GYNECOLOGY

Bridging the gap: determinants of undiagnosed or untreated urinary incontinence in women

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BACKGROUND: More than a third of middle-aged or older women suffer from urinary incontinence, but less than half undergo evaluation or treatment for this burdensome condition. With national organizations now including an assessment of incontinence as a quality performance measure, providers and health care organizations have a growing incentive to identify and engage these women who are undiagnosed and untreated.

OBJECTIVE: We sought to identify clinical and sociodemographic determinants of patient-provider discussion and treatment of incontinence among ethnically diverse, community-dwelling women.

STUDY DESIGN: We conducted an observational cohort study from 2003 through 2012 of 969 women aged 40 years and older enrolled in a Northern California integrated health care delivery system who reported at least weekly incontinence. Clinical severity, type, treatment, and discussion of incontinence were assessed by structured questionnaires. Multivariable regression evaluated predictors of discussion and treatment.

RESULTS: Mean age of the 969 participants was 59.9 (±9.7) years, and 55% were racial/ethnic minorities (171 black, 233 Latina, 133 Asian or Native American). Fifty-five percent reported discussing their incontinence with a health care provider, 36% within 1 year of symptom onset, and with only 3% indicating that their provider initiated the discussion. More than half (52%) reported being at least moderately bothered by their incontinence. Of these women, 324 (65%) discussed their incontinence with a clinician, with 200 (40%) doing so within 1 year of symptom onset. In a multivariable analysis, women were less likely to have discussed their incontinence if they had a household income $<$ \$30,000/y vs $\geq$ \$120,000/y (adjusted odds ratio [AOR], 0.49, 95% confidence interval [CI], 0.28–0.86) or were diabetic (AOR, 0.71, 95% CI, 0.51–0.99). They were more likely to have discussed incontinence if they had clinically severe incontinence (AOR, 3.09, 95% CI, 1.89–5.07), depression (AOR, 1.71, 95% CI, 1.20–2.44), pelvic organ prolapse (AOR, 1.98, 95% CI, 1.13–3.46), or arthritis (AOR, 1.44, 95% CI, 1.06–1.95). Among the subset of women reporting at least moderate subjective bother from incontinence, black race (AOR, 0.45, 95% CI, 0.25–0.81, vs white race) and income $<$ \$30,000/y (AOR, 0.37, 95% CI, 0.17–0.81, vs $\geq$ \$120,000/y) were associated with a reduced likelihood of discussing incontinence. Those with clinically severe incontinence (AOR, 2.93, 95% CI, 1.53–5.61, vs low to moderate incontinence by the Sandvik scale) were more likely to discuss it with a clinician.

CONCLUSION: Even in an integrated health care system, lower income was associated with decreased rates of patient-provider discussion of incontinence among women with at least weekly incontinence. Despite being at increased risk of incontinence, diabetic women were also less likely to have discussed incontinence or received care. Findings provide support for systematic screening of women to overcome barriers to evaluation and treatment.

Key words: comorbidity, health care delivery, socioeconomic factors, urinary incontinence, women

More than a third of middle-aged and older women suffer from urinary incontinence,[1] a condition leading to depression, social isolation, falls and fractures, and admission to long-term care facilities.[2-5] Despite the burden of this condition, up to half of women with incontinence in the community do not discuss it with a health care provider.[6,7] Currently little is known about why so many women with incontinence go undiagnosed and untreated.[8]

To date, studies investigating barriers to diagnosis and treatment have tended to focus on the role of incontinence-specific factors such as severity and type of incontinence.[6,9-11] Nevertheless, a variety of other factors may influence whether women obtain treatment, including comorbid conditions that may take precedence over incontinence, complicate the clinical course of incontinence, or interfere with incontinence management.[12,13] Furthermore, sociodemographic factors may influence whether women obtain treatment independent of whether they have access to care.

With national organizations now including assessment and treatment of incontinence as a quality performance measure,[14] health care organizations have a growing incentive to identify and engage patients with incontinence. To provide additional insight into the underdiagnosis and undertreatment of incontinence, we examined determinants of patient-provider discussion of incontinence and treatment utilization among ethnically diverse women enrolled in an integrated health care system, all of whom had a primary care provider and access to care.

Materials and Methods

Participants and setting

This research was conducted within an observational study of risk factors for urinary tract dysfunction in middle-aged and older women, the Reproductive Risks of Incontinence Study at Kaiser (RRISK). Details about the methods used to construct the cohort have been reported previously.[15-17] Briefly, participants were women aged 40–80 years enrolled in Kaiser Permanente Northern

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California (KPNC), an integrated health care delivery system serving approximately 30% of the northern California population.

Because the original goal of the RRISK study was to examine the effect of childbirth on incontinence risk, women had to have been continuously enrolled in KPNC since the age of 21 years and to have given birth to at least half their children within the KPNC system to facilitate abstraction of obstetric records.

Women were sampled from within race/ethnicity strata to ensure an overall composition of 20% black, 20% Latina white, 20% Asian or Native American, and 40% non-Latina white women. For the second and third data waves of RRISK (RRISK2, 2003–2008; and RRISK3, 2008–2012), 20% of participants were also recruited from the KPNC Diabetes Registry to ensure robust participation by diabetic women.[18]

For this study, analyses focused on participants who reported at least weekly incontinence during either RRISK2 or RRISK3, the 2 waves in which detailed information about patient-provider discussion of incontinence and treatment utilization were collected (n = 969). For those reporting at least weekly incontinence during both waves, data from the most recent wave were used to capture their cumulative experience with seeking and undergoing treatment. All data were collected through clinic- or home-based study visits, and informed consent was obtained at the time of data collection. All procedures were approved by the Institutional Review Boards of the University of California, San Francisco, and Kaiser Permanente Division of Research.

Measurements

Frequency, severity, and clinical type of incontinence were assessed using structured-item questionnaire measures previously validated against a detailed 7 day voiding diary.[15] Participants were asked, "During the past 12 months, on average, how often have you leaked urine, even a small amount?" Women reporting at least weekly leakage were then asked to clarify the frequency and average amount of urine loss per episode.

The validated Sandvik Severity Scale was used to classify clinical incontinence severity as low moderate, high moderate, or severe based on frequency and amount of urine lost per episode.[19] Participants were also asked to indicate the level of bother associated with their urine loss, with the response options including not at all, slightly, moderately, quite a bit, and extremely.

Clinical type of incontinence was assessed by asking women to distinguish leakage occurring when they felt the urge to urinate but could not reach a bathroom in time (urgency incontinence) from leakage occurring when they laughed or coughed or during physical activities (stress incontinence). Women with a majority of stress-type episodes in the past 7 days were classified as having stress-predominant incontinence; those with majority urgency-type were considered as having urgency-predominant incontinence. Women reporting a combination, with neither type comprising the majority, were considered to have mixed incontinence. If the majority of the episodes occurred without activity or urgency, the label of other-type incontinence applied.

Among women with weekly incontinence, interviewer-administered questionnaires assessed patient-provider discussion and treatment of incontinence. Women were first asked, "Have you ever discussed your urine leakage with your doctor or health care provider?" Those who replied affirmatively were asked who initiated the discussion; how long they had experienced symptoms prior to discussion; and the types of providers involved, including primary care, specialist (gynecologists and more), and allied health professionals.

Women who denied discussing their leakage were asked to indicate their primary reason from a list derived from past qualitative research,[20-23] including the following: preferring to manage leakage on their own or tending to put up with leakage; considering incontinence to be a small or insufficiently bothersome problem; believing incontinence to be a normal part of aging; not knowing what help was available or where to seek it; being too embarrassed to discuss their leakage; not wanting to bother their provider; or not wanting examinations, tests, or surgery.

Women who reported discussing incontinence were asked about treatments recommended by their provider for this condition. Pharmacological treatments included antimuscarinics, antispasmodics, tricyclic antidepressants, phenazopyridine, and vaginal estrogen. Behavioral treatments included timed voiding, pelvic floor exercises, and biofeedback. Surgical/invasive treatments included retropubic suspension, retropubic or abdominal sling, tension-free vaginal tape, needle suspension, anterior or cystocele repair, anterior colporrhaphy and urethropexy procedures.

Using questionnaires, patients identified comorbid health conditions providers had diagnosed them with from a list of conditions prior research has linked with incontinence. These included cardiometabolic (myocardial infarction, angina, other coronary heart disease, diabetes mellitus, hypertension), gynecological (pelvic organ prolapse, endometriosis), neuropsychiatric (stroke, Parkinson's disease, depression), respiratory (asthma, chronic obstructive pulmonary disease), gastrointestinal (irritable bowel syndrome, inflammatory bowel disease), musculoskeletal conditions (arthritis), and cancer.[24,25]

Diabetes diagnosis was further confirmed using data from the KPNC Diabetes Registry, which contains abstracted clinical records indicating the use of a glycemic control medication or serial fasting blood glucose greater than 125 mg/dL. Comorbid conditions with a minimum prevalence of 5% in the study population were included in analyses.

Other sociodemographic characteristics were also assessed by a self-administered questionnaire. Participants were asked to self-identify as non-Latina white/Caucasian, Latina/Hispanic, African American/black, Asian American/Asian, or Native American. They reported their highest level of educational attainment up to completion of graduate or professional school. Household income for the past 12 months was reported in $30,000 increments; income levels were then consolidated into 3 categories: < $30,000 (less than half the area median