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Pelvic Floor and Urinary Distress in Women with Fibromyalgia

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Abstract

Fibromyalgia (FM) patients were recently found to have more symptom burden from bothersome pelvic pain syndromes that women seeking care for pelvic floor disease at a urogynecology clinic. We sought to further characterize pelvic floor symptoms in a larger sample of FM patients using of validated questionnaires. Female listserv members of the Fibromyalgia Information Foundation completed an online survey of three validated questionnaires: the Pelvic Floor Distress Inventory 20 (PFDI-20), the Pelvic Pain, Urgency and Frequency Questionnaire (PUF), and the Revised Fibromyalgia Impact Questionnaire (FIQR). Scores were characterized using descriptive statistics. Patients (n = 204 with complete data on 177) were on average 52.3 ± 11.4 years with a mean parity of 2.5 ± 1.9. FM severity based on FIQR score (57.2 ± 14.9) positively correlated with PFDI-20 total 159.08 ± 55.2 ($r = .34$, $p < .001$) and PUF total 16.54 ± 7 ($r = .36$, $p < .001$). Women with FM report significantly bothersome pelvic floor and urinary symptoms. Fibromyalgia management should include evaluation and treatment of pelvic floor disorders recognizing that pelvic distress and urinary symptoms are associated with more severe FM symptoms. Validated questionnaires, like the ones used in this study, are easily incorporated into clinical practice.

Fibromyalgia (FM) is a common, debilitating disorder of widespread pain affecting an estimated 5 million persons in the United States (Lawrence et al., 2008). Similarly, chronic pelvic pain is estimated to affect at least 9 million women (Mathias, Kuppermann, Liberman, Lipschutz, & Steege, 1996), and 4 to 7 million women report bladder pain/interstitial cystitis symptoms (Berry et al., 2011). Given that these three chronic pain syndromes are highly prevalent, it is not surprising that they often coexist. Indeed, people with FM often report numerous regional pain syndromes, including headaches, temporomandibular disorders, low back/neck pain, myofascial pain, irritable bowel, pelvic pain, and bladder pain (Adams & Denman, 2011; Arnold, Clauw, & McCarberg, 2011; Rodriguez, Afari, & Buchwald, 2009; Williams & Clauw, 2009).

Like FM, chronic pelvic pain and bladder pain have been characterized by some as functional or sensory hypersensitivity pain disorders for which there are conflicting etiologic theories and lack of standardized treatments (Clemens, Elliott, Suttorp, & Berry, 2012;

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Clemens et al., 2014; Adams & Denman, 2011). Pelvic floor disorders negatively influence a woman's activities of daily living, sexual function, bowel and bladder function, and overall quality of life. Despite their high prevalence and negative impact, little known about the relationship between pelvic/bladder symptoms and FM severity. The purpose of this study was to characterize pelvic floor and urinary symptoms in patients with FM. A secondary aim was to describe the strength of the relationship between pelvic floor and urinary symptoms with the total impact of FM.

MATERIALS AND METHODS

Design, Participants, and Procedures

This study was a cross-sectional descriptive survey in women with FM. Five hundred female patients were contacted via e-mail and requested to complete an online "women's health survey" (SurveyMonkey, Inc., Palo Alto, CA). These patients were originally seen in an academic rheumatology practice in the Pacific Northwest and belong to the Fibromyalgia Information Foundation (FIF) patient database. Inclusion criteria for the FM group included (1) age over 18, (2) female, (3) active e-mail access, (4) diagnosed with FM according to the 1990 American College of Rheumatology guidelines (Wolfe et al., 1990) by a medical provider, and (5) able to understand English.

Measures

Demographic and clinical data were collected via an investigator-designed questionnaire and the Revised Fibromyalgia Impact Questionnaire (FIQR). The FIQR is a validated questionnaire commonly used in clinical practice to measure the FM patient's current level of negative impact from FM symptoms and physical function in the context of three domains: level of function (range 0–30), overall impact (range 0–20), and symptoms (range 0–50). Symptom questions assess pain, fatigue, disrupted sleep, muscle tenderness, stiffness, memory, anxiety, depression, balance, and sensitivity to light/noise/smell. Higher scores on the FIQR total score (range 0–100) indicate greater negative impact of FM on overall functioning; an FIQR total score of 0–39 represents mild symptoms, 40–58 represents moderate symptoms, and 59–100 represents severe impact on overall functioning (Bennett et al., 2009).

Pelvic floor symptoms were measured using the PFDI-20, a short version of the 46-question Pelvic Floor Distress Inventory (PFDI) found to be reliable and valid with high and consistent correlation to the long-version PFDI (Barber, Kuchibhatla, Pieper, & Bump, 2001; Barber, Walters, & Bump, 2005). Scores range from 0 to 300, with higher scores indicating higher levels of dysfunction. This questionnaire is made up of three subscales to assess prolapse symptoms (e.g., heaviness in the pelvic area, feel something falling out, have to push up on bulge in vaginal area to start or complete urination), urinary distress (e.g., urinary frequency, urgency, leakage), and anal distress (e.g., not completely emptying bowels, strain/pain with defecation, bulging rectum during or after defecation). The subscales are commonly abbreviated as the Pelvic Organ Prolapse Distress Inventory (POPDI), the Colorectal-Anal Distress Inventory (CRADI), and the Urinary Distress Inventory (UDI). For each subscale, scores range from 0 to 100 with higher scores indicating higher rates of

dysfunction. At the present time there is no generally agreed upon “cut score” or minimally important difference score for the PFDI-20, though much work is ongoing in this area (Barber et al., 2001; Gafni-Kane, Goldberg, Sand, & Botros, 2012; Jelovsek et al., 2014; Lowder, Ghetti, Oliphant, Moalli, & Zyczynski, 2010). The PFDI-20 has been reported once in persons with FM (Adams, Osmundsen, & Gregory, 2014).

Pelvic pain associated with urinary urgency and frequency was assessed with the Pelvic Pain, Urgency and Frequency Questionnaire (PUF). This eight-item questionnaire, widely used to assess symptoms of interstitial cystitis, is composed of two subscales: symptom severity and level of bother. Total scores range from 0–35 (symptom subscale 0–23 and bother subscale 0–12). Higher scores indicate higher levels of symptom severity and bother (Brewer, White, Klein, Klein, & Waters, 2007). Questions assess urinary pain, frequency, urgency, bother, and symptom association with sexual intercourse. Scores >12 indicate significant symptoms; scores of ≥15 have an 84% sensitivity in diagnosing interstitial cystitis based on positive potassium testing, which indicates abnormal permeability of bladder epithelium (Parsons et al., 2002). The PUF has not been reported to date in persons with FM.

Ethics

This investigation received approval by Oregon Health & Science University’s Institutional Review Board (IRB). Participants provided consent on the first page of the online survey.

Statistical Analysis

Clinical characteristics and scale scores were summarized using descriptive statistics. Correlations were calculated between FIQR symptom subscale and PFDI-20 total scores and the FIQR symptom subscale and PUF total scores.

RESULTS

Of the 500 invitations e-mailed to participate, 483 were successfully received by potential participants. A total of 204 potential respondents completed the survey (42% response rate). Of those, 177 had complete data. All data were preprocessed for completeness and appropriate response ranges. The data were analyzed using Stata software (Stata Statistical Software, Release 13, StataCorp LP, College Station, TX). The mean age was 52.3 ± 11.4 years, with a history of 2.5 ± 1.9 births. Patients were mostly married (71%). As is reflective of the Pacific Northwest, 92% were Caucasian. Additional data indicated that most reported FM symptoms for >10 years (69%), with almost half (45%) having received a diagnosis >10 years ago. Almost all reported problems with concentration or memory (94%); more than half reported co-morbidities, including chronic fatigue syndrome (56%), chronic headache (74%), temporomandibular joint disorders (55%), dry eyes/dry mouth (74%), balance problems (73%), restless leg (55%), anxiety symptoms (63%), and depressive symptoms (79%). With regard to pelvic/urinary/abdominal symptoms, 80% endorsed having irritable bowel/gastrointestinal (GI) problems, whereas only 39% were diagnosed with irritable bladder or interstitial cystitis (Table 1).

Mean responses to the PFDI-20 were 159.1 ± 55.2. In addition, the colorectal distress was the most bothersome subscale at 58.2 ± 22.5. The mean total score of the PUF was 16.5 ± 7.0. The symptom score was 10.3 ± 4.5; mean bother score was 6.3 ± 3.1 (Table 2). The majority of patients indicated that they experienced bladder or pelvic pain at least occasionally (93%), with greater than half reporting symptoms on a usual basis. The majority of participants reported feelings of urinary urgency after voiding (93%), with greater than half reporting that they experience this on a usual basis.

The revised Fibromyalgia Impact Questionnaire was 57.2 ± 15.0, indicating moderate to severe FM impact. Symptom severity was 28.2 ± 7.3 with a pain score of 5.5 ± 2.0. Five FM symptoms were ranked as more severe than pain. The most severe symptoms were sleep problems and fatigue, followed by stiffness; sensitivity to odors, cold, bright light, and loud noise; and tenderness to touch (Table 3).

In general, as FM impact was worse, pelvic and bladder symptoms were also worse. Most notably, the FIQR symptom subscale was positive correlated with PFDI-20 total ($r = .34$, $p < .001$). The CRADI and the FIQR symptom subscale were similarly correlated ($r = .34$, $p < .005$). The PUF total was also correlated positively with the FIQR symptom subscale ($r = .36$, $p < .001$).

DISCUSSION

The findings of this study support findings in the literature that FM is commonly associated with self-reported co-morbidities such as irritable bowel or gastrointestinal problems, depressive symptoms, anxiety symptoms, temporomandibular dysfunction, chronic pelvic pain and irritable bladder (Clauw, 2014; Mease, 2009). The following data, however, are novel to the literature: (1) the majority (93%) of women indicated that they experience bladder or pelvic pain at least occasionally, with more than half reporting that they experience discomfort on a usual basis, and (2) FIQR scores positively correlated with PFDI-20 (total and CRADI subscale) and PUF scores, indicating that among those with more severe FM impact, there is an increased presence and severity of urinary and pelvic floor distress symptoms.

Newly published data report that women with FM have 50% greater pelvic floor symptoms compared with matched women without FM who were evaluated at a urogynecology clinic for pelvic floor distress (Adams et al., 2014). The women with FM had significantly worse pelvic floor distress than age-matched women without FM (PFDI scores 145.0 [63.3] versus 110.5 [64.5; $p = .005$]). Patients in Adams' study were of similar age, parity, and race compared with patients in our study. These authors also report physical examination data. The most notable were that most FM patients had levator myalgia on examination, OR 3.8 (95% CE 1.3, 9.1). Patients in our cohort, compared with Adams' FM cohort, reported greater levels of total pelvic floor distress (159.1 [55.2] vs. 145.0 [63.3]) and colorectal symptoms (58. 2 [22.5] vs. 37.9 [22.6]). Both groups had similar levels pelvic organ prolapse symptoms (50.5 [27.3] vs. 51.6 [26.9]). Adam's sample had greater levels of urogenital symptoms (48.1 [29.0] vs. 55.4 [29.1]). To explore these findings farther, we extracted baseline demographics as well as PFDI-20 data from an IRB-approved

urogynecology data repository. We queried the database for new patients presenting during the time frame matching our study. The 627 urogynecology patients' mean age was 51.8 ± 16.5 years, mean parity was 2.2 ± 1.5, and mean PFDI-20 score was 86.4 ± 53.4. We compared these data to data from the present study and also found that in a simple linear regression controlling for parity, women with FM reported pelvic floor symptoms at a severity greater than women presenting to a urogynecology practice despite being the same age ($p < .01$).

There is evidence that patients with urologic chronic pelvic pain syndrome are more likely to suffer from bothersome symptoms in other body systems similar to those found in FM compared with healthy controls (Lai, North, Andriole, Sayuk, & Hong, 2012). Additionally, women with FM are more likely to have had a hysterectomy compared with the general population, yet hysterectomy may not improve chronic pelvic pain in women with FM (Pamuk, Donmez, & Cakir, 2009; Santoro, Cronan, Adams, & Kothari, 2012; ter Borg, Gerards-Rociu, Haanen, & Westers, 1999). Similarly patients with chronic pelvic pain compared with those without recently were found to be at increased risk of not improving or even worsening after undergoing transvaginal mesh revision (Danford, Osborn, Reynolds, Biller, & Dmochowski, 2015).

There are four possible explanations for the high reports of pelvic floor distress among the FM group. First, these responses may be a reflection of the relatively high prevalence of pelvic floor disorders in the general population (Nygaard et al., 2008), coupled with the high prevalence of FM in the general population. Another possible explanation is that women with FM are more likely to have had previous hysterectomy compared with the general population (Santoro et al., 2012), which is also associated with higher prevalence and degree of pelvic organ prolapse (Swift, 2000). Retrospective survey data recently identified that the presence of functional somatic syndromes, including FM, was found to be a separate, independent risk factor for hysterectomy in women with bladder pain/interstitial cystitis (Williams & Clauw, 2009). Third, there is a large body of evidence that sensation is enhanced in persons with FM through a variety of dysfunctional pain pathways (Julien, Goffaux, Arsenault, & Marchand, 2005), which may explain why these patients were highly symptomatic. Lastly, women with more severe symptoms may have opted to complete the survey.

Based on responses from the PUF questionnaire, we found that the majority (93%) of women with FM indicated that they experience bladder or pelvic pain at least occasionally, with more than half reporting that they experience discomfort on a usual basis. This is interesting because only 39% self-report a diagnosis of irritable/pain bladder or interstitial cystitis. Perhaps nonurogyencologic providers are less confident in diagnosing specific bladder disorders. Although this study does not address whether the women in our FM cohort fit the diagnostic criteria for interstitial cystitis, the results do suggest that women with FM should be evaluated for these comorbidities, including interstitial cystitis. This finding is consistent with previous studies linking FM and interstitial cystitis as shared comorbidities with possible shared pathophysiology. De Araujo et al. (2008) used both validated questionnaires and urodynamic assessment to evaluate symptoms of urinary distress among the FM population and found that symptoms of lower urinary tract distress

such as frequency and incontinence were statistically more prevalent among the FM population with known lower urinary tract symptoms (LUTS) (n = 51) compared with a group with LUTS but without FM (n = 50) (de Araujo et al., 2008). Objectively, urodynamic studies revealed that the FM population had higher detrusor overactivity compared with the LUTS-only group and significantly worse quality of life as evaluated by validated questionnaire. A telephone survey published in 2006 by Shaver et al. found that 68.4% of FM patients studied (n = 442) had complaints of cystitis compared with only 47.2% of healthy controls (n = 205) (Shaver, Wilbur, Robinson, Wang, & Buntin, 2006). In 1997 a study evaluating pain threshold and FM symptoms in people with FM (n = 60), in people with interstitial cystitis without FM (n = 30), and in healthy controls (n = 30) found that both the FM and interstitial cystitis groups exhibited increased pain sensitivity to both tender points and control points compared with the healthy control group (Clauw et al., 1997). Furthermore, both the FM and interstitial cystitis groups reported higher levels of FM symptoms compared with the healthy controls.

Our findings may contribute to the growing body of literature suggesting that pelvic floor distress could play a significant role in FM as a potential pain generator that perpetuates and exacerbates chronic pain and hyperalgesia. Given the high prevalence of pelvic distress among the FM group, this could also indicate that those diagnosed with a pelvic floor disorders should also be evaluated for FM and vice-versa. Co-investigators on this study report that screening for undiagnosed FM is not typically completed in the urogynecologic evaluation.

There are several limitations to our study. Because it was a cross-sectional survey, we cannot make inferences about directionality or cause and effect. Additionally, the study represents a largely Caucasian sample of women in one geographic area, limiting generalizability. Patients self-selected to participate in the study and responded to questionnaires online; thus the sample may overrepresent those with women's health issues and create a bias toward higher reports of pelvic symptoms. Similarly, patients' FM was severe enough that it had been evaluated at least once in a rheumatology practice. Lastly, we did not complete physical examinations on our patients, thus we cannot replicate Adams' findings of levator myalgia (Adams et al., 2014) or determine its correlates.

CONCLUSIONS

This survey was the first to date to evaluate the severity of pelvic floor distress symptoms using the PFDI-20 and PUF in an FM population and correlate to levels of overall pain and functioning (FIQ-R). Ninety-three percent of women indicated that they experience bladder or pelvic pain at least occasionally, with more than half reporting that they experience discomfort on a usual basis. FM patients have significant symptoms of pelvic floor distress, including pain, urinary and colorectal dysfunction, and pelvic organ prolapse. Our findings also suggest that symptoms of pelvic floor distress are positively correlated with worse overall FM pain and functioning. Future studies are needed to better characterize those patients with pelvic floor disease comorbid with FM to determine if they have similar characteristics and treatment trajectories. Physical exam data such as degree of pelvic organ prolapse or presence of levator myalgia would also further these findings. It is possible that

enhanced sensory processing makes women with FM more aware of organ prolapse symptoms than women without FM. It is imperative to learn if women with FM have differing outcomes from the treatment of pelvic floor disorders than women without FM. Ultimately, clinicians need to know if early recognition and treatment of pelvic floor disorders among women with FM could improve their overall FM functioning and decrease pain.

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Table 1

Demographic and Clinical Characteristics (N = 177)

Variable	Mean/SD or %
Age, years (mean [SD])	52.3 ± 11.4
Ethnicity (%)	
African American	2%
Caucasian	92%
Native American	6%
Marital status (%)	
Married	71%
Divorced/separated	15%
Widowed	10%
Never married	3%
Parity (mean [SD])	2.5 ± 1.9
Duration of symptoms attributable to fibromyalgia (%)	
1–5 years	11%
6–10 years	19%
>10 years	69%
Years since fibromyalgia diagnosis (%)	
0–6 months	1%
13 months to 4 years	16%
5–10 years	37%
>10 years ago	45%
Self-reported comorbidities (%)	
Problems with concentration	95%
Irritable bowel syndrome or GI problems	83%
Depressive symptoms	81%
Problems with balance	74%
Dry eyes/dry mouth	74%
Chronic headaches	74%
Anxiety symptoms	63%
Temporomandibular joint disorders	55%
Restless leg syndrome	55%
Chronic fatigue syndrome	56%
Irritable bladder or interstitial cystitis	39%

GI = gastrointestinal.

Table 2

Pelvic Floor Distress and Pelvic Urgency and Frequency Scores (Mean/SD)

Questionnaire	Mean/SD
PFDI total score	159.08 ± 55.2
POPDI subscale	50.52 ± 27.3
CRADI subscale	58.23 ± 22.5
UDI subscale	48.10 ± 29.0
PUF total score	16.54 ± 7
Bother score	6.26 ± 3.12
Symptom score	10.26 ± 4.15

PFDI = Pelvic Floor Distress Inventory–20 total score; POPDI = Pelvic Organ Prolapse Distress Inventory subscale; CRADI = Colorectal Anal Distress Inventory subscale; UDI = Urinary Distress Inventory subscale; PUF = Pelvic Urgency and Frequency Questionnaire.

Scores indicate significant impairment.

Table 3

Revised Fibromyalgia Impact Questionnaire and Pelvic Urgency and Frequency Scores (Mean/SD)

Questionnaire	Mean/SD
FIQR Total	57.2 ± 15.0
Function score	11.2 ± 5.5
Overall impact	15.6 ± 6.8
Symptom score	28.2 ± 7.3
Pain	5.5 ± 2.0
Energy	6.7 ± 2.2
Stiffness	6.6 ± 2.1
Sleep	7.1 ± 2.5
Depression	3.9 ± 2.9
Memory problems	5.0 ± 2.6
Anxiety	3.8 ± 2.9
Tenderness to touch	6.3 ± 2.4
Balance	4.0 ± 2.6
Sensitivity to odors and cold bright, light, loudness noise	6.5 ± 2.6

FIQR = Fibromyalgia Impact Questionnaire Revised.

Scores represent moderate to severe impairment.