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Knowledge Of Urinary Incontinence And Pelvic Organ Prolapse In Community-Dwelling Women

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Knowledge of Urinary Incontinence and
Pelvic Organ Prolapse in Community-dwelling Women

A Thesis Submitted to the
Yale University School of Medicine
In Partial Fulfillment of the Requirements for the
Degree of Doctor of Medicine

by
Charisse Laura Mandimika
2014

KNOWLEDGE OF URINARY INCONTINENCE AND PELVIC ORGAN PROLAPSE IN COMMUNITY-DWELLING WOMEN.

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Urinary incontinence (UI) and pelvic organ prolapse (POP) are common, costly and debilitating problems that have a known negative impact on women's quality of life. Our study assessed women's baseline knowledge, demographic factors associated with a lack of knowledge, and specific areas of knowledge deficiency about UI and POP among White, African American (AA), and Other Women of Color (OWOC), a group comprised of Hispanic, Asian and Other women. This community-based, cross-sectional survey of 431 racially and socioeconomically diverse women aged 19-98 years used the validated Prolapse and Incontinence Knowledge Questionnaire to assess participants' knowledge. Primary endpoints were the total number of correct responses on the UI and POP scales respectively. Percentages of individuals achieving knowledge proficiency about UI (>80% correct) and POP (>50% correct) and demographic factors that predicted a lack of knowledge proficiency were explored as secondary outcomes. A sub-analysis evaluated associations between areas of knowledge lacking proficiency (etiology, diagnosis and treatments) and race/ethnicity. The average number of correct responses was 6.7 ± 3.7 (55.8% \pm 30.8%) for UI knowledge and 5.5 ± 3.5 (45.8% \pm 29.2%) for POP knowledge. Overall, 28.8% and 51.9% achieved knowledge proficiency in UI and POP respectively. AA women and OWOC demonstrated significantly less knowledge about UI and POP than White women, both before and after adjustment for age, education, and household income. Specific areas of deficiency for AA and OWOC were UI and POP etiology and POP treatments. Most women who reported symptoms of UI had not received treatment for their problems. There is a global lack of knowledge about UI and POP among community-dwelling women, with more pronounced knowledge gaps among AA and OWOC. UI and POP are chronic medical conditions that should be included in routine screening questions for well-woman care.

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INTRODUCTION

Background

The pelvic floor is a term used to collectively describe the muscles, ligaments and connective tissue supporting the pelvic organs—bladder, urethra, uterus, cervix, vagina, intestines, rectum and anus. Pelvic floor disorders (PFD) are a broad category of disorders in the gynecologic, lower urinary and gastrointestinal tract that affect the structure and/or function of organs in the female pelvis. The three most prevalent PFD are urinary incontinence (UI), fecal incontinence (FI) and pelvic organ prolapse (POP). In 2008, data from the National Health and Nutrition Examination Survey (NHANES) found that approximately 23.7% of women 20 years or older in the United States suffer from at least one of the three most prevalent PFD (1). The incidence of PFD increases substantially with age. With the rapidly growing aging population, the prevalence of American women with PFD is projected to exponentially increase over the next 40 years, making PFD a major public health concern (2-4).

In addition to the bothersome physical symptoms associated with PFD, women with PFD suffer significant emotional distress, including depression, loss of self-esteem and social isolation (5), with proven negative effects on their overall wellbeing and quality of life. In elderly populations, UI is often presented as a risk factor for urinary tract infections, disability, functional and cognitive decline, institutionalization and mortality, especially after cardiovascular events (6, 7). In spite of this, there remains limited public awareness about these problems and current statistics may underreport PFD prevalence and

incidence. Women are often too embarrassed to seek help and instead suffer silently with their symptoms (7-17), the well-known 'iceberg' phenomenon. This body of work focuses specifically on UI and POP.

Urinary Incontinence Overview

Urinary incontinence (UI) is defined as an involuntary loss of urine. The two most common types of incontinence are urgency urinary incontinence and stress urinary incontinence. Urgency Urinary incontinence (UUI) is characterized by loss of bladder control associated with the sudden or pressing need to urinate. This is often associated with increased daytime voiding frequency and nocturia. Stress urinary incontinence (SUI) is the involuntary loss of urine during physical exertion including but not limited to laughing, coughing, sneezing or lifting. While UI affects individuals of all ages, the prevalence increases with age, making it most common among elderly persons (1, 18). Other important risk factors for UI include childbearing, obesity, and decreased level of physical activity (19).

Several treatment options exist for UI. Conservative therapy consists of dietary and behavioral modifications, and has been found to be efficacious without posing added risk or cost (20). Dietary changes focus on weight loss, restricting caffeinated beverages and other bladder irritants, smoking cessation, as well as modifying timing and type of fluid intake. Behavioral modifications include bladder retraining and pelvic floor muscle exercises also known as Kegel exercises (20, 21). Non-surgical therapies such as biofeedback and pelvic neuromodulation are also efficacious treatment options (3, 21).

Bladder reflexivity is mediated by the cholinergic activation of muscarinic receptors. Consequently, medical management with anticholinergic agents has become the treatment of choice to counteract the effects of UUI (22). Conservative treatments are also successful in improving symptoms of SUI; however, when conservative treatments fail, surgery has been found to offer efficacious outcomes and provide curative treatment for many women (23, 24).

Pelvic Organ Prolapse Overview

Pelvic organ prolapse (POP) is characterized by the descent of the pelvic organs from their normal anatomical position down the vaginal canal, and results from the weakening of the pelvic floor support muscles, ligaments and connective tissue (25-27). POP is diagnosed by examination and quantified using the Pelvic Organ Prolapse Quantification (POP-Q) assessment tool (28). Classification is based on the location of the defect: anterior vaginal prolapse or cystocele is the descent of the vaginal wall overlying the bladder; posterior vaginal prolapse or rectocele refers to a bulge in the back wall of the vagina that overlies the rectum; apical or uterine prolapse describes descent of the uterus and/or cervix; and lastly, vaginal vault prolapse refers to the descent of the vaginal cuff in women who have undergone a hysterectomy. Patients often present with symptoms such as pelvic heaviness, feelings of a bulge, lump or protrusion from the vagina, difficulty in emptying their bladder (i.e. slow stream, hesitancy or difficulty initiating urination), problems with defecation and/or sexual dysfunction. With advanced stages of POP, urinary retention or inability to evacuate the rectum can occur resulting in women frequently having to insert their fingers into their vagina in order to void or defecate.

POP may affect women of any age, however, incidence increases proportionally with age (1). Prevalence estimates differ, in part, due to varying definitions and inconsistencies between examination and symptom based diagnosis. A single vaginal delivery increases a woman's risk of having POP by 3-5 fold and this is thought to result from stretch injury to the support system and vaginal walls during labor and as the fetus passes through the vaginal canal (29). Other commonly reported risk factors include prior hysterectomy, chronic repetitive elevations of intra-abdominal pressure resulting from constipation, obesity, and chronic obstructive pulmonary disease, and connective tissue disorders. Heavy lifting also increases intra-abdominal pressure, and thus women with jobs where repetitive or extended periods of heavy lifting (couriers, nursing aids, laborers/factory workers) are required are more likely to develop POP (25, 30, 31).

Treatment options for women with symptomatic POP include observation, pelvic floor muscle exercises, the insertion of mechanical support devices such as pessaries, and surgery (26). Observation is typically used in asymptomatic or mildly symptomatic women. In women desiring conservative management, pelvic floor muscle exercises have been shown to prevent progression of and reduce symptoms associated with POP with no adverse effects (32-35). Silicone or latex rubber pessaries can be placed intravaginally to hold the pelvic organs in their normal anatomical position. Furthermore, surgical procedures can be done to restore pelvic floor support or to obliterate the vaginal canal and prevent the descent of the pelvic floor organs.

Racial Disparities in the Prevalence of Pelvic Floor Disorders

UI prevalence has consistently been shown to be affected by race and ethnicity (36-38). In an age-adjusted population-based cohort study of over 2000 randomly selected women aged 40-69 years, weekly UI was highest in Hispanic women, followed by White, African American and Asian American women respectively (36). Similar findings have been reported in other large population based studies (37, 38). It has also been noted that types of incontinence differ among racial and ethnic groups. White women have an increased risk of SUI when compared to African American and Asian-American women, while UUI tends to be more prevalent in African American women (36-41).

Consensus is lacking regarding the influence of race on POP prevalence. Genetic factors that may result in anatomic and physiologic variations in pelvic floor neuromuscular function and collagen synthesis are thought to influence POP development (42). Consistent with this, several studies have shown that African American women demonstrate the lowest risk for POP (29, 43), and that symptomatic POP is more prevalent among Asian and Hispanic women compared with African American and White women (43, 44).

In contrast, however, other investigators have reported no difference in POP prevalence between racial or ethnic groups in an equal access healthcare system (40). This has led some to postulate that disparities in PFD prevalence are related to access to and utilization of care, and are consequently influenced by women's knowledge, attitudes, and socioeconomic status (39, 45).

Economic Burden of PFD

PFD affect not just the patient, but their families, caregivers and society at large. UI and FI are among the main motivating factors for placing family members in nursing homes (5). The majority of economic data exists for UI. Expenditure in the U.S. exceeds 12 billion dollars annually for the management and treatment of UI alone (direct annual costs) (46). The largest proportion of these costs (70%) are for routine care, including payment for absorbent pads, diapers, briefs, and protective skin care products (18, 47-49). These costs are disproportionately borne by elderly, community-dwelling women (50). Diagnosis and treatment costs account for only 10% of UI costs (46, 47). A 2003 study estimating the relative and absolute costs of lifetime medical costs of three common medical problems in women found that women with SUI have a total lifetime medical cost 1.8 times greater when compared with women without SUI (51).

Studies focusing on economic estimates for POP are much less prevalent. The current literature is largely based on the cost of surgery which provides an incomplete economic perspective for a number of reasons (52). Most importantly, this type of analysis negates women who choose conservative treatments such as observation or pessaries. It is estimated that approximately 355,000 POP surgeries are performed annually, a number comparable to other common surgeries on women such as cholecystectomies and appendectomies (53). Estimates of direct POP surgical costs alone exceed 1 billion dollars annually (53).

Care-Seeking Patterns and Attitudes Among Women with PFD

It is estimated that only between 18-50% of women with PFD seek care from health care providers, although therapies are available to treat or improve symptomology (9, 10, 12-15). Notably, women under 55 years of age have been found to be less likely to seek care than those over 55 years old (1). Approximately 27% of women between the ages of 20 and 39 have at least one PFD, while nearly 37% of women between the ages of 40 and 59 suffer from at least one PFD (1, 14). A population-based study showed that women with POP are more likely to seek care than women with UI, possibly due to the presence of more bothersome symptoms (14).

Overall Barriers to Care-Seeking for PFD

Both external and internal barriers to care-seeking behaviors have been identified among women with PFD (39). External barriers include factors such as convenience of consultation (e.g. too long a wait for an appointment), provider gender preference (e.g. female physician over male physician), and access to health care facilities (e.g. transportation unavailable, or distance to facility) (45). Women's expectations from their health care provider, language proficiency, incurred service cost (i.e. the cost of consultation) and perceptions of the medical encounter may also negatively affect a woman's decision to seek care (45).

Internal barriers primarily consist of attitudes and beliefs preventing care-seeking such as embarrassment, fear, or anxiety. Additionally, insufficient knowledge and misperceptions about PFD, are thought to represent the largest internal impediments to seeking care (7, 8,

10, 11, 16, 17, 54, 55). Compared to women who seek care, non care-seeking women are more likely to believe that PFD are a normal part of aging, and to report that they are unaware of available treatment options or that they fear the need for invasive procedures (7, 8, 10, 15, 16). Moreover, many women do not consider UI symptoms to be a medical problem, and thus may not provide information about their symptoms to their providers unless specifically asked (17, 55). Collectively these findings suggest that there are several factors that can lead to women being undereducated about PFD and that the lack of education is negatively impacting their ability to seek care.

Provider Barriers to Care-seeking for PFD

Health care providers play a critical role in the recognition, accurate diagnosis and successful treatment of PFD. Many physicians are not adequately equipped to identify UI and POP, especially when patients do not overtly disclose what they deem as embarrassing symptoms. A number of studies have demonstrated that due to inadequate expertise or education in recognition of PFD, the likelihood of screening for or successfully treating PFD in the average primary care setting is low (56, 57). A survey of general practitioners cited pessimism about treatment success as a reason they fail to comply with recommendations for assessing and treating women with UI (58). These practitioners viewed a lack of patient motivation, particularly in the elderly, as one of the greatest barriers to symptomatic improvement. Time limitations were also seen a major obstacle, especially in women who have numerous comorbid conditions. Additionally patients may perceive, perhaps falsely, that physicians and other health care providers

have negative attitudes towards discussing or managing PFD (17, 56). Invariably, many women are unsure about discussing PFD with their doctors.

Knowledge as a Barrier to Care-seeking for PFD

Few studies have been done to determine women's knowledge about PFD. In 2008, Shah et al. validated a questionnaire that can be used evaluate women's knowledge about UI and POP (59). This tool was tested on women routinely seen in a gynecology practice and women presenting to a urogynecology specialist. The authors confirmed that women who were presenting to a urogynecologist with pelvic floor complaints had significantly higher scores or greater baseline knowledge about PFD than women presenting for routine gynecology visits. They also found that education level was associated with UI knowledge but not POP knowledge and that overall POP knowledge was lower than knowledge about UI. The authors attributed barriers to treatment for UI to inadequate knowledge about UI and available treatment options. This was the first conclusive study suggesting that patient education around POP and UI may be lacking. While this information was valuable, it limited our knowledge to a subset of women who were already connected to the healthcare system and those who had already been identified as having a problem. Additionally, the mean age of the women in one cohort was 35 years, and thus the findings might not be generalizable to older women who have sought care for PFD.

Racial Disparities in Knowledge

The U.S. population continues to become increasingly more racially and ethnically diverse. Approximately 36 percent of the population consider themselves a racial and/or ethnic minority. White race has been associated with improved knowledge about UI, although race has not been found to affect POP knowledge scores (41). Additionally, there is limited data about Hispanic and Asian women's knowledge of PFD.

A 2011 qualitative study by Hatchett et al. used focus groups consisting of 32 African American and Hispanic women to explore knowledge, barriers to care-seeking and perceptions of PFD (60). The three major themes emerging from this study centered on low knowledge, information needs, and sociocultural barriers. Women had significant knowledge gaps with regards to PFD, as well as general misconceptions. There was also a demonstrated high demand for information in understandable terminology and social forums for PFD. Lastly, previously identified external barriers such as health insurance were perceived as a barrier for care-seeking among the women who were evaluated.

STATEMENT OF PURPOSE

The current evidence suggests that women's knowledge about UI and POP is limited.

Moreover, the current body of evidence suggests that differences in knowledge about UI might fall along racial and socioeconomic status lines. In order to enhance the paucity of existent literature, further studies are necessary to assess knowledge deficiencies among a broad range of women about PFD.

The study hypotheses were:

1. Community-dwelling women have low knowledge proficiency of both UI and POP.
2. Racial and ethnic differences in proficiency of UI and POP exist among community-dwelling women.

The aims of this study were three-fold:

1. To assess knowledge proficiency of UI and POP in a racially, ethnically, and socioeconomically diverse population of community-dwelling women.
2. To identify demographic factors associated with lack of knowledge proficiency.
3. To assess areas of disproportionate knowledge about UI and POP among women of color compared to White women.
4. To evaluate for disparities in care-seeking.

METHODS

Summary of contributions

Research design: Mandimika, Guess

Questionnaire distribution and data collection: Mandimika, Guess, Wedderburn, Wentworth, Barlow

Data entry: Mandimika, Wedderburn, Wentworth, Barlow

Statistical analysis: Murk

Data interpretation: Mandimika, Murk, Guess, Connell, Collier, McPencow, Lake

Study population and design

We conducted a cross-sectional written survey of women's knowledge of UI and POP in New Haven County, Connecticut from February 2010 to August 2011. The study was reviewed and granted exemption status by the Yale University Human Subjects Committee prior to initiation. Women aged 18 years and older were invited to participate by one of five study investigators at events free and open to the public. Potential venues were identified from advertisements in newspapers, local banners, billboards, and word of mouth. Venues were selected based on event location (within New Haven County), anticipated number (> 50) and racial and ethnic diversity of attendees, as well as ease of access (walking or public transportation). These included two women's health conferences (n = 81, 18.8 %), five summer outdoor concerts or arts events (n = 213, 49.4 %), one outdoor sports event (n = 33, 7.7 %), two senior centers (n = 58, 13.5 %), and other or missing location data (n = 46, 10.7%). No selective outreach strategies were employed to identify low-income populations. Women were approached and asked to

complete a survey on women's health. Each packet included a cover sheet explaining that this was a research study about an important women's health care issue and a copy of the unmodified Prolapse and Incontinence Knowledge Questionnaire (PIKQ) (59). Those agreeing to participate were asked to place completed surveys in a covered box or opaque envelope. The study was limited to English-speaking women as a validated Spanish version of the questionnaire was not available at the time of the study. Age was confirmed by direct inquiry at the time of distribution. Women reporting ever having completed the survey were excluded. Questionnaires were self-administered and no personal identifiers were required.

Study measurements and outcomes

Participants' knowledge about UI and POP was assessed by the previously validated PIKQ (59), a 24-item questionnaire that includes 12 questions focused on UI knowledge (UI scale) and 12 questions focused on POP knowledge (POP scale). Each scale assessed patient knowledge in relation to the epidemiology, pathogenesis, diagnosis and treatment of the two conditions. Each question had three possible responses: "yes", "no", and "I don't know" (59). The PIKQ is illustrated in Figure 1. As per the original scoring criteria, 1 point was given for each correct response and no points were given for incorrect responses, blank responses or for the response "I don't know". The primary endpoints were the total UI and POP scale scores, defined as the sum of the total number of correct responses, with a maximal score of 12 for each scale. UI and POP questions were also evaluated as individual items, as well as by the type of knowledge reflected-etiology,

diagnosis and treatment (Figure 1). The percentages of individuals answering each item or group of items correctly were explored as secondary outcomes.

Demographic information obtained included age, race, categorized as Hispanic, White (non-Hispanic), African American, Asian and Other, parity, menopausal status, marital status, yearly household income and highest level of completed education. Questions about whether or not participants had a job in the medical field, had ever experienced prior problems with UI and/or POP, had ever seen a urologist or urogynecologist, and whether or not they had ever received treatment(s) for UI or POP were also included. This information was used to assess factors that could positively or negatively influence total UI and POP scale scores. Proficiency was defined as scores $\geq 80\%$ on the UI scale and $\geq 50\%$ on the POP scale, based on frequency data from the original authors showing that this represented higher-than-usual knowledge for the stated scales (41).

Statistical analysis

Questionnaire data were manually entered into a Microsoft[®] Excel[®] database (Microsoft Excel 2007) with verification and variables examined for implausible values, missing data and deviations from normality. Demographic data were presented as means \pm SD and/or percentages. Unadjusted and adjusted odds ratios (ORs) with 95% confidence intervals (CIs) were calculated for the odds of lacking UI or POP proficiency ($< 80\%$ and $< 50\%$ correct scale scores, respectively). For the adjusted ORs, multivariate models were constructed using logistic regression and backwards variable elimination, starting from a model containing all covariates listed in Table 2 as predictors (except for UI% correct

and POP% correct), and using $P \geq 0.05$ as the criterion for elimination from the model.

Since age, race, household income, and education may be potentially important confounders, they were retained in the models even if they were not significantly associated with the outcomes. The adjusted ORs are presented for variables that were retained in the final model, adjusted for each of the other variables that were maintained.

To assess the presence of multicollinearity among all of the variables included in the models, variance inflation factors (VIFs) were determined, and a $VIF > 5$ was considered to be indicative of high multicollinearity. Among all of the model variables, the highest VIF value observed was 2.35. Thus, we concluded that multicollinearity among the variables was not strong enough to warrant corrective action in the modeling.

Calculations were performed using SAS 9.1 (SAS Institute; Cary, NC). Statistical significance was defined as $P < 0.05$.

In a secondary analysis to further evaluate racial disparities in knowledge, racial/ethnic groups were divided into White, African American and Other Women of Color (OWOC) [consisting of Hispanic, Asian and Other due to the small subject size of those individual groups]. Due to the overall lack of knowledge in our cohort, knowledge proficiency was redefined as a UI score $> 50\%$ for this analysis. Consistent with the first analysis, a score $> 50\%$ was used to define POP proficiency in the secondary analysis. Unadjusted and adjusted odds ratios (ORs) with 95% confidence intervals (CIs) were calculated for the odds of lack of knowledge proficiency by question type, where proficiency for each question type was defined as correctly answering at least 3 out of 5 UI-etiology questions, 1 out of 2 UI diagnosis questions, 3 out of 5 UI treatment questions, 3 out of 6 POP

etiology questions, 1 out of 2 POP diagnosis questions, or 2 out of 4 POP treatment questions. ORs were also calculated for the odds of correctly answering each individual scale question and the odds of answering “yes” on a question related to care-seeking. Models were constructed using logistic regression and including race/ethnicity (AA, OWOC, White) as the main variable of interest. For the adjusted ORs, multivariate models were constructed by including age, household income, education, working in a medical field, marital status, and a reported history of problematic urine leakage or POP. In the analysis of care-seeking, a reported history of problematic urine leakage or POP were not included in the models. Calculations were performed using SAS 9.3 (SAS Institute; Cary, NC). Statistical significance was defined as $P < 0.05$.

RESULTS

Knowledge about UI and POP among the study population

Overall, 431 subjects were enrolled. Table 1 provides demographic data for the study participants. One subject (0.2%) did not complete the UI scale, while 13 subjects (3.0%) did not complete the POP scale. These subjects were excluded from the respective UI or POP analyses. All subjects, however, completed at least the UI or POP questionnaire, and thus were retained in the overall study. Based on the type of events from which we recruited participants, and our method of questionnaire distribution, we did not have the ability to accurately determine our response rate.

Table 1. Subject demographics (total N=431).

Age, years	
mean \pm SD	49.2 \pm 17.9
19-29, N (%)	61 (14.7%)
30-39	74 (17.8%)
40-49	82 (19.8%)
50-59	88 (21.2%)
60-69	45 (10.8%)
70-79	34 (8.2%)
> 79	31 (7.5%)
Race, N (%)	

White	266 (63.9%)
Hispanic	26 (6.3%)
African American	93 (22.4%)
Asian	13 (3.1%)
Other	18 (4.3%)
Marital Status, N (%)	
Not currently married	224 (53.5%)
Currently married	195 (46.5%)
Parity	
Mean \pm SD	1.6 \pm 2.1
0, N (%)	152 (36.5%)
1	71 (17.1%)
2	100 (24.0%)
3	53 (12.7%)
> 3	40 (9.6%)
Menstrual status, N (%)	
Still having periods	203 (50.1%)
Near menopausal	38 (9.4%)
Menopausal	164 (40.5%)

Work in a medical field, N (%)	
No	297 (71.7%)
Yes	117 (28.3%)
Household income, N (%)	
< \$10,000	33 (8.8%)
\$10,000 - \$49,000	100 (26.5%)
\$50,000 - \$100,000	156 (41.4%)
> \$100,000	88 (23.3%)
Education, N (%)	
8 th grade or less	10 (2.4%)
High school	82 (19.6%)
College	191 (45.7%)
Graduate school	135 (32.3%)
Ever seen a urologist/urogynecologist? N, (%)	
No	328 (78.7%)
Yes	89 (21.3%)
Ever had a problem with urine leakage? N, (%)	
No	282 (67.8%)
Yes	134 (32.2%)

Ever been treated for leakage of urine? N, (%)	
No	397 (95.4%)
Yes	19 (4.6%)
Ever had a problem with POP? N, (%)	
No	389 (94.0%)
Yes	25 (6.0%)
Ever been treated for POP? N, (%)	
No	401 (95.9%)
Yes	17 (4.1%)

Totals do not sum to N=431 due to missing data.

In total, 71.2% of subjects lacked UI proficiency (<80% correct), while 48.1% lacked proficiency in POP knowledge (<50% correct). The average scale score (number of correct responses) for UI knowledge among all subjects was 6.7 ± 3.7 (55.8% \pm 30.8%); the median and interquartile range (IQR) were 7 (58.3%) and 6 (50.0%), respectively. For POP knowledge, the average scale score was 5.5 ± 3.5 (45.8% \pm 29.2%); the median and IQR were 6 (50.0%) and 5 (41.7%), respectively.

Association between question type and baseline knowledge

The percentage of correct responses did not vary significantly between groups categorized according to the type of knowledge they represented ($P > 0.05$, for all comparisons). For UI, the lowest scores were for questions regarding diagnosis (mean % correct 55 ± 40 %), while the highest scores were for questions regarding treatment (58 ± 38 %). For POP, the lowest scores were for questions regarding etiology (mean % correct 45 ± 32 %), and treatment (45 ± 35 %), while the highest scores were for questions regarding diagnosis (50 ± 40 %).

Factors associated with UI or POP knowledge

To assess whether UI or POP knowledge varied by subject demographics, univariate analyses were conducted (Table 2). The odds of lacking UI proficiency were significantly higher among subjects who lacked POP proficiency, were of age > 79 years (vs. 19-29 years), were African American (vs. White), had >3 children (vs. none), had a household income of \$10,000 - \$49,000 (vs. $> \$100,000$), and had a high school or college education (vs. graduate school education). In contrast, subjects who worked in a medical field had significantly lower odds of lacking UI knowledge proficiency, compared to those who did not.

Table 2. Unadjusted univariate analysis of factors associated with a lack of proficiency in UI or POP knowledge.

Stratum	Lack of Proficiency on UI Scale ^B (<80% correct)			Lack of Proficiency on POP Scale ^C (<50% correct)		
	%	OR	95% CI	%	OR	95% CI
Total	71.2	N/A		48.1	N/A	
UI % correct						
< 80%				61.3	8.97	5.16, 15.58 *
>= 80%				15.0	1.0	Ref
POP % correct						
< 50%	91.0	8.97	5.16, 15.59 *			
>= 50%	53.0	1.0	Ref.			
Age, years =						
19-29	68.8	1.0	Ref.	50.8	1.0	Ref
30-39	73.0	1.22	0.58, 2.58	46.6	0.84	0.43, 1.67
40-49	69.1	1.01	0.49, 2.08	49.4	0.94	0.49, 1.84
50-59	59.1	0.65	0.33, 1.30	37.6	0.58	0.30, 1.34
60-69	80.0	1.81	0.73, 4.49	36.6	0.56	0.25, 1.26
70-79	73.5	1.26	0.49, 3.20	47.1	0.86	0.37, 1.99
> 79	93.5	6.56	1.42, 30.35 *	79.3	3.71	1.33, 10.38 *
Race						
White	64.5	1.0	Ref.	42.5	1.0	Ref.
Hispanic	80.8	2.31	0.84, 6.32	61.5	2.17	0.95, 4.96
African American	83.9	2.86	1.56, 5.25 *	55.1	1.66	1.02, 2.70 *
Asian	100.0	N/E	N/E	53.8	1.58	0.52, 4.83

Other	77.8	1.92	0.62, 6.01	66.7	2.71	0.99, 7.44
Marital Status						
Not married	75.8	1.0	Ref.	48.2	1.0	Ref.
Married	67.2	0.65	0.43, 1.00	48.4	1.01	0.69, 1.49
No. children						
0	65.8	1.0	Ref.	42.6	1.0	Ref.
1	67.1	1.06	0.58, 1.94	41.4	0.95	0.54, 1.70
2	72.0	1.34	0.77, 2.32	52.6	1.50	0.89, 2.50
3	77.4	1.78	0.86, 3.67	54.7	1.63	0.87, 3.07
> 3	87.5	3.64	1.35, 9.85 *	54.0	1.59	0.77, 3.27
Menstrual status						
Still having periods	70.3	1.0	Ref.	48.8	1.0	Ref.
Near menopausal	65.8	0.81	0.39, 1.70	50.0	1.05	0.53, 2.10
Menopausal	74.4	1.23	0.77, 1.95	45.5	0.88	0.58, 1.34
Work in a medical field						
No	78.4	1.0	Ref.	57.2	1.0	Ref.
Yes	53.8	0.32	0.20, 0.51 *	23.9	0.24	0.14, 0.38 *
Household income						
< \$10,000	72.7	1.85	0.77, 4.43	48.5	1.51	0.67, 3.40
\$10,000 - \$49,000	80.8	2.92	1.51, 5.62 *	59.8	2.39	1.32, 4.33 *
\$50,000 - \$100,000	67.9	1.47	0.85, 2.52	42.5	1.19	0.69, 2.04
> \$100,000	59.1	1.0	Ref.	38.4	1.0	Ref.
Education						
8 th grade or less	70.0	1.56	0.39, 6.28	60.0	2.13	0.34, 13.22

High school	89.0	5.41	2.50, 11.71 *	66.2	2.07	1.08, 3.97 *
College	71.6	1.68	1.05, 2.68 *	44.4	1.02	0.63, 1.65
Graduate school	60.0	1.0	Ref	40.5	1.0	Ref.
<hr/>						
Ever seen a urologist/urogynecologist?						
No	70.6	1.0	Ref.	48.6	1.0	Ref.
Yes	73.0	1.13	0.67, 1.90	44.7	0.86	0.53, 1.38
<hr/>						
Ever had a problem with urine leakage?						
No	73.4	1.0	Ref.	50.5	1.0	Ref.
Yes	66.9	0.73	0.47, 1.15	42.2	0.71	0.47, 1.09
<hr/>						
Ever been treated for leakage of urine?						
No	71.2	1.0	Ref.	47.7	1.0	Ref.
Yes	73.7	1.13	0.40, 3.22	47.4	0.99	0.39, 2.39
<hr/>						
Ever had a problem with POP?						
No	71.4	1.0	Ref.	49.3	1.0	Ref.
Yes	64.0	0.71	0.31, 1.67	20.8	0.27	0.10, 0.74 *
<hr/>						
Ever been treated for POP?						
No	71.0	1.0	Ref.	48.5	1.0	Ref.
Yes	76.5	1.33	0.42, 4.16	29.4	0.44	0.15, 1.28
<hr/>						

UI-Urinary incontinence; POP-Pelvic Organ Prolapse; “%”- the percentage of subjects with low UI or POP knowledge within each stratum; OR-odds ratio; CI-confidence interval; N/E- not estimable due to 100% of subjects lacking proficiency; Ref-, referent stratum; *- P < 0.05

The odds of lacking POP proficiency were significantly higher among subjects who lacked UI proficiency, were of age > 79 years (vs. 19-29 years), were African American (vs. White), had a household income of \$10,000 - \$49,000 (vs. > \$100,000), and had a high school education (vs. graduate school education). Significantly lower odds of lacking POP proficiency were found among subjects who worked in a medical field, and among subjects who had ever had a problem with POP.

After adjustment for potential confounders, multivariate analysis (Table 3) of factors associated with a lack of proficiency in UI and POP knowledge showed that African American subjects remained significantly less likely to be proficient in both UI and POP knowledge compared to White women. Asian subjects reported lower UI knowledge than White women, but an odds ratio could not be calculated for this group due to all women having scores reflective of a lack of proficiency. Although racial backgrounds other than African American were not significantly associated with UI or POP proficiency individually, they showed relatively strong effect sizes (adjusted ORs greater than 2 or 3, except for “Other” in the case of UI proficiency). When OWOC (Hispanic, Asian, and Other) were analyzed as a collective group, compared to White women, OWOC had a 3.37 fold increased odds of lacking UI proficiency (95% CI: 1.41, 8.09) and 2.74 increased odds of lacking POP proficiency (95% CI: 1.29, 5.83), after adjustment (Table 3).

Table 3. Multivariate analysis of factors associated with knowledge of urinary incontinence (UI) or pelvic organ prolapse (POP).

Stratum	Lack of proficiency on UI scale (<80% correct)		Lack of proficiency on POP scale (<50% correct)	
	OR	95% CI	OR	95% CI
Age, years =				
19-29	1.0	Ref	1.0	Ref
30-39	1.65	0.67, 4.06	0.66	0.29, 1.54
40-49	1.30	0.53, 3.20	0.68	0.29, 1.61
50-59	0.87	0.36, 2.08	0.52	0.21, 1.28
60-69	2.37	0.80, 7.06	0.38	0.14, 1.05
70-79	0.73	0.23, 2.31	0.31	0.10, 0.97
>79	2.88	0.31, 26.89	2.53	0.42, 15.26
Household Income				
< \$10,000	1.47	0.44, 4.85	1.25	0.38, 4.11
\$10,000 - \$49,000	1.58	0.71, 3.54	1.44	0.64, 3.23
\$50,000 - \$100,000	1.12	0.60, 2.08	0.91	0.47, 1.75
> \$100,000	1.0	Ref	1.0	Ref
Education				
8 th grade or less	1.38	0.12, 15.94	0.41	0.05, 3.34
High school	2.68	1.08, 6.67 *	1.28	0.60, 2.77
College	1.39	0.81, 2.38	0.89	0.51, 1.53
Graduate school	1.0	Ref	1.0	Ref
Race				
White	1.0	Ref	1.0	Ref
Hispanic	3.05	0.91, 10.21	2.26	0.82, 6.26

African American	2.39	1.18, 4.87 *	1.99	1.07, 3.70 *
Asian	N/E	N/E	3.12	0.73, 13.41
Other	1.58	0.44, 5.68	3.41	0.93, 12.51
Work in a medical field				
No	1.0	Ref	1.0	Ref
Yes	0.38	0.22, 0.66 *	0.23	0.12, 0.41 *
Marital Status	Not retained in model.			
Not currently married			1.0	Ref
Currently married			1.77	1.02, 3.06 *
Ever had a problem with POP?	Not retained in model.			
No			1.0	Ref
Yes			0.07	0.01, 0.53 *

Multivariate models were constructed to estimate the adjusted odds ratios of lack of UI or POP knowledge proficiency, using backwards variable selection of all covariates listed in Table 1 (excluding UI or POP % correct as predictors) and with the requirement that age, household income, education, and race be retained in the models. †For UI knowledge, Asian subjects were excluded due to a non-estimable (N/E) odds ratio (as a result of 100% of those subjects having low UI knowledge.). ‡, Covariates retained in the final model are listed, together with their odds ratio estimates for lack of proficiency, adjusted for the other covariates listed in this table. *- P < 0.05. The multivariate analysis included N=347 (80.5%) subjects who had complete data available for all covariates.

Education level (high school vs. graduate school) remained associated with UI proficiency but not POP proficiency, and working in a medical field remained associated with higher proficiency on both scales. For POP, marital status (currently married vs. not) became significantly associated with lack of proficiency after adjustment, and ever having a problem with POP remained associated with proficiency.

Association between UI or POP symptoms, treatment and care-seeking

Approximately one-third of participants reported ever having a history of UI; however, only 4.6% of all women reported having ever been treated for this condition (Table 1). Additionally, women reported having ever had a problem with urine leakage were not more likely than those who did not report a problem with urine leakage to have seen a urologist/urogynecologist in the past (24.1% vs 19.6%, $p = .30$). Six percent of women reported ever having a problem with POP and 4.0 % of women reported having been treated for POP (Table 1). In contrast to women with UI, women who reported having ever had POP were also significantly more likely to have seen a specialist than women who did not report problems with POP (45.8% vs 19.2, $p=0.002$).

Racial disparities related to UI or POP knowledge

Models were constructed to evaluate the association between race/ethnicity and knowledge proficiency (Table 4, 5A and 5B). An analysis of the association between lack of knowledge proficiency and race/ethnicity by question type (etiology, diagnosis and treatment) showed that compared with White women, both African American and OWOC were significantly more likely to lack knowledge proficiency about both UI and POP etiology and POP treatment, both before and after adjustment for model covariates (Table 4). After adjustment, OWOC were significantly more likely to lack knowledge proficiency on questions about UI treatment compared to White women, while African American women did not show a significant difference in knowledge about UI treatment either before or after adjustment. The adjusted associations between race/ethnicity and incorrect response to individual PIKQ questions are provided in Table 5A and 5B.

Table 4. Unadjusted and adjusted associations between lack of knowledge proficiency and race/ethnicity, by question type

Question type	# of Questions	Race/Ethnicity	Median % of questions with incorrect responses	% Subjects not passing	Unadjusted		Adjusted	
					OR	95% CI	OR	95% CI
UI Etiology	5	AA	60.0	57.0	3.08	1.89, 5.01 *	2.99	1.67, 5.36 *
		OWOC	60.0	54.4	2.77	1.55, 4.97 *	3.49	1.74, 7.01 *
		White	40.0	30.1	Ref		Ref	
UI diagnosis	2	AA	50.0	28.0	1.05	0.62, 1.77	0.98	0.52, 1.88
		OWOC	50.0	29.8	1.15	0.61, 2.15	1.78	0.82, 3.83
		White	50.0	27.1	Ref		Ref	
UI treatment	5	AA	40.0	46.2	1.45	0.90, 2.34	1.17	0.65, 2.10
		OWOC	60.0	54.4	2.01	1.13, 3.58 *	2.33	1.17, 4.64 *
		White	20.0	37.2	Ref		Ref	
POP Etiology	6	AA	66.7	54.8	1.72	1.07, 2.77 *	2.16	1.20, 3.89 *
		OWOC	66.7	59.7	2.10	1.17, 3.75 *	2.94	1.43, 6.04 *
		White	50.0	41.4	Ref		Ref	
POP diagnosis	2	AA	50.0	29.0	1.02	0.61, 1.72	1.13	0.60, 2.14
		OWOC	50.0	28.1	0.98	0.52, 1.84	1.17	0.54, 2.51
		White	50.0	28.6	Ref		Ref	

POP treatment	4	AA	75.0	60.2	2.36	1.46, 3.82 *	2.55	1.40, 4.65 *
		OWOC	75.0	61.4	2.48	1.38, 4.46 *	3.02	1.47, 6.22 *
		White	50.0	39.1	Ref		Ref	

UI-urinary incontinence; POP-pelvic organ prolapse; AA-African American; OWOC-combined group of Hispanic, Asian and subjects identifying themselves as “other”; #-number; OR-odds ratio. Ref-referent stratum. *, P < 0.05. Refer to Figure 1 for specific questions included in each question type. This model was constructed to estimate the odds ratios of not passing, where a pass was defined as obtaining at least 50% of the total # of questions per question type (rounded up to the nearest whole number of questions). Adjusted analyses included the following covariates: age, household income, education, working in a medical field, marital status, ever had a problem with urine leakage, and ever had a problem with POP. The analysis included N=363 subjects who had complete information.

Table 5A. Adjusted associations between race/ethnicity and giving an incorrect response to individual PIKQ UI scale questions

Question	Race/ Ethnicity	% Incorrect	OR	95% CI
Women are more likely than men to leak urine	AA	64.5	2.90	1.62, 5.18 *
	OWOC	56.1	2.55	1.28, 5.10 *
	White	37.0	Ref	
It is not important to diagnose the type of urine leakage before trying to treat it	AA	54.8	1.46	0.83, 2.58
	OWOC	54.4	2.40	1.20, 4.81 *
	White	43.0	Ref	
Many things can cause urine leakage	AA	43.0	2.01	1.09, 3.70 *
	OWOC	40.4	2.48	1.19, 5.17 *
	White	23.4	Ref	
Certain exercises can be done to help	AA	34.4	1.97	1.06, 3.66 *

control urine leakage	OWOC	52.6	4.27	2.07, 8.81 *
	White	24.5	Ref	
Surgery is the only treatment for urine leakage	AA	52.7	1.45	0.82, 2.58
	OWOC	64.9	2.69	1.32, 5.50 *
	White	57.2	Ref	
Giving birth many times may lead to urine leakage	AA	66.7	3.10	1.72, 5.60 *
	OWOC	59.7	2.97	1.45, 6.07*
	White	36.6	Ref	
Most people who leak urine can be cured with some kind of treatment	AA	48.4	1.45	0.82, 2.58
	OWOC	54.4	2.61	1.32, 5.18 *
	White	37.0	Ref	

Table 5B. Adjusted associations between race/ethnicity and giving an incorrect response to individual PIKQ POP scale questions

Question	Race/ Ethnicity	% Incorrect	OR	95% CI
Pelvic organ prolapse (bulging of the vagina, uterus, bladder, or rectum) is more common in young women than in old women	AA	57.3	2.02	1.12, 3.64 *
	OWOC	57.9	1.79	0.89, 3.58
	White	43.2	Ref	
Giving birth many times may lead to pelvic organ prolapse	AA	60.7	2.6	1.44, 4.71 *
	OWOC	56.1	2.83	1.41, 5.68 *

	White	36.7	Ref	
Pelvic organ prolapse can happen at any age	AA	62.9	2.06	1.12, 3.80 *
	OWOC	66.7	3.29	1.55, 6.98 *
	White	53.3	Ref	
Certain exercises can help to stop pelvic organ prolapse from getting worse	AA	59.6	1.28	0.70, 2.33
	OWOC	61.4	2.22	1.08, 4.59 *
	White	52.5	Ref	
Symptoms of pelvic organ prolapse may include pelvic heaviness and/or pressure	AA	44.9	1.16	0.64, 2.11
	OWOC	61.4	3.54	1.71, 7.36 *
	White	37.1	Ref	
Once a patient has pelvic organ prolapse, not much can be done to help her	AA	69.7	3.18	1.67, 6.06*
	OWOC	68.4	3.03	1.44, 6.41*
	White	48.7	Ref	
Heavy lifting on a daily basis can lead to pelvic organ prolapse	AA	69.7	1.57	0.81, 3.02
	OWOC	84.2	3.34	1.38, 8.10 *
	White	68.7	Ref	
Surgery is one type of treatment for pelvic organ prolapse	AA	51.7	1.29	0.71, 2.35
	OWOC	63.2	2.79	1.33, 5.83 *
	White	41.7	Ref	
A rubber ring called a pessary can be	AA	71.9	2.07	1.07, 3.99 *

used to treat symptoms of pelvic organ prolapse	OWOC	77.2	2.31	1.05, 5.06 *
	White	58.7	Ref	

PIKQ-Prolapse and Incontinence Knowledge Questionnaire; UI-urinary incontinence; POP-pelvic organ prolapse; AA-African American; OR = odds ratio of giving an incorrect response; Ref-referent stratum. Associations were adjusted for the following covariates: age, household income, education, working in a medical field, marital status, ever had a problem with urine leakage, and ever had a problem with POP. Only questions with a significant difference (compared to White women) were included. For 5A: AA, N=93; Other, N=57; White, N=265. For 5B: AA, N=89; OWOC, N=57; White, N=259.

Racial disparities related to UI or POP care-seeking

African American women (vs. White women) were less likely to report having ever had a problem with urine leakage both before and after adjustment for confounders (Table 6). Few women from all of the groups reported seeking care for their urine leakage (4.6%, N=19). There was no significant difference between the groups in the likelihood of previously being treated for UI. No racial/ethnic disparities were found in the likelihood of having ever had a problem with POP; however, when compared with White women, African American and OWOC were significantly more likely to report having ever been treated for their POP both before and after adjustment.

Table 6. Unadjusted and adjusted analyses of racial disparities related to care-seeking for UI/POP problems

Question	Race/ Ethnicity	% "yes" response	Unadjusted		Adjusted	
			OR	95% CI	OR	95% CI
Ever seen a urologist/ urogynecologist?	AA	23.1	1.12	0.63, 1.98	0.86	0.42, 1.78
	OWOC	17.9	0.81	0.39, 1.71	1.24	0.50, 3.08
	White	21.1	Ref		Ref	
Ever had a problem with urine leakage?	AA	22.8	0.51	0.30, 0.88 *	0.38	0.20, 0.76 *
	OWOC	28.6	0.69	0.37, 1.30	1.06	0.51, 2.20
	White	36.7	Ref		Ref	
Ever been treated for leakage of urine?	AA	6.5	1.94	0.67, 5.60	0.62	0.14, 2.81
	OWOC	5.3	1.56	0.41, 5.96	1.92	0.36, 10.08
	White	3.4	Ref		Ref	
Ever had a problem with POP?	AA	6.6	1.02	0.39, 2.68	0.61	0.16, 2.34
	OWOC	3.6	0.54	0.12, 2.39	0.89	0.17, 4.78
	White	6.5	Ref		Ref	
Ever been treated for POP?	AA	7.5	2.99	1.02, 8.76 *	13.35	1.67, 106.38 *
	OWOC	3.6	1.36	0.28, 6.73	11.75	1.11, 124.92 *
	White	2.7	Ref		Ref	

UI-urinary incontinence; POP-pelvic organ prolapse; AA-African American; OWOC-other women of color; OR = odds ratio of answering “yes” for each question; Ref-referent stratum. Associations were adjusted for the following covariates: age, household income, education, working in a medical field, and marital status. Each analyses included between N=364 and N=366 subjects who had complete information.

DISCUSSION

Our cross-sectional study of community-dwelling women found considerable deficits in knowledge about UI and POP in women of all ages, races and socioeconomic levels. After adjusting for age, race, household income, and education, African American women and OWOC were significantly less knowledgeable about UI and POP than their White counterparts. This suggests that non-White groups, in general, have lower UI and POP knowledge, compared to Whites. Our sub-analysis showed that compared to White women, African American and OWOC are particularly lacking in knowledge regarding risk factors and treatment options for common PFD. A history of UI was not associated with UI knowledge and over 90% of women who experienced UI had not received treatment for their problem. African American women were less likely than White women to report having had urine leakage. In contrast, a history of POP predicted improved POP knowledge over those who had not had a problem with POP and the majority of women with POP had received treatment. It is also interesting to note that although African American and OWOC were more likely to lack knowledge about treatments for POP, they were significantly more likely than white women to report having been treated for POP.

Our study is one of the largest community-based studies to date. Prior studies with comparable population sizes have evaluated patients already seeking care (41, 60, 61). Our community-based approach facilitated our ability to sample a racially, ethnically and socioeconomically diverse population, encompassing a wide age range. This enhanced result generalizability.

Our findings contrast work by Kubik et al., who found that race was not associated with women's knowledge after correction for socioeconomic status (61). These authors stratified race into Whites and "minority", used a different tool to evaluate knowledge, and had a significantly smaller study population. These differences likely contributed to the disparate results. In a study assessing knowledge using the same instrument, Shah et al. also noted poor overall knowledge about UI and POP, as well as racial disparities in knowledge about UI after controlling for education and income (41). Although they did not find racial disparities in POP knowledge, they defined race as White and non-White, had a small sample size and used only women who presented for routine gynecologic care.

It has long been recognized that one of the barriers to seeking care for women is poor knowledge about treatment options (7, 8, 16, 60) and preventative strategies cannot be successfully implemented without adequate knowledge about the etiology and risk factors of disease. It is therefore particularly concerning that African American women and OWOC are less likely to recognize childbirth as a risk factor for both UI and POP compared to White women, since childbirth has been identified as the most influential risk factor for both of these disorders (42, 62). This appears to be a common area of poor knowledge as another study found that 71% of women were unaware that vaginal delivery increases a woman's future risk of PFD (63). Furthermore, Centers for Disease Control statistics show that Hispanic and non-Hispanic black populations tend to have children earlier and have higher fertility rates than other groups (64). This augments the

effect of the lack of knowledge about childbirth as a risk factor for PFD for these populations and highlights why educating them about risk factors could be so valuable.

Although bothersome POP was associated with care-seeking, a lack of knowledge about the diverse symptoms may preclude women with asymptomatic PFD from seeking care (65, 66). This is compounded by the fact that African American women and OWOC were less likely to demonstrate knowledge about the benefits of pelvic floor muscle exercises on UI and/POP. This is particularly disheartening since knowledgeable women with PFD may consider initiating these simple, conservative measures (67, 68). Pelvic floor muscle exercises have been shown to be both an inexpensive and efficacious way to reduce UI and slow the progression of POP and are an ideal tool that can easily be implemented by patients to improve their quality of life (69). Several studies provide evidence for the efficacious role of pelvic floor muscle exercises during and after pregnancy (70, 71). A single-blind randomized control trial with 301 nulliparous women found that pelvic floor muscle training during pregnancy reduced the incidence of UI both during pregnancy and during the postpartum period, as well as significantly improved pelvic floor muscle strength (71). Unfortunately, a study by McLennan et al. looking at patient's knowledge of potential pelvic floor changes associated with childbirth found that 46.1% of women received no information about pelvic floor muscle exercises and 46.6% received no information about UI during the prenatal and peripartum periods (72). Another study surveyed 205 postpartum women and found that 42% of women studied had not ever heard of pelvic floor muscle exercises (63). Furthermore, evidence suggests that when providers do counsel their patients, they frequently overestimate patient literacy levels,

particularly in African American patients (73, 74). Omission of this information during prenatal and peripartum counseling negatively impacts patient's knowledge and represents a missed opportunity for practitioners to educate their patients about PFD.

Additionally, the misbelief by OWOC that surgery is the only treatment option for both UI and POP may further increase patients' apprehension about care-seeking and the perceived risk incurred. Ensuring that all women are provided with literate-level, appropriate information about effective preventative strategies and conservative therapeutic options to treat UI and POP could help to improve the quality of life of many women and reduce the increasing financial burdens from PFD.

In our study, the ratio of women who had ever been treated for UI to those who had a UI problem (1:7, 14.3%), was lower than would be expected based on previous studies evaluating care seeking behaviors (18-50%) (9, 10, 12-15)(9, 10, 12-15)(9, 10, 12-15)(9, 10, 12-15)(9, 10, 12-15). This may be explained by the fact that the PIKQ neither qualified the degree of bother women may have experienced, nor did it assess quality of life. African American and OWOC were more likely to report having been treated for POP compared to White women despite significant knowledge disparities. A number of possible explanations exist for this finding. Evidence suggests that diseases with symptoms patients deem as significantly bothersome are more likely to inspire patients to initiate conversations with their health providers (75), thus leading to treatment. It is also possible that women did not understand the question or recognize the terms pelvic organ prolapse or POP, and therefore answered the question incorrectly. Lastly, African

American and OWOC may not have considered themselves as having had a problem with POP if they had been successfully treated. Thus, the number of women experiencing POP may have been underreported, falsely raising the percentage of women who had been treated. Future evaluations that include quality of life and symptom bother questionnaires are needed to better understand the relationship between knowledge, quality of life, and care seeking among women.

Of the most prevalent PFD, UI is the most widely recognized for a plethora of reasons: it affects both males and females, and it has received the most cumulative research funding, and health policy initiatives when compared with the other PFD. UI has also made gains in media recognition in recent years. *Poise* medical products in 2011 ushered in a TV advertising campaign, which featured actress Whoopi Goldberg and reality-TV personality, Kris Jenner. The *Depend* brand by Kimberly-Clark, also embarked upon an advertising campaign in 2011 which was specifically targeted at the baby boom generation (persons born from 1946 to 1964), and in 2012, made use of celebrities. While current campaigns may decrease stigmatization of the condition and increase awareness of UI as a common problem, they provide minimal information about the etiology, diagnosis and treatment options for UI. Instead, the use of celebrities for TV advertising campaigns for both *Poise* and *Depend* further perpetuates myths that UI is inevitable and effective therapies are lacking. It is not surprising that disposable products account for 70% of an approximately \$13 billion dollar industry for women (46). It follows that this dramatic broadcasting and publicizing of routine care, leaves only 1% and 9% of direct annual costs being spent on diagnosis and treatment respectively (46).

To date, the media's coverage of POP has been limited. It is primarily focused on the July 2011 safety report ushered by the FDA that noted that serious complications are associated with transvaginal placement of surgical mesh (76). This report launched several internet and television advertising campaigns and lawsuits seeking millions of dollars in damages. This may have led to a subconscious fear of treatments for POP in women who came across these campaigns although several other surgical and non-surgical treatment options are available.

An important limitation to our study was the small number of subjects in the Hispanic, Other, and particularly Asian groups. Independent studies evaluating Japanese, Chinese and Korean women have shown that Asian women lack knowledge about UI (15, 77, 78), and a recent study showed a lack of knowledge about UI and POP among a focus group of Latina women (60). Additionally, women classified as Other could include a variety of racial and ethnic representatives. Larger studies with more Hispanic and Asian women and more specific ethnic designations are needed to confirm the independent relationship between these groups and PFD knowledge. Furthermore, whether an individual had a family member or knew someone with PFD may have been an additional factor influencing knowledge proficiency, however this was not evaluated. Future studies evaluating this variable are warranted. Our study focused on UI and POP. While FI is the second most prevalent PFD after UI, to our knowledge, no validated questionnaire exists to evaluate women's knowledge of FI. Future studies are warranted to validate an appropriate tool to evaluate FI knowledge among women.

While our study population was fairly representative of New Haven County, it included a higher percentage of women with graduate degrees (32.3%) and a lower percentage of those with a household income < \$49,000 (35.3%) compared with national statistics of 10.1% and 49.8%, respectively (79-81). Moreover, our study had a high percentage of women working in the medical field, likely due to healthcare being the largest employment industry in the state of Connecticut. Thus, although our study encompassed a diverse group of women, it was not fully representative of national levels, possibly reducing the generalizability of our findings. The PIKQ was previously validated in a population with similar racial, ethnic and socioeconomic diversity to our own study population. Lastly, our use of direct inquiry to recruit study participants may have resulted in inherent selection bias. Although perceptions about participant's likelihood of participating may have resulted in some selection bias, this was likely limited given our ability to recruit women representing multiple ages, races, ethnicities, and socioeconomic strata.

Knowledge deficits amongst minority women may exist for numerous reasons, including lack of access to health care and educational forums, embarrassment related to discussing the subject with providers, and concerns about social stigma, precluding initiating conversation about these issues among friends and family (16, 60, 82). Our study shows that African American women have significantly reduced knowledge proficiency for both UI and POP after controlling for socioeconomic status. African Americans are historically more prone to mistrust and to negatively perceive medicine, public health and

research due to a legacy of past abuses by the healthcare system (83, 84). Previous literature sculpts a multifactorial picture including cultural differences, lifestyle patterns, inherited health risks, social inequality, provider bias, and residential segregation (85). Moreover, recent interdisciplinary studies argue that African American/White health disparities continue to exist and increase because of continued actual and perceived race-based discrimination (85). Use of community-based participatory research principles in the design of the study may have helped to mitigate mistrust and enhance the diversity of our study population (86).

Our results demonstrate the need for addressing patient knowledge about PFD. In a population of 40-70 year old community-dwelling women, over 60% reported acquiring their knowledge about UI from the media or television while only 6% received education from providers (15). This may explain the multitude of misconceptions that women harbor about PFD, and highlights the important role that providers can play. A critical role in educating women about PFD exists for both primary care and specialist physicians. This is highlighted by Jeter et al. whose survey found that 35% of their predominantly female population had sought help for their UI from a family practitioner while 37% had sought help from a urologist (87). Only 17% had sought care for their UI from a gynecologist. Additionally, Sutton and Donner showed that nearly 75% of women age 40 and older had visited a family/general practitioner, internist or “just a doctor” in the last year while less than 20% of women over age 50 and less than 10% over age 65 reported visiting a gynecologist in the last year (75). It is possible that the number of US women who regularly see gynecologists will continue to decrease with the United States

Preventive Services Task Force and American Cancer Society now recommending pap smears every 5 years for women between the ages of 30 and 65, and cessation of pap smear screening for low risk women 65 and older, and women who have had hysterectomies (88, 89).

An anthropologic meta-analysis of attitudes of elderly, incontinent community-dwelling women highlighted the failing of physicians to diagnose and/or treat UI, instead, leaving management to nurses and other ancillary medical staff (90). Management strategies employed by ancillary medical staff disproportionately include in-home health services targeted at collecting urine, and controlling wetness and odor. They also noted that when providers consider a patient's incontinence to have become flagrant, they are most likely to recommend placement in a home as the best, and sometimes only, treatment option.

Enhancing knowledge about health problems has proven effective in promoting behavioral change, reducing levels of disease symptoms and improving compliance with treatments in other chronic diseases, and may play a critical role in reducing morbidity from PFD (91-94). A study by Geoffrion et al. used a workshop-based educational intervention, covering topics on UI and POP, and found that at a 3-month follow-up, women's knowledge, symptoms and quality of life were improved compared with their baseline (95). Literature from psychology and addiction medicine also suggests that engaging family and significant others in the intervention is helpful in improving patient outcomes (96, 97). Hatchett et al.'s study highlights the importance of culture-centric and culture-specific designed knowledge interventions (60). Additionally, within African

American populations, the most effective health behavioral modification strategies have been found to be those that integrate personal responsibility as well as advocate for social systems change (98). To that end, community-based coalition partnerships and community health worker training have been found to be particularly efficacious.

Meaningful use is a set of standards defined by the Centers for Medicare and Medicaid Services (CMS) Incentive Programs (99). Meaningful use was designed with the goal of promoting the electronic health record to improve health care in the U.S. It enables eligible providers and hospitals to earn incentive payments once certain criteria are met. Despite government-endorsed UI performance measures and meaningful use incentive programs, evidence suggests that many practitioners are not routinely evaluating women for UI (58, 99-103). Cited reasons providers fail to comply with recommendations include provider pessimism about treatment success, particularly in the elderly, and time limitations, especially in women with numerous comorbidities (58, 103). Greater awareness and emphasis on financial incentives through performance measures and meaningful use could potentially have a positive impact on PFD knowledge by utilizing provider-patient education. Development of performance measures for POP may also aid in encouraging clinicians to adopt routine screening for symptoms of POP, thus introducing a safe environment for women to ask questions and learn more about PFD.

With the rapidly expanding aging population, it is critical that we prepare for the anticipated dramatic increase in PFD prevalence among women. Improving knowledge of these disorders could serve a number of purposes including modifying health behavior

thereby impacting care-seeking and thus a potential increase in patient quality of life, improved treatment compliance, and reduction of symptom severity. Practicing primary care providers should be encouraged to inform women about PFD and routinely screen for symptoms during well-woman examinations. Community-based educational tools and practice redesign models using preprinted educational materials may help ensure that women are familiarized with PFD (104). Further studies identifying effective community-centric outreach strategies that effectively educate women of diverse backgrounds about PFD symptomology and treatment options are also warranted.

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FIGURES

Figure 1.

#	Type	Questions from the PIKQ Urinary Incontinence Scale	Correct Answer
1	E	Urinary incontinence (loss of urine or leaky bladder) is more common in young women than in old women.	Disagree
2	E	Women are more likely than men to leak urine.	Agree
3	T	Other than pads and diapers, not much can be done to treat leakage of urine.	Disagree
4	D	It is NOT important to diagnose the type of urine leakage before trying to treat it.	Disagree
5	E	Many things can cause urine leakage.	Agree
6	T	Certain exercises can be done to help to control urine leakage.	Agree
7	E	Some medications may cause urinary leakage.	Agree
8	T	Once people start to leak urine, they are never able to control their urine again.	Disagree
9	D	Doctors can do special types of bladder testing to diagnose urine leakage	Agree
10	T	Surgery is the only treatment for urinary leakage.	Disagree
11	E	Giving birth many times may lead to urine leakage.	Agree
12	T	Most people who leak urine can be cured or improved with some kind of treatment	Agree
#	Type	Questions from the PIKQ Pelvic Organ Prolapse Scale	Correct Answer
1	E	Pelvic organ prolapse (bulging of the vagina, uterus, bladder, or rectum) is more common in young women than in old women.	Disagree
2	E	Giving birth many times may lead to pelvic organ prolapse.	Agree
3	E	Pelvic organ prolapse can happen at any age.	Agree
4	T	Certain exercises can help to stop pelvic organ prolapse from getting worse.	Agree
5	E	Symptoms of pelvic organ prolapse may include pelvic heaviness and/or pressure.	Agree
6	D	A good way for a doctor to diagnose pelvic organ prolapse is by examining the patient.	Agree
7	T	Once a patient has pelvic organ prolapse, not much can be done to help her.	Disagree
8	E	Heavy lifting on a daily basis can lead to pelvic organ prolapse.	Agree
9	T	Surgery is one type of treatment for pelvic organ prolapse.	Agree
10	D	Doctors can run a blood test to diagnose pelvic organ prolapse.	Disagree
11	T	A rubber ring called a pessary can be used to treat symptoms of pelvic organ prolapse.	Agree
12	E	People who are obese are less likely to get pelvic organ prolapse.	Disagree

FIGURE LEGEND

Figure 1: Prolapse and Incontinence Knowledge Questionnaire. # = question number; type = type of knowledge question reflects; E = etiology; D = diagnosis; T = treatment