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Do Women Understand Urogynecologic Terminology?

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Abstract

Objectives—The aims of this study were to describe women’s stated knowledge of the primary urogynecologic diagnostic terms (urinary incontinence, pelvic floor disorder, and pelvic organ prolapse) and to assess factors associated with knowledge.

Methods—Before any education about pelvic floor disorders, 376 women presenting to primary care-level gynecologic clinics were asked whether they knew what the terms urinary incontinence, pelvic organ prolapse, and pelvic floor disorder meant. χ^2 and *t* tests were used to compare characteristics of women with complete knowledge versus partial or no knowledge of terms. *P* < 0.05 was considered significant.

Results—Of all women, 25% knew all 3 terms and 18% knew none. Moreover, 80%, 52%, and 27% of women reported that they knew the meaning of the terms urinary incontinence, pelvic organ prolapse, and pelvic floor disorder, respectively. Of women with stress urinary incontinence symptoms, 88% knew the term urinary incontinence compared with 78% without stress urinary incontinence (*P* = 0.07). Of 41 women, 31 (76%) with the symptom of vaginal bulge knew the term pelvic organ prolapse compared with 49% without (*P* = 0.001). Only higher education and symptom of vaginal bulge were associated with complete knowledge of the 3 terms; 30% of women who completed college or higher reported complete knowledge compared with 18% who did not (*P* = 0.013).

Conclusions—Public health campaigns using terms pelvic organ prolapse or pelvic floor disorders are unlikely to reach most women. Further education and research are needed to improve women’s health literacy in urogynecology.

Keywords

pelvic floor disorder; health literacy; pelvic organ prolapse; urinary incontinence

Communication is vital to health education. Communication encompasses a host of interactions between not only health practitioners and patients but also between patients and written material. Health literacy, defined as basic reading and numerical skills that allow a

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person to function in the health care environment, impacts communication between practitioners and patients by impeding patients' understanding of health conditions as well as the instructions given to them.¹ In communicating with patients, it is important that practitioners use terms that patients understand.

The American Urogynecologic Society and other organizations have conducted public awareness campaigns about pelvic floor disorders. However, it is not known whether women understand the meaning of the medical terms used to describe common urogynecologic conditions. If women have a poor understanding of common urogynecologic terms, either different terms should be used or more effort should be placed on educating the public about the meaning of these terms.

The aims of this study were to describe women's stated knowledge of the primary urogynecologic diagnostic terms (urinary incontinence, pelvic floor disorder, and pelvic organ prolapse) and to assess factors associated with perceived comprehension.

METHODS

This is a planned ancillary analysis of an ongoing cross-sectional study that will assess the association between physical activity and pelvic floor disorders. In the broader study, most women are recruited from private practice and university clinic-based primary care-level OB/GYN practices and the remainder is recruited from advertising or a tertiary care-level clinic. Only participants recruited from primary care-level clinics are included in this ancillary analysis, such that inclusion is limited to a population with access to health care that is not seeking treatment for pelvic floor disorders. The research coordinator approached eligible women and told them that the general purpose of the larger cross-sectional study was to look at how physical activity affects aspects of women's health. She then administered an eligibility screening form that included 3 additional questions: "Do you know what these terms mean?: 'urinary incontinence,' 'pelvic organ prolapse,' and 'pelvic floor disorder.?" The research staff did not provide any prompts and, if women noted "yes," did not confirm correct knowledge. After completing these questions, eligible women then underwent a full-consent process in which the study aims as well as these terms were explained in more detail. Women then completed questionnaires about pelvic floor symptoms, including the Incontinence Severity Index,² the 3-IQ,³ and the Epidemiology of Prolapse and Incontinence Questionnaire.⁴ The coordinator completed a Pelvic Organ Prolapse Quantification examination.⁵

Inclusion criteria included ambulatory nonpregnant women aged 39 to 65 years, with no history of surgical procedures for urinary incontinence (UI) or pelvic organ prolapse (POP), and with no history of neurologic conditions associated with UI, radiation therapy for the pelvis or abdomen, radical hysterectomy, or current treatment of cancer. In the primary study, women were included if they had stress UI (SUI), POP, or neither (as controls) but were excluded if, based on responses to the 3-IQ, they were categorized as having urge or unconscious leakage.

We categorized a woman as continent if she had a score of 2 or lower on the Incontinence Severity Index and as having SUI if she scored 3 or higher and responded affirmatively to leaking urine most often "when performing some physical activity such as coughing, sneezing, lifting, or exercise" (from the 3-IQ).⁶ For this ancillary analysis, we categorized anatomic prolapse as maximum vaginal descent to or beyond the hymen (ie, ≥ 0 cm), no prolapse as above the hymen (< 0 cm), and symptomatic prolapse as a positive response to the prolapse question on the Epidemiology of Prolapse and Incontinence Questionnaire ("Do

you have a sensation that there is a bulge in your vagina or that something is falling out from your vagina?”).

We considered a participant to have complete knowledge if she stated that she knew the meaning of all 3 terms, incomplete knowledge if she knew 1 to 2 terms, and no knowledge if she knew none of the terms.

Analysis was primarily descriptive. We based our sample size on an assumption that at least 20% of women would have complete knowledge of the terms; to assess the independent effect of up to 5 variables in a logistic regression model, our minimal sample size was 200. We included all eligible women for this ancillary study enrolled at the time of data analysis ($n = 376$). Continuous variables were analyzed using t tests and categorical variables using χ^2 . Multiple logistic regression models were constructed to assess independent effects of parity, age, education, and presence of pelvic floor symptoms on knowledge outcomes. We considered associations significant if $P < 0.05$.

RESULTS

The first 376 women meeting the inclusion criteria above recruited into the larger cross-sectional study made up our study population for this ancillary analysis. Women had a mean age of 50.4 years (SD, 7.0 years; range, 38–68 years); 350 (92.0%) described themselves as white, 14 (3.7%) as Hispanic, and 12 (3.2%) as Asian. Fifty-five percent were college graduates or had completed a graduate or professional degree and 45% had not completed college. Three hundred six (81%) were parous. The mean parity of the population was 2.3 (SD, 1.8; range, 0–12).

Seventy-two (19%) met our criteria for SUI. One hundred (27%) had POP with maximal vaginal descent of 0 cm or greater, whereas 41 (11%) reported symptomatic prolapse.

Ninety-three (25%) had complete knowledge, 214 (57%) had incomplete knowledge, and 67 (18%) had no knowledge of the 3 terms. Overall, 300 (80%) reported knowing what the term urinary incontinence meant, whereas 195 (52%) knew the term pelvic organ prolapse and 102 (27%) knew the term pelvic floor disorder.

Women with SUI were more likely to know the term “urinary incontinence” than were women without, although this was not statistically significant (63/72 women [88%] with SUI vs 237/304 [78%] without SUI, $P = 0.07$). Women with POP on examination were more likely to know the term pelvic organ prolapse (64/100 [64%] with POP vs 131/276 [47%] without POP, $P = 0.005$), as were women with the symptom of vaginal bulge (31/41 [76%] with bulge symptom vs 164/335 [49%] without, $P = 0.001$). However, women with SUI were not more likely to know the term POP than women without SUI; similarly, women with POP were not more likely to know the term SUI than women without POP. Compared with women without POP, women with POP were more likely to know the term pelvic floor disorder (42/100 [42%] with POP vs 60/276 [22%] without POP, $P = 0.0001$). However, no such difference was seen in women with SUI (19/72 [22%] with SUI vs 83/304 [28%] without SUI, $P = 0.81$).

Education and symptom of a vaginal bulge were the only factors evaluated associated with complete knowledge of the 3 terms. Of the 206 women who completed college, 61 (30%) reported complete knowledge compared with 31 (18%) of 170 who did not complete college ($P = 0.013$). Race/ethnicity, age, and being parous were not associated with complete knowledge, nor was having a pelvic floor disorder. In separate models, after adjusting for age, parity, and presence of pelvic floor symptoms, education was also associated with knowing the term POP (odds ratio [OR], 2.2; 95% confidence interval [CI], 1.4–3.5) and

pelvic floor disorder (OR, 2.1; 95% CI, 1.3–3.4) but not UI. Endorsing the symptom of vaginal bulge was associated with knowledge of all 3 terms when age, parity, and education were adjusted (OR, 4.3; 95% CI, 2.0–9.3).

DISCUSSION

Overall, only one fourth of women in our study understood the term pelvic floor disorder and half understood the term pelvic organ prolapse. Most reported knowing what UI means. This suggests that public awareness campaigns or Internet search strategies directed at pelvic floor disorders are not likely to catch the attention of most women.

There has been little research about health literacy in uro-gynecology. Greater literacy is expected as formal education rises. Although true in our study, it is remarkable that fewer than one third of women with at least a college degree reported knowing what all 3 terms meant.

We do not know how women obtained the knowledge they had. It is likely that they accrue knowledge from several sources, including friends and family, magazines and newspapers, advertising, direct medical education, and health care providers. In our population, women with symptoms of POP or SUI were more likely to understand the terms pelvic organ prolapse and urinary incontinence, respectively, but they were not more likely to understand the term associated with symptoms they did not endorse. Symptoms likely drive women to seek knowledge and to improve health literacy to understand these symptoms.

Although knowledge of terms (the focus of this study) is an important first step to achieving health literacy, comprehension of terms is needed to allow patients to make informed decisions about their health. After explaining what the terms urinary incontinence and pelvic organ prolapse meant (“loss of urine or leaky bladder,” “bulging of the vagina, uterus, bladder, or rectum”), Shah et al⁷ administered a 24-item questionnaire about knowledge of UI and prolapse and found that most women answered fewer than 80% of UI questions and fewer than 50% of POP questions correctly. This suggests that both lack of knowledge about the meaning of terms, found in our study, and lack of knowledge about symptoms themselves, found in the study of Shah et al, affect comprehension. Limited comprehension impairs patients’ autonomy over their care and creates barriers to obtaining informed consent. Future research should focus on both knowledge and comprehension of concepts related to pelvic floor disorders.

Our study provides a glimpse into the underresearched area of health literacy in urogynecology. Strengths of the study include the large sample selected among women attending primary care-level gynecologic clinics. Although this obviously limits the generalizability of our findings, we suspect that our results are a best-case scenario representing largely educated women with access to health care. Thus, a more real-life population is likely to have an even poorer understanding of these urogynecologic terms. It is possible that younger or older women outside our study’s age range have a different understanding of terms, but our age range does represent women likely to seek treatment of pelvic floor disorders. When women stated that they knew what each term meant, we did not validate this knowledge; actual knowledge may, therefore, be less than reported. Finally, our population did not include women with fecal incontinence or urgency UI, and thus, our study does not reflect the full spectrum of pelvic floor disorders.

Given that 1 in 4 women endorses symptoms of moderate to severe pelvic floor disorders, improving health literacy in this area is a crucial step to improving the care that women seek and receive. Urinary incontinence now seems to be part of daily language for most women,

but major educational efforts are needed to bring POP and pelvic floor disorders into the common vernacular.

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