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Research Article

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Underlying Factors Contributing to the Delay in Patients Seeking Care for Pelvic Floor Dysfunction

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Abstract

Objective: To investigate barriers and variables associated with the delay in seeking urogynecologic care by women with pelvic floor dysfunction.

Methods: Cross sectional study of 300 new patients presenting for outpatient evaluation of pelvic floor dysfunction from August 2011 through March 2012. Patients were mailed a survey prior to initial visit. Delay in seeking care was defined as 12 months or more from symptom manifestation, persistence or recurrence after prior intervention, or being informed about the condition to time of visit. Data are presented as proportion or mean (±standard deviation). Comparisons were made using chi-square and t tests.

Results: Two hundred and thirty one (77.0%) surveys were returned. Mean age was 55.9 years (± 17.4). Majority (91.3%) were Caucasian, 57.4% sexually active, and 96.1% saw a health care provider annually. Commonly reported causes were child birth (32.6%) and aging (23.4%). Delay was seen in 140 women (61.4%). Of these, 81 (57.9%) had been previously asked about symptoms by their primary care provider. The most common reason reported for delay was "Did not have time to care for myself" (19.8%). There was no statistically significant difference in level of education (p=0.86), annual health care visits (p=0.74), and sexual activity (p=0.28) between women with and without delay. However, women who delayed seeking care were more likely to report increased symptom severity (p=0.005) and to have been asked about symptoms (p=0.01).

Conclusion: There is significant delay in seeking care with an urogynecologist. Additional resources are needed to promote patient and primary care provider awareness.

Keywords: Care seeking pattern; Diagnosis delay; Pelvic floor dysfunction

Introduction

Pelvic floor dysfunction is a common health issue among women. While the exact prevalence is unknown, its impact on the health care system, including cost of treatment and nursing home admissions, is substantial [1,2]. Women with pelvic floor dysfunction present with symptoms of pelvic organ prolapse; lower urinary tract symptoms such as recurrent urinary tract infection, urinary incontinence, overactive bladder, chronic myofascial pelvic pain and fecal incontinence.

Among women with pelvic floor dysfunction, reasons for the delay in seeking care are not well studied or understood. Factors that have been cited as playing a role in the delay include the perceived seriousness of symptoms, under-reporting of symptoms by patients to their primary care provider, as well as a lack of recognition by providers that pelvic floor dysfunction is a significant problem [1]. Studies have shown that pelvic floor dysfunction contributes to depression, anxiety, poor life satisfaction, and impaired quality of life [2].

As these conditions and available management options have become better understood, it is important that providers understand barriers to seeking care in order to design targeted education programs and raise awareness among patients and providers. The purpose of this study is to investigate characteristics associated with a delay in seeking urogynecologic care for pelvic floor dysfunction and potential barriers to seeking care.

Materials and Methods

We conducted a cross-sectional study of new patients presenting to our office practice for evaluation of pelvic floor dysfunction including pelvic organ prolapse, urinary incontinence and fecal incontinence. From August 2011 through March 2012 women were mailed a survey before their scheduled initial office visit. The survey was developed by Urogynecologists and included questions regarding sociodemographic characteristics, duration since onset of symptoms, symptom severity, and care seeking pattern. The survey was pilot tested with office administrative personnel to determine appropriate wording and identify items or questions that created confusion. The language of the questionnaire was adjusted based on this feedback. All physician providers and office medical assistants were aware the study was occurring, but were not instructed to change their routine approach to patient care in any fashion. The study was approved by our institutional review board.

Delay in care seeking was defined as a lapse of 12 months or more in the time from the onset of symptoms, persistent or recurrent symptoms after prior intervention or treatment, or being informed of the condition by a primary care provider to the first visit in our urogynecology practice. This arbitrary time duration was chosen after determination of the average time for all providers in our office practice to schedule a new patient after their initial call for scheduling. Reasons for the delay in seeking care were assessed by directed responses

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categorized as "Did not have time to care for myself", "Most women my age suffer from the same symptoms", "Afraid the physician might recommend surgery", "Did not believe or know the problem could be solved", "Was ashamed or embarrassed to reveal the problem" or "Other reasons." We also asked women their opinion as to the cause of the pelvic floor dysfunction. Patients were also asked describe their symptom severity on the questionnaire as mild, moderate or severe based on their perception of the symptom prior to seeking care.

All statistical analyses were performed using SAS 9.3 (SAS institute Inc., Cary, NC). All tests were two sided, and P values <0.05 were considered statistically significant. Data are presented as proportions, mean ± standard deviation (SD), or median (interquartile range). Comparisons were made using a Chi-square or Fisher's exact test for categorical variables and parametric or non-parametric tests for continuous variables, as appropriate.

Results

We mailed surveys to 300 new patients, and 231 surveys were returned, yielding a response rate of 77.0%. The mean age of respondents was 55.9 (± 17.4) years (range: 20-93 years) and the median parity was 2.0. Most respondents were Caucasian (91.3%), slightly more than half (57.4%) were sexually active and 76.1% had completed at least some college education. Half (49.6%) of the women perceived their general health to be excellent or very good. Nearly all respondents (96.1%) reported seeing a health care provider annually (Table 1).

Symptom severity was described as mild, moderate or severe by 17.5%, 53.5%, and 29.0% of women, respectively. Thirty-five women (15.3%) first noticed symptoms of pelvic floor dysfunction or were told about their condition less than 3 months before the visit, 23.6% had symptoms for 3-12 months prior while 61.1% reported waiting at least one year before their initial visit and 39.7% of responders with symptoms ongoing for over one year had delayed seeking care for more than 2 years. Overall, 51.3% of respondents had been asked about these symptoms by their primary care doctor. This proportion was slightly higher (57.9%) among women who delayed seeking care for at least one year after symptoms of pelvic floor dysfunction developed.

Of the 140 women who delayed seeking care for at least one year prior to presentation, among reasons given for this delay in seeking care, the most common was "Did not have time to care for myself" (19.8%); other reasons included "Did not believe or know the problem could be solved" (16.0%); "Sure most women my age suffer from the same symptoms" (14.5%); "Afraid the physician might recommend surgery" (15.3%); and "Was ashamed or embarrassed to reveal the problem" (17.6%) (Table 2).

With broad categorization of education level completed into any college versus high school or less, there was no statistically significant association with delay in care seeking (p=0.62). Similarly, women who delayed seeking care were similar to those who did not with respect to age, parity, seeing a healthcare provider annually and being sexually active (all p>0.28) (Table 3).

There was a statistical significant association between symptom severity and delay in seeking care (p=0.005). One third of women who delayed seeking care reported severe symptoms compared with only 21.8% of women who did not delay seeking care. Similarly, women who delayed seeking care were less likely to report mild symptoms (11.4%) (Table 3). There was also a statistically significant association between being asked about pelvic floor symptoms by the primary care physician and delay in seeking care with the Urogynecologist (p=0.01). Being asked about symptoms by primary care physicians appeared to be associated with delay in presentation to the urogynecology office. Among women who delayed seeking care, 81 (57.9%) reported being asked about symptoms by their primary care provider, while 35 (40.2%) were not asked about symptoms. Among the 87 women (38.3%) that did not delay seeking care, 35 (40.2%) reported being asked about symptoms by their primary care compared with 52 (59.8%) that were not asked about symptoms.

Characteristic	Full cohort n=231
Age (years)–mean (± SD)	55.9 (± 17.4)
Parity–median (IQR)	2.0 (0-3.0)
Race/ethnicity–n (%)	
White/Caucasian Non-Hispanic	211 (91.3)
Black/African American Non-Hispanic	5 (2.2)
Hispanic or Latino	7 (3.0)
Asian or Pacific Islander	5 (2.2)
Native American	1 (0.4)
Other/no response	2 (0.8)
Tobacco use-n (%)	
Yes	17 (7.4)
No	213 (92.6)
Sexually active-n (%)	
Yes	132 (57.4)
No	98 (42.6)
Marital status-n (%)	
Single	41 (17.8)
Married	133 (57.6)
Divorced	24 (10.4)
Separated	6 (2.6)
Widowed	27 (11.7)
Highest education-n (%)	
Junior High/High School	55 (23.9)
College	100 (43.5)
Graduate/Professional School	75 (32.6)
Current employment status-n (%)	
Employed	117 (50.7)
Unemployed	13 (5.6)
Retired	60 (26.0)
Disabled	11 (4.8)
Student	6 (2.6)
Homemaker	24 (10.4)
General health status-n (%)	
Excellent	35 (15.2)
Very Good	79 (34.4)
Good	77 (33.5)
Fair	36 (15.7)
Poor	3 (1.3)
Yearly health care provider visit-n (%)	
Yes	221 (96.1)
No	9 (3.9)

Table 1: Participant characteristics.

Reasons-n (%)	n=140
Did not have time to care for myself	26 (19.8)
Was ashamed or embarrassed to reveal the problem	23 (17.6)
Did not believe or know the problem could be solved	21 (16.0)
Afraid the physician might recommend surgery	20 (15.3)
Sure most women my age suffer from the same symptoms	19 (14.5)
Other	22 (16.8)

Table 2: Patient-reported reasons for delay in seeking care.

	Delay in seeking care		p
	Yes n=140 n (%)	No n=88 n (%)	
Age (years)-mean (± SD)	55.6 (± 17.6)	56.0 (± 17.2)	0.89
Parity-median (IQR)	2.0 (0-3.0)	2.0 (0-3.0)	0.89
Level of education			0.62
Any college	109 (77.9)	66 (75.0)	
No college	31 (22.1)	22 (25.0)	
Annual healthcare visit			0.74
Yes	134 (95.7)	85 (96.6)	
No	6 (4.3)	3 (3.4)	
Sexually active			0.28
Yes	85 (60.7)	47 (53.4)	
No	55 (39.3)	41 (46.6)	
Symptom severity			0.005
Mild	16 (11.4)	24 (27.6)	
Moderate	77 (55.0)	44 (50.6)	
Severe	47 (33.6)	19 (21.8)	
Primary care Symptom Enquiry			0.01
Yes	81 (57.9)	35 (40.2)	
No	59 (42.1)	52 (59.8)	

Table 3: Relationship between demographic variables, symptom severity and delay in seeking care.

Many patients, 43.1% (94 women), reported not knowing the cause of their condition. Of the women that reported potential causes, the most common opinion for the cause of their pelvic floor dysfunction was as a result of child birth (32.6%) and aging (23.4%). The remaining women listed other reasons, including heavy lifting, menopause, taking medications, weak muscles, severe coughing, genetics, prior surgeries, various bladder problems, caffeine consumption, sexual activity, weight gain, hormone changes, hysterectomy, fibroid, vaginal or urinary infections, endometriosis, stress, nerves, urination habits, in vitro fertilization, sexual assault, poor immune function, intrauterine device, diet, and chronic constipation.

The majority of respondents (73.3%) sought medical care for the pelvic floor dysfunction at some point in the past. Time lapsed since last seeking care in this group of women showed that 49 had (29.3%) sought medical care less than 3 months prior, 39 (23.4%) 3-12 months prior, 29 (17.4%) 1-2 years prior, and 50 (29.9%) more than 2 years prior to the current urogynecology visit.

Amongst these women, 44.0% first approached their primary care physician, 40.4% a gynecologist, 9.6% a urogynecologist and 6.0% a urologist. The majority of women who sought medical care, 65.3% had received some form of treatment for the same condition previously; treatment modalities included medication (26.0%), surgery (14.7%), physical therapy (11.3%), pessary use (6.5%) and other treatments (1.7%).

Discussion

Our study aims to investigate the delay in care seeking pattern among new patients presenting to our urogynecology outpatient clinic during an eight month period. There was significant delay in seeking care with an urogynecologist for pelvic floor dysfunction among women in our cohort. Common pelvic floor dysfunctions such as pelvic organ prolapse and urinary incontinence are often viewed by patients as normal or expected consequence of childbirth and aging. The impact of this attitude and patient understanding of the nature of their condition was evident in the study by Margalith et al. who found that 74% of women delayed seeking help for at least 1 year and 46% for 3 years since experiencing urinary incontinence. These women reported lack of time (36.3%), shame (15.7%) and fear of surgery (14.7%) as reasons for their delay in seeking care for their urinary incontinence symptoms [3].

Other studies have looked at delay in seeking medical help in women with lower urinary tract symptoms and pelvic organ prolapse. Krissi et al. in a cohort of 223 women with lower urinary tract symptoms and pelvic organ prolapse found a mean length of delay in seeking care of 43.8 months without significant difference between the lower urinary tract symptoms group and the pelvic organ prolapse group. The study also showed that the main reason for seeking medical care was the severity of symptoms (75.6%). Another reason demonstrated to contribute to seeking care was the exposure to new information on pelvic floor dysfunction (22.9%) [4]. In our cohort, we show a similar trend with the majority of our patients presenting 12 months or more from the time of onset of symptoms or being informed of the condition by a primary care provider to the first visit for urogynecology evaluation. The most common reason for the delay in seeking care for patients in our cohort is "not having time to care for themselves". Other studies have found reasons such as patient's "hoping that symptoms would get better" and "too embarrassed to talk to general practitioners" as common reasons for their delay in seeking care for pelvic floor dysfunctions relating to incontinence, frequency and urgency [5].

We also found that increased severity of symptoms from moderate to severe correlated to patients' delay in seeking care. The reason for this delay may be due to fear of the underlying problem, thus resulting in some degree of denial until the symptoms become severe and unbearable. We also found a statistically significant association between being asked about pelvic floor symptoms by the primary care physician and delay in seeking care with the Urogynecologist. We may presume that patients felt they did not need to seek further care as they already discussed the symptoms with their primary care provider. They may have felt some degree of reassurance about the symptoms or cause of the symptoms. The timing of presentation could have thus been influenced by worsening symptoms as a result of progression of the condition or they may have reached a threshold at which their primary care provider advised further specialist consultation.

Age, parity, level of education, yearly visit to primary healthcare provider or being sexually active did not have a statistically significant correlation with care seeking pattern or delay in our patient cohort. This is in support of other studies that looked at delay between onset of lower urinary tract symptoms such as urinary incontinence and patient seeking professional help [6]. Since the majority of patients in our cohort reported a yearly visit to a primary health care provider, the delays in seeking urogynecologic care for their pelvic floor dysfunction may be from the patient not discussing these issues at their annual visit or the provider not asking about these symptoms or may have received some degree of reassurance that the condition was not urgent or life threatening.

We found that reasons for delay in our patient's cohort reflected some lack of information such as not knowing that their problem could be treated, being afraid the physician might recommend surgery, or acceptance of symptoms as being a normal process that most women suffer from. This may explain a gap in patient education and available resources for patient education on pelvic floor dysfunction. Development of educational resources addressing pelvic floor dysfunction both for the patient and the primary health care provider are needed.

Although clinical significance of delay in care seeking among

women with pelvic floor dysfunction is not well understood, there is no evidence that early medical intervention is more effective in treating pelvic floor dysfunction [7]. However, early intervention might incorporate more behavioral therapies, spare patients' distress, control symptomatic progression, and improve quality of life [4]. In order to implement early intervention in this patient population, it is paramount to understand and identify the potential barriers to seeking care for pelvic floor dysfunction.

Some limitations of our study design include not investigating individual pelvic floor dysfunction complaints or the different components such as incontinence, prolapse, myofascial pelvic pain and other complaints for analysis of potential differences in the delay in care seeking pattern. Including patients with conditions with acute symptomatology such as urinary tract infection can potentially result in overestimating care seeking behavior since these women are more likely to present sooner than later as a result of their symptoms. We also reported on a relatively homogenous population, so our findings may not be generalizable to other patient populations. Furthermore, data obtained were self-reported and may be subject to recall bias. This limitation however is inherent to studies throughout the wider literature that have assessed retrospective recall of symptoms, onset of symptoms and duration of symptoms. This study provides important information on our experience with patients presenting for evaluation of pelvic floor dysfunction and potential barriers for the delay in seeking Urogynecologic care. Further studies targeting primary care providers are needed to investigate pattern of patient evaluation and referral of patients with pelvic floor dysfunction.

In conclusion, there is significant delay in seeking urogynecologic care for pelvic floor dysfunction. Education and awareness about pelvic floor dysfunction is needed to provide consistent and concrete recommendations both for the patient as well as the primary health care provider regarding the array of pelvic floor dysfunction, effective evaluation, timely referral, and treatment options. With understanding the barriers to seeking care from both the provider and the patient's perspective, we can develop needed interventions to help close the gap in the delayed care seeking pattern for women with pelvic floor dysfunction.

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Authors Contribution

A Adelowo: Project development, Data collection, Manuscript writing

E O'Neal: Statistical data Analysis, manuscript editing

L Hota: Project development, manuscript writing and editing

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