

## Peer review

# Pelvic organ prolapse: a patient-centred perspective on what women encounter seeking diagnosis and treatment

## Abstract

The purpose of this study was to identify how pelvic organ prolapse (POP) impacts the lives of women, to understand the barriers and frustrations that women encounter in seeking diagnosis and intervention and to determine priorities consumers consider most important for future research and government action.

Between May and November 2006, the National Association For Continence (NAFC) distributed a survey via the association's quarterly public newsletter, *Quality Care*<sup>®</sup>. Surveys were completed and returned by 6.8% of the female readership who self-reported symptoms of POP. A total of 97 women agreed to participate in an in-depth telephone interview. Telephone contact was successfully made and interviews were completed by a single interviewer with one-third, or 33, of the 97 women.

Respondents reported issues that limit quality of life including urinary and faecal incontinence, inability to enjoy sport and dissatisfaction with conservative management and surgical treatment. Respondents also reported difficulty in discussing symptoms with their doctors and a lack of recognition of the severity of POP by primary care physicians. In addition, adequate public health education and promotion on the subject is lacking, according to respondents.

There is an identified need for health professionals to recognise the importance of prompt diagnosis and treatment of POP. In addition, there is a need to develop educational material for both primary care health professionals and consumers in order to encourage more open dialogue between providers and their patients on the subject. By identifying barriers and frustrations encountered in seeking diagnosis and intervention, the research findings also indicate the need for developing an instrument to assess consumer attempts to access diagnosis and intervention for POP.

*Keywords: pelvic organ prolapse, consumer survey, research priorities, quality of life, patient–doctor relationship, women's health*

## Introduction

### Background

The pelvic organs (bladder, uterus and rectum) are supported by a complex group of structures known as the pelvic floor and connective tissue known as endopelvic fascia including collagen, elastin, smooth muscle, blood vessels and nerves. The pelvic floor is considered synonymous with the levator ani because this muscle forms the effective contractile support structure of the pelvic region. Contraction of the levator ani is responsible

for support of the urethra and thus ensures urinary continence, especially when force is exerted such as during coughing. Another key component is the coccygeus, a musculotendinous surface of the sacrospinous ligament to which it is attached<sup>1</sup>. Together, this structure resembles the shape of a hammock. Pelvic organ prolapse (POP) occurs when the support structure of the pelvic organs weakens or breaks. From its Latin root, the term *prolapse* literally means 'falling forward' and refers to the descent of an organ from its normal position.

The current literature reports that half of all women who have a vaginal delivery will incur some degree of disruption to the pelvic floor musculature and 20% of those women will have symptoms that warrant intervention<sup>2,3</sup>. Over the lifetime of women, one in nine, or 11.1%, will have surgery for prolapse or incontinence. Nearly one in three, or 29.2%, of them will need repeat surgery due to further failure or recurrence of prolapse or treatment of subsequent dysfunction of the pelvic floor musculature<sup>4</sup>.

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### Competing interest statement

*No external funding received for this study.*

Symptoms of POP include the feeling of a 'ball' or protrusion from the vagina, a lump in the vagina and feelings of heaviness or pressure, especially at the end of a day of standing. Depending on the stage, positioning and specific pelvic organ affected, a woman may be able to see or touch a protrusion or feel little that is discernible<sup>5-8</sup>. Obstetric risk factors for POP include difficult or prolonged vaginal delivery and use of forceps in delivery; other risk factors include obesity, advancing age and hysterectomy<sup>9</sup>. While there is documentation in the literature of clinical symptoms and risk factors for POP, there is little if any published research to support an understanding of what women with symptoms face in seeking diagnosis and treatment.

Although researchers have developed and validated the Pelvic Floor Disorders Distress Inventory (PFDI) and the Pelvic Floor Disorders Impact Questionnaire (PFIQ) to fill the void in condition-specific instruments for examining quality of life of women affected by POP<sup>10</sup>, to date there is no condition-specific instrument for assessing the experiences of women in search of diagnosis and treatment for their POP.

Headquartered in the United States (US), the National Association For Continence (NAFC) seeks to improve the lives of people with loss of bladder and bowel control, voiding dysfunction, nocturnal enuresis and related pelvic floor disorders such as POP. Over the years, NAFC has found that a number of female consumers contacting the organisation for information and guidance reported symptoms of POP or were undergoing surgery for pelvic reconstruction to correct POP as well as treat stress urinary incontinence. To serve the needs of these women not represented by any other consumer education and advocacy organisation, the Board of Directors voted in May 2005 to broaden its mission to address, in addition to incontinence, related pelvic floor disorders such as POP. Since that time, NAFC has undertaken this research and other programme initiatives to improve its understanding of the patient perspective about POP, patient experiences in searching for diagnosis and remedies and patient needs and priorities.

### **Aims of the study**

The purpose of this study was to capture the experiences that American women confront in seeking diagnosis and intervention for symptoms of POP so that barriers and frustrations might be identified as an indication of the need for developing an instrument to assess attempts to access care. Secondly, the study sought to determine condition-specific priorities such patients consider important for future research and government action.

### **Methodology**

The research described in this paper was undertaken in two steps. The first step was a written survey distributed in Volume 24 No 1 First Quarter 2006 *Quality Care*® newsletter, in which

NAFC published a theme issue on POP. That edition was mailed in May 2006 to 7,120 female subscribers listed in the organisation's consumer database, of which it was estimated 1,424 would be potential respondents to the survey based on published statistics of incidence. Respondents had the option of completing the survey online at NAFC's website or returning the completed survey by mail. A 50% discount on the cost of a one-year subscription to the newsletter was offered as an incentive.

The survey included questions designed to obtain demographic information including age, parity, self-reported health status, education and marital status. Other questions sought to clarify diagnosed health disorders or disease and use of pharmaceuticals for managing chronic conditions. Multiple-choice questions were used to obtain information about whether women self-reporting POP symptoms had sought diagnosis and treatment for their symptoms, their satisfaction with different types of treatment and where priorities should lie for improved public health education and government-funded research. Respondents to the survey were asked to provide consent to be contacted by telephone to participate in the second step. Contact information had to be provided for volunteers willing to be interviewed. Written responses to survey questions were integrated by NAFC staff with the online submissions of respondents, via an encrypted survey software tool accessed through a portal on NAFC's website ([www.nafc.org](http://www.nafc.org)). Tabulation and statistical analysis of results were completed using the survey software package. The written survey can be viewed at the URL: <http://www.nafc.org/library/articles/>.

The second step was an in-depth telephone interview. Inclusion criteria for an interview were women who self-reported symptoms of POP, described as a bulge, protrusion, or pressure in the vagina, shared a medical diagnosis of POP, or self-reported past treatment for POP. Exclusion criteria were an incomplete survey, failure to make contact for an interview, or an absence of one of the inclusion criteria. All those who volunteered to be interviewed by telephone in their response to the written survey were telephoned up to three times to schedule an interview between October and December 2006. Ethics approval was discussed and advice sought from Northwestern University and the Medical University of South Carolina. It was deemed that institutional review board approval was not required given permission for contact was granted in writing in the survey.

In the absence of a specific instrument for assessing the experiences of women in search of diagnosis and treatment for their POP, the researcher relied on possible parallel circumstances revealed in the literature, such as obstacles to access that patients encounter in treating a sexual problem<sup>11</sup>. Typical reactions have been identified in a telephone survey of women regarding physicians unprepared to hear sexual complaints and thus

include embarrassed silences, misinformation, the imposition of one's personal values, a surprised or shocked expression, apparent boredom or preoccupation, personal discounting and belittling of the patient<sup>12</sup>. Wording of the questions used in this study was modelled similarly but not separately tested. Thus, telephone interviews undertaken to qualitatively identify barriers to healthcare for POP did not use a validated tool but followed other published examples of questions. An outline of questions asked during the telephone interview are available at URL: <http://www.nafc.org/library/articles/>.

Following a common outline of scripted questions, researcher NM conducted all of the interviews, lasting 25 to 45 minutes. These in-depth interviews were private and conversational in tone, allowing open-ended responses to gather verbatim remarks. Examples of questions include:

- Is commonality of the condition important to know? How does this affect you and your behaviour with respect to motivation for diagnosis and treatment?
- What do you generally feel to be the responsibility of the government with respect to public health information versus that of your own private doctor?
- How can older women be better educated to talk to their primary care provider or obstetrician/gynaecologist (OB/GYN) about POP?

Verbatim responses to interview questions were captured manually and grouped by keywords and phrases for categorical interpretation of responses. Captured responses, however, were de-identified so as to prevent any possible breach in confidentiality or privacy of respondents.

## Results

### Written survey tabulation

A total of 97 completed, written surveys were submitted from women who claimed symptoms or past diagnosis of prolapse, representing a response rate of 6.8% among the estimated 1,424 considered potential respondents. Based on these returns, the survey results can be interpreted with a +/-3% of error within a 95% confidence interval<sup>13</sup>.

The weighted average age of survey respondents was 64 years, with 26.2% aged 75 years or older. They were well-educated, with one-third (33.8%) having one or more graduate degrees. Two-thirds (66.2%) were married. Responses were received from 31 different states, representing a cross-section of all geographic regions of the US. Leading states of residency among respondents were: California (10.3%), Ohio (5.2%) and Florida (5.2%). The large majority of respondents (93.8%) identified themselves as white or Caucasian race.



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Half (50.0%) considered themselves to be in good or excellent health. On the question of medicines used, 23.8% of all survey respondents reported they were on prescription medication for bladder control symptoms. Approximately one-third had been diagnosed with hypertension and all were on prescription medication to manage it. Other predominant health problems revealed were arthritis (48.8%) and allergies (41.2%), with nearly half of the women on prescription drugs for these conditions.

Two-thirds reported urinary incontinence as well as POP, with the majority of those indicating either urge or mixed incontinence. Two-thirds (67.5%) reported having a cystocele, or prolapse of the anterior wall of the vagina. Half as many (33.8%) reported a rectocele, or prolapse of the posterior wall of the vagina. Approximately one-third (37.6%) self-reported prolapse of multiple vaginal compartments.

A list of quality of life issues was provided in the survey and respondents were asked to rank categories from one to seven, using one to signify the most affected and seven to signify the least affected. One of the seven options was open-ended to be completed by respondents if not described elsewhere in the list. The results of these selections are summarised in Table 1.

Table 1. Quality of life impacts from POP survey of women results.

Negative impact	Average ranking by respondents	Overall rank based on averages
Compromises with respect to bladder and/or bowel control	2.6	1
Inability to enjoy sports and other physical activities	3.1	2
Compromised enjoyment of intimacy with spouse or partner	3.4	3
Inability to exercise for good cardiovascular health and weight management	3.7	4
Physical pain and discomfort	3.8	5
Other	3.8	6
Compromises in the workplace	4.3	7

Table 2. Reasons cited for not ever pursuing treatment for POP survey of women results.

Choices of response	% of respondents
I do not understand or know what treatment options are available	25.0%
I do not have a specialist that I trust	20.8%
I do not have faith that the treatment will be lasting	16.7%
I do not have confidence that the outcome will be good	11.1%
I do not have health insurance or the financial resources to afford treatment	5.6%
I do not like any of the treatment options currently available	-
All other	20.8%

Among all respondents, 27.8% did not indicate they had pursued any treatment or intervention for their symptoms of POP. Survey responses to the question regarding the chief reason for not pursuing treatment suggest that lack of knowledge about options, lack of access to a trustworthy specialist and lack of confidence in outcomes are among the leading obstacles blocking pursuit of treatment by women (Table 2).

Those who had pursued one or more interventions were less likely to have tried a pessary than pelvic floor muscle training (PFMT) or surgery (Table 3).

A Likert scale was used to capture satisfaction with the interventions pursued. Respondents indicated their satisfaction with an individual choice, regardless of the number of different interventions experienced. Their responses revealed a lower level of satisfaction with a pessary than with PFMT or surgery (Table 4). Complaints volunteered about a pessary most often described the device as “ill-fitted” or “ill-fitting”.

Respondents to the written survey were asked to identify what they consider national research priorities and half stated that finding the primary causes of POP to develop measures for its

Table 3. Pursuit of intervention for POP survey of women results.

Intervention	Intervention	Intervention	% of respondents
Surgery only			23.0%
Surgery	PFMT		20.0%
Surgery	Pessary		1.5%
Surgery	PFMT	Pessary	18.6%
PFMT only			16.9%
PFMT	Pessary		12.3%
Pessary only			7.7%
Total – all respondents seeking intervention for POP			100.0%
Memo: PFMT option			67.8%
Memo: surgery option			63.1%
Memo: pessary option			40.1%

prevention should be of highest priority. Equal importance was attached by others to the development of procedures to assure a cure without the need for repeat surgery or other, subsequent intervention.

**Interpretation and analysis of interview results**

Qualitative work using patient interviews is routinely undertaken to strengthen the creation of quantitative instruments such as population questionnaires and patient-centered rating scales. Thus recognition of its contribution to the value of evidence-based research is considered to be growing<sup>14</sup>. Parallel to descriptive studies on the hierarchy of evidence-for-practice, the in-depth, one-on-one telephone interviews undertaken for purposes of this research admittedly still represent a level beneath the rigour of generalisable studies or conceptual studies<sup>15</sup>. Still, in the absence of a rich and exhaustive repertoire of literature examining the experiences of women in search of diagnosis and treatment for POP, this study is offered as a worthy contribution

Table 4. Satisfaction with intervention for POP survey of women results.

Type of intervention	% of respondents somewhat or extremely pleased with outcomes or experiences
PFMT	25%
Pessary	7%
Surgery	28%

towards better understanding of the obstacles faced by women with POP symptoms to accessing healthcare in the US.

Interviews were completed with 33 (34.0%) of the 97 women who completed the written survey and consented to participate in an in-depth telephone interview. The script for questions posed by the interviewer sought to amplify responses to three primary questions in the written survey, namely:

1. What do you feel is most lacking in public health information regarding POP?
2. What do you feel is most lacking with respect to the patient-doctor relationship regarding POP?
3. What is needed most with respect to research and innovation regarding POP?

**Public health information**

Somewhat surprisingly, it was learned from interviews that the majority of women squarely place the burden of consumer education about POP on the shoulders of private gynaecologists and internists responsible for the pelvic health of their female patients rather than government agencies. Many of those interviewed concluded that prolapse is being considered a “nuisance” by doctors, or a condition of secondary importance. While most interviewees agreed that it was helpful and motivating to know about the commonality of prolapse and the existence of treatment options, they also stress that the dialogue about prolapse needs to take place between the patient and her provider. According to those women who were interviewed, it is the government’s role to help publicise the efficacy and safety of

devices and procedures made available to women and to police objectivity exhibited by the medical profession. Some concern was expressed in interviews that American surgeons may be unduly influenced by the marketing of device companies or by how they are compensated for their time in surgery versus the clinic. The following verbatim remarks from interviews reflect this attitude:

- [Respondent 30] “It’s not embarrassment that keeps women from talking freely about it to their doctor. It’s a lack of knowledge. But doctors discount prolapse as less important than other problems. Women have to take responsibility for initiating questions when it’s affecting their quality of life.”
- [Respondent 17] “I don’t have faith in what the government could provide in the way of public health information. The FDA has been too lax too long. It’s really the private doctors’ responsibility to educate their patients.”
- [Respondent 5] “It’s important to know treatment [for prolapse] is possible. I didn’t know anything about prolapse. But this is between me and my doctor. It’s not the government’s place to educate me.”
- [Respondent 28] “It’s primarily the government’s role to make sure providers are objective and not pushing products on their patients.”

**Patient–doctor relationship**

In interviews, women described the lack of a sense of urgency by doctors when they wish to discuss symptoms of prolapse. They expressed the opinion that there needs to be a more open acknowledgement by providers once symptoms of prolapse are apparent. In the interviews, some expressed concern that primary care providers and OBGYNs are failing to inform patients soon enough when early stages of prolapse are noted upon routine pelvic examination. Some believe that these practitioners are doing little to help women avoid progression of the prolapse in severity, ultimately requiring surgical intervention. In the interviews, they explain this absence of dialogue, in their opinion, by a lack of knowledge and understanding about prolapse on the part of such providers. Examples of such attitudes and beliefs are captured by the following statements:

- [Respondent 15] “Women may have to mention it several times to get the doctor’s attention, but it’s really the doctor who is reluctant. Doctors don’t talk to their patients about this because they don’t want to look ignorant when they really don’t know much about something. So they pass over the discussion.”
- [Respondent 22] “OBGYNs never mention it when women are young. They need to be told about the risks, like heavy lifting. I’ve had five children and my doctors never mentioned prolapse to me when I was pregnant.”

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- [Respondent 3] “For more than four years I had back pain. My gynaecologist alerted me that symptoms [of prolapse] were present but didn’t discuss it. I have since changed doctors because I decided he didn’t know enough and discounted the importance of prolapse. There was no dialogue.”
- [Respondent 29] “... I have no idea why OBGYNs don’t bring this up to women who they think might be at risk. I had a 9lbs. baby at age 40 and I was overweight. I had no idea I could be at risk of prolapse. This was a chief role of my OBGYN and he failed to fulfil it.”
- [Respondent 31] “The lack of urgency is real with OBGYNs. Maybe younger doctors are more open, but the attitude of older gynaecologists is to do what they did to me. He just gave me a pat on the butt and told me I could live with it.”

### Other fears and frustrations

During in-depth interviews, women expressed trepidation regarding surgery and frustration with unsuccessful past surgeries. Most remain confused by the apparent multitude of different procedures and therefore lack confidence that the doctor who performs the surgery will be choosing the best procedure for them. Examples of such concerns are reflected in the following:

- [Respondent 4] “I had to do a lot of work to decide what to do. I went to several doctors because I didn’t want to have a foreign body in my body. One urologist told me that he did the same procedure on everyone. I couldn’t believe that I was just like everyone else, so I kept looking.”
- [Respondent 11] “I’ve had six bladder surgeries and most of them didn’t work. I had seen urologists and had five surgeries that did nothing ... The last surgery was the best, the most successful, even though I have some urgency.”
- [Respondent 32] “This was the worst surgery I’ve ever had. I was 16 days in rehab to regain my strength ... The doctor said he had to remove the uterus ‘to make room to do the repairs.’ I never understood why.”
- [Respondent 6] “... The first urologist didn’t connect the dots with my symptoms. Initially he tried Detrol. Then I had a hysterectomy. Then a sling ... and then I ended up diagnosed with prolapse!”
- [Respondent 25] “Every doctor I went to told me something different. I didn’t know what or whom to choose ... No one knows what works.”
- [Respondent 19] “I get discouraged by the need for multiple procedures.”
- [Respondent 9] “There’s a lot of disagreement among professionals about how to address prolapse. I found this in my research trying to decide what to do for myself. My father was a doctor, so I’m used to disagreement. I’m not

freaked that doctors might have different opinions and approaches.”

Interestingly, the clinic nurse was infrequently mentioned and therefore not considered by those interviewed to be an educator on the subject or the healthcare professional that a woman would turn to for advice or information. If anything, the feeling was negative, as echoed by the following remarks:

- [Respondent 2] “The nurse educators are not educating patients!”
- [Respondent 20] “The post-partum nurses need to know [Kegels are essential], too and deliver the message.”
- [Respondent 23] “Neither doctors nor do nurses tell anyone about lifelong pelvic health when women are young and the role this plays in sexual vitality.”
- [Respondent 8] “Labour and delivery doctors and midwives need to talk about it. I assure you, this has never come up ...”

### Discussion

The most important finding from the results is evidence that doctors on whom women routinely rely for their pelvic health may need to be better educated about the risk factors for POP, its symptoms, the proven treatment options and the means of managing symptoms so they are equipped to address the problem with their patients. In addition, the findings indicate that doctors should be more sensitive to the significance attached to POP symptoms by their patients. If they lack the time or interest in becoming more knowledgeable, doctors should be prepared to refer patients complaining of possible POP symptoms to specialists who are trained to diagnose the problem and promptly offer treatment to patients.

The research also suggests that women in general lack awareness of the risk factors associated with POP, its physical signs and its incidence. Their lack of knowledge about how to manage or surgically treat POP makes their search for a provider difficult. The findings indicate that women look first to their doctors to serve as their primary pelvic health educators. Nevertheless, access to greater public health education on the subject could better arm them with the vocabulary and questions to engage in dialogue more satisfactorily with their providers.

### Limitations of the study

Screening for POP without a physical examination is subject to bias across a spectrum of different groups of patients. While a group, such as women presenting to a tertiary care urogynaecology clinic, would be considered a high prior probability of POP, a simple screening question has been found to accurately screen for advanced POP without a physical exam. However, in a group with a low prior probability of POP such as a population-based epidemiologic study, this question

has poorer sensitivity<sup>16</sup>. Without access to medical records of respondents, it is therefore possible that some respondents to the survey were in error in self-reporting symptoms of POP. The evidence or extent of prolapse was not verified clinically in any of the respondents. Nor was the medical history of respondents verified.

The relatively low response rate to the survey could well have been, in part, due to the difficulty that women have in detecting early stages of prolapse. In addition, women currently experiencing prolapse who had previously been diagnosed with bladder or bowel control problems and successfully cured would have been less likely to still be readers of NAFC's newsletter and thus not likely recipients of the survey. Consequently, those who did respond were more likely to have had more advanced stages of, or recurrent, prolapse and therefore represented perhaps more complex medical cases and hence with greater frustration than the average adult female. Interpretation of verbatim comments captured in personal interviews needs to take this possibility into consideration, as remarks may have been skewed and might not be representative of the experiences of all women with POP.

There is, as well, the presence of survey error, that is to say those people who could have responded to the written survey but elected not to participate. Those willing to be interviewed personally after completing the questionnaire may have been willing to do so because of the desire to share extreme experiences, either very good or very poor. This possible bias to the research also needs to be taken into consideration and is always present in similar research in different fields of study. There was no attempt to contact non-respondents to the survey to quantify or reduce the presence of survey error.

While certain ethnic groups such as African-American women are viewed as having a low risk for POP, less is known and documented in the literature about Latinas<sup>17</sup>. Therefore, a demographically skewed sample such as the one witnessed does threaten external validity and thus the generalisability of results.

Lastly, there is the possible bias from variation in questioning of interviewees by the interviewer herself. While effort was made to frame queries objectively, probing questions may have inadvertently solicited stronger responses than might have otherwise been felt by the interviewee or otherwise influenced remarks. Still, having a single interviewer as opposed to multiple interviews provided some consistency from one case to the next.

## Conclusions

There is no known, previously published research documenting the experiences, feelings and attitudes of women experiencing POP in their search for diagnosis and intervention. This patient-centred, two-tiered study combining quantitative survey data

with qualitative input from American women provides helpful insight into the frustrations and barriers impeding quality in healthcare delivery, laying the groundwork for future research on the subject.

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