviewed. Patients included in the study were English-speaking females aged 18–99 who presented to our tertiary center and filled out a questionnaire during the visit. Excluded from the study were patients who did not speak English and those who did not complete the questionnaire at the initial visit. During an initial visit, patients were asked to complete the ICIQ-SF prior to seeing the urogynecologist. Then, responses were reviewed and confirmed by the evaluating physician. Each patient was specifically asked about the presence and frequency of stress urinary incontinence, urgency urinary incontinence, urinary incontinence without sensory awareness, nocturnal enuresis, and post-void dribbling, as defined by the International Urogynecological Association and International Continence Society (ICS) [6].

The ICIQ Short Form (ICIQ-SF) comprises six questions (Appendix 1). The first two questions ask for the date of birth and gender of the patient. The third, fourth, and fifth questions assess the impact of the frequency of leakage (scored 0–5), the amount of leakage (scored 0–6), and the impact of incontinence on the quality of life score (0–10) respectively. A higher score indicates more severe incontinence. The last is a self-diagnostic question about the perceived causes of UI that asks, "When does urine leak?" Patients can select multiple choices. Our analysis is based on answers to this sixth question of the ICIQ-SF. It was designed by an expert committee, and, even though not scored, it has significant clinical utility, as it could help clinicians to better understand the patient's perceived cause of her UI.

The patients' ICIQ-SF responses were compared with the symptoms elicited by the physician at the first patient encounter. During the patient encounter the physician was not blinded to the questionnaire and had the questionnaire answers readily available. These physician-derived incontinence symptoms were obtained through billing codes and chart review and were compared with the responses to the ICIQ-SF question 6 to assess the reliability of patient-determined incontinence symptoms. The diagnosis codes that were extracted included: 625.6/N39.3 (stress incontinence), 788.31/N39.41(urinary urge incontinence), 788.34/N39.42 (incontinence without sensory awareness), 788.36/N39.44 (nocturnal enuresis), and 788.35/N39.43 (post-void dribbling). Data were examined and analyzed using Microsoft Excel Version 15.39.

Results

A total of 432 unique new patient visits were identified. The mean patient age and BMI were 61 ± 14.5 years and 29 ± 6.9 kg/m^2 respectively, and the median parity was 2 (range 0–10). As determined by the physician interview, 357 (82.6%) patients had symptoms of urgency urinary incontinence, 308 (71.3%) had complaints of stress urinary incontinence, 119 (27.5%%) had urinary incontinence without sensory awareness, 89 (20.6%) were found to have nocturnal enuresis, and 140 (32.4%) were noted to have post-micturition dribbling. The majority of patients had mixed urinary incontinence. A disparity was found for the presence of UI and each UI symptom when comparing the patients' UI symptoms during the physician interview and the patients' report of the UI symptom on the ICIQ-SF. There were 53 (12.2%) women who

reported never leaking urine in response to ICIQ-UI question 6, who later reported some symptom of UI to the physician (Fig. 1). Cohen's kappa coefficient was performed on the data. A kappa coefficient of >0.75 is noted to be excellent, 0.40–0.75 as fair to good, and below 0.40 is regarded as poor. Table 1 illustrates kappa coefficients in our data sample. Overall UUI ($\kappa = 0.30$) appears to have poor agreement, as does nocturnal enuresis ($\kappa = 0.39$) when compared with physician historical assessment. Only fair agreement was found for stress urinary incontinence, with a κ of 0.452, as well as for post-micturition dribbling ($\kappa = 0.43$) and insensible urine loss ($\kappa = 0.41$) between the ICIQ-SF and the physician assessment.

Discussion

The ICIQ-SF is widely used to obtain a brief and comprehensive summary of the extent, impact, and perception of a patient's UI symptoms. The expert committee that designed the questionnaire thought that question number 6, even though not scored, had significant clinical utility, as it could help clinicians to better understand a patient's perceived cause of her UI and therefore facilitate further questioning. In their study, Rotar et al. noted that the perceived cause of leakage presented in question 6 was a good indicator and correlated well with urodynamic findings [7].

In the present study, there is a substantial discrepancy between patient-reported UI symptoms on the ICIQ-SF and the UI history elicited by the physician-validated symptoms following a detailed patient interview. The kappa statistic was used to determine the degree of agreement between different variables. Urgency urinary incontinence and nocturnal enuresis were noted to have poor agreement, whereas other variables were noted to have only fair agreement.

This emphasizes the importance of in-person detailed interviewing, as it appears that the interview allows for clarification of the UI symptoms and their causes. This is consistent with the knowledge that even patients educated about UI often do not understand their symptoms. Although there is value in the use of the ICIQ-SF, our data suggest that physician confirmation of the UI symptoms identified on this questionnaire is necessary. Direct patient-entered symptomatology into electronic medical records has often been shown to be inaccurate. It is also clear that careful questioning of women who do not complain of UI on the ICIQ-SF may reveal that many of these women do, in fact, have UI (as demonstrated by the 9% of patients in our study who answered "never—urine does not leak" on ICIQ-SF question 6, but reported UI to the physician). Although some of these women may not be bothered by their UI, others likely are bothered, but may not understand the terminology on the ICIQ-SF.

Studies of self-reported urinary symptoms and their verification are scarce in the urogynecology literature. To our knowledge, the only study examining this topic was performed by Hajebrahimi et al. in 2004. They compared the results of the ICIQ-SF of 64 women on three separate occasions: twice during the same visit, one by self-administration, the second by physician interview, and then once at home, 1 week later. The results of the study noted that information obtained by self-administration of the ICIQ-SF in the office or

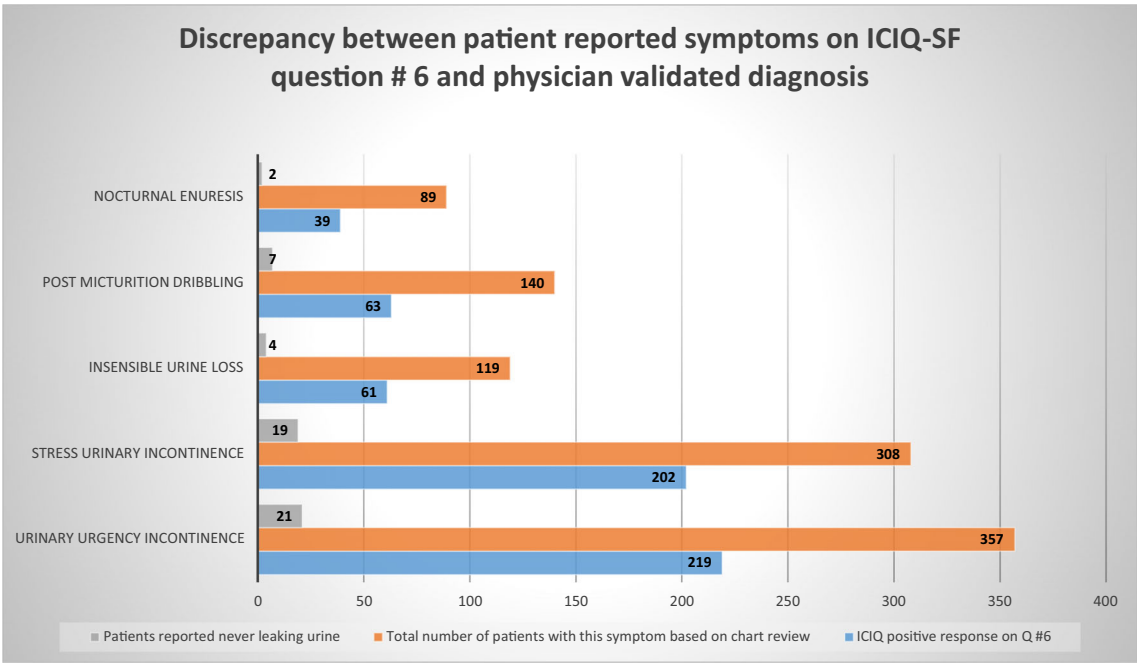

Fig. 1 Discrepancy between patient reported symptoms on International Consultation on Incontinence Questionnaire Short Form (ICIQ-SF) question 6 and physician-validated diagnosis

Table 1 Cohen's kappa statistic between different patient-reported symptoms on International Consultation on Incontinence Questionnaire (ICIQ) question 6 and physician-validated diagnosis

	Sample size	Kappa statistic	Strength of agreement
Urinary urgency incontinence	432	0.30	Poor
Stress urinary incontinence	432	0.45	Fair
Nocturnal enuresis	432	0.39	Poor
Post-micturition dribbling	432	0.43	Fair
Insensible urine loss	432	0.41	Fair

*For kappa statistic, κ >0.75 is noted as excellent, 0.40–0.75 as fair to good, and below 0.40 as poor

at home or when completed by the physician in the office were all similar. However, this study only compared total ICIQ-SF scores and did not mention any answers to question 6, which is an unscored subjective question [8].

A significant body of literature concerning symptom self-reports exists in geriatrics and internal medicine [9]. Bergmann et al. compared patients' responses during an in-person interview with a self-administered questionnaire and found agreement between the interview and questionnaire information for serious diseases requiring hospitalization, such as malignant tumors, myocardial infarction, and for diseases requiring chronic medical care, such as diabetes mellitus. Agreement between in-person interviews and self-reported questionnaires was significantly lower for diseases that were less well-defined, such as benign tumors, diseases of the skin, or diseases with intermittent appearance, such as gastritis or irritable bowel syndrome. The investigators noted that without the presence of the interviewer, participants thought that less serious and intermittent conditions were not important enough to report [4].

Self-reported questionnaires are excellent epidemiological tools; however, further questioning along with explanation and clarification of questionnaires is crucial to obtaining accurate data. This is especially important with the further development of electronic medical records, where patients' questionnaire answers may stream directly into their medical record. Our study emphasizes the importance of reviewing data entered into the medical records by patients, noting that a significant portion of the data might not be accurate and therefore the treatment approach to the stated condition might not be adequate. It became apparent that subjects' ability to discern what is being asked in question 6 or in any online or printed questionnaire is limited. They often do not assess whether their incontinence episodes are associated with urgency or increases in intra-abdominal pressure. They especially do not realize that they might be losing urine involuntarily after they finish voiding and stand up or having insensible urine loss, coital incontinence, or nocturnal enuresis. For the majority of women, this requires a broader interactive discussion to help a patient to understand what incontinence symptoms may be impacting them. The data presented in our study exemplify the importance of physician review of patient-reported symptoms on self-administered questionnaires.

The study is limited by its retrospective nature and by the data being derived from one physician's patient population. This may limit its generalizability to other populations. However, the examining physician consistently questions all patients in a standardized fashion that did not change during the study period. The strength of our study is the availability of the ICIQ-SF for all patients upon their initial presentation to our practice—prior to history taking by the physician. To our knowledge, this is the first study to examine patient-reported UI symptoms on the ICIQ-SF at their initial visit to a urogynecology practice and physician-elicited history of UI later in that same presenting visit. Self-reported UI diagnoses based on the ICIQ-SF do not generate equivalent information to a detailed physician interview.

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Contributions S. Lozo: project development, data collection, data analysis, manuscript writing; C. Botros: project development, data collection, data analysis; S. Iyer: manuscript writing/editing; A. Gafni-Kane: manuscript writing/editing; P. Sand: project development, data collection, manuscript writing/editing.

Compliance with ethical standards

Conflicts of interest None.

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