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Women's Experience with Overactive Bladder Symptoms and Treatment: Insight Revealed from Patient Focus Groups

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Abstract

Aims—Research has focused on treatment of overactive bladder (OAB) symptoms in women with the goal of cure. The objective of this study was to assess women's perceptions of their OAB symptoms, treatment experience, and outcomes by conducting patient focus groups.

Methods—Women seen in our academic center female urology referral clinics were identified by ICD-9 codes for OAB symptoms and recruited to participate in one of five focus groups, totaling 33 patients. Non-clinician moderators conducted the focus group sessions incorporating topics related to patients' perceptions of OAB symptoms, treatments, and outcomes. Data analysis was performed using grounded theory methodology.

Results—Qualitative analysis yielded several preliminary themes: impact of OAB on quality of life, strategies to control wetness, medications and side effects, and triggers. The majority of focus group participants reported only a partial response to medication and other physician-recommended treatments for OAB. They therefore developed self-reliant personalized strategies to improve their quality of life. These strategies included fluid restriction, preventive toileting, and, most importantly, the use of incontinence pads.

Conclusions—The majority of the women who participated in the focus groups reported only a partial response to medical and other treatments for OAB. As a result, they developed personalized self-management strategies to improve their quality of life. Although most studies addressing the treatment of OAB aim at curing the condition, such a strategy may be unrealistic. Applying a chronic care model that uses a patient-centered symptom management approach to OAB may optimize patient outcomes and improve quality of life.

Keywords

focus groups; qualitative research; urinary incontinence; grounded theory

Introduction

Overactive bladder (OAB) is defined by the International Continence Society as urinary urgency, with or without urge urinary incontinence, typically accompanied by frequency and nocturia¹. These symptoms are often the result of involuntary detrusor contractions while the bladder is filling². It is estimated that OAB affects 16.9% of women in the US and 16.0% of men³. The prevalence of OAB among both genders increases markedly after age 64. In a survey of community-dwelling adults, the National Overactive Bladder Evaluation (NOBLE) Program found that more than 34 million people in the US have OAB³. In 2000, the estimated total economic cost of OAB was \$1.79 billion for men and \$7.37 billion for women⁴.

Research and marketing have focused on the benefits and side effects associated with various treatments for OAB. Although many studies of anticholinergic agents demonstrate good short-term efficacy, a large percentage of patients prescribed anticholinergic therapy stop taking their medication due to poor efficacy or problematic side effects including dry mouth, dry eyes, and constipation^{5, 6}. Moreover, a cure for OAB, such that medications or other therapy are no longer required, is difficult to achieve.

In addition, vast efforts have been made to better measure clinical response to treatment, as evidenced by a multitude of questionnaires developed in the literature^{7,8,9}. Numerous definable clinical outcomes measures have been used in studies, such as number of incontinence episodes, frequency, severity of urgency, voided volumes, and even the ability to complete tasks before voiding. Despite the availability of these measurement tools, we still lack knowledge regarding which symptoms of OAB bother patients most and which outcomes of OAB treatment patients feel are important. With the long-term goal of improving the quality of care provided to aging women with OAB, our objective was to find out from patients what matters most to them. We specifically sought to assess patient perceptions of OAB symptoms and treatment by conducting focus groups among women seen in specialty urology clinics.

Methods

Because of the paucity of information regarding patient perspectives and OAB, we sought a qualitative research method that would facilitate exploration of ideas and create a foundation for future research. Grounded theory is different from other research methods in that it is “emergent”¹⁰. Rather than testing a hypothesis, it aims to understand the research situation, and thereby discover the theory implicit in the data¹¹. Specifically, focus groups permit a discussion of many topics while allowing for probing of certain topics further when needed.

After obtaining institutional review board approval, we recruited patients from the female urology specialty clinics in the UCLA Department of Urology. Potential subjects were first selected based on International Classification of Diseases (9th edition, ICD- 9) codes for the following OAB-related symptoms: 788.31 (urge incontinence), 788.41 (urinary frequency), 788.43 (nocturia), and 788.63 (urgency of urination). Records were then reviewed for exclusion criteria, which included pelvic prolapse, interstitial cystitis, pelvic pain, as well as complications from anti-incontinence or other pelvic surgery. Potential subjects were also excluded if they did not speak English, were younger than age 21, were unable to ambulate, or had dementia prohibiting effective focus group participation.

After files were screened, we recruited participants by telephone and asked them to participate in a 90-minute focus group session. We offered patients a small honorarium for their time. Focus groups were conducted by trained female non-clinician moderators. A standardized open-ended script was used. Focus groups were audio taped and transcribed

verbatim. The topics covered in the focus groups encompassed women's perceptions of OAB symptoms, as well as OAB treatments and outcomes (Appendix 1). Topics for the focus group script were developed through reviews of the literature and validated questionnaires. Grounded theory methodology, as described by Charmaz, was used to analyze the data¹². Briefly, this includes initial line-by-line coding of transcripts utilizing key phrases in the participant's own words. This is followed by a grouping together of similarly-coded phrases into preliminary themes. Preliminary themes are then grouped together to develop categories, from which core categories, or emergent concepts, are derived. Four investigators separately performed line-by-line coding. Preliminary themes were then compared and merged.

Results

We conducted five focus groups, comprising 33 participants (Table 1). The majority of women were non-Hispanic Caucasians. There was a wide range in the severity of OAB symptoms as well as the treatments that the women had experienced. Four women had undergone sacral neuromodulation, and one had previously undergone intravesical botulinum toxin injection.

Qualitative data analysis was utilized to extract key phrases that emerged from each focus group. The analysis resulted in four preliminary themes (Table 2). The first was triggers for incontinence. Although many triggers were raised in the focus groups, a few were mentioned frequently. These included putting the house key in the door and undoing the knot of one's pants in preparation for using the bathroom. The second preliminary theme was medications and side effects. The study indicated that most women had, at best, a partial and/or temporary response to medication. In fact, only a minority who had previously tried anticholinergic medication continued it on a long-term basis. Among the four women who had undergone neuromodulation testing, all had sufficient response that they underwent neurostimulator placement. Three of the four patients had persistent improvement at the time of the focus groups, though none was cured of symptoms.

The third preliminary theme was the impact of OAB on quality of life. Participants reported the most impact of OAB on travel away from home and nocturia. Some stated that they abstained from movies or other activities that would be compromised by the interruption of using the bathroom. Women bothered by nocturia complained of chronic sleep deprivation and fatigue during the day. The fourth theme was strategies to control wetness. Only some of these strategies were taught to the participants by medical providers; most of the strategies were self-taught. The strategies most often mentioned were preventive toileting (using the bathroom before feeling the urge to urinate), Kegel exercises (despite mixed results), and fluid and caffeine reduction (Table 2). Incontinence pads were lauded as the most trustworthy and successful self-management strategy, as pads allowed women to travel distances away from the toilet without the fear of wetting their clothing. Pads also prevented leakage onto their bedding at night.

Three important emergent concepts surfaced from the qualitative analysis. The first was self-responsibility and self-blame. The women expressed that they felt they should be able to control their bladder, and that incontinence episodes reflected a psychological weakness on their part (Table 3). As such, it was clear that many women did not understand the pathophysiology of OAB, nor did they understand the purpose of many diagnostic studies. The second emergent concept was a desperate quest for a cause and for a cure. While in the focus group sessions, they questioned and probed each other, hoping to discover something new that might be superior to their current methods. Despite this desperation, surprisingly few women in the focus groups had elected sacral neuromodulation or intravesical

botulinum administration, procedures routinely offered to patients with medication-refractory OAB. It was apparent that, although participants had tried various treatments, incontinence pads were the only management strategy that provided them the freedom to participate in activities without the worry of leakage. The third emergent concept was self-reliance and the development of personalized symptom management strategies. When the treatments that physicians prescribed had failed, the women developed their own strategies to manage the symptoms of incontinence (Table 3).

Discussion

The OAB focus groups were conducted to gain a better understanding of women's perceptions of their OAB treatment and symptoms. Several important findings resulted from this study. First, OAB has a profound impact on the quality of life of the women in the study. The extent of the effect varied from impeding movie-going to preventing one from leaving the house for any extended period of time. The women also identified numerous everyday occurrences that acted as triggers. For example, putting the house key in the lock caused many women to have an incontinent episode. The many triggers frustrated the women and detracted from their quality of life.

Second, the overall response to anticholinergics was poor among the participants. Most of the women who had been on medications for more than a few months had stopped taking them. Some had even tried numerous anticholinergics before finally giving up on them. Overall, we found that those who had taken medications for more than a few months reported initial success for the first few months and subsequent disappointment with the treatment. Those women stopped taking the medication once it was no longer helpful.

The women who failed medical treatment began using a symptom management approach that they had designed for themselves through trial and error. Incontinence pads were lauded as the most trustworthy and successful treatment. Aside from utilizing pads, many women stated that they tried to reduce the amount of fluid they drank during the day as well as the amount of caffeine that they consumed. Some women stated that they successfully used preventive toileting as a means to manage their symptoms. The last conservative treatment mentioned by the women was Kegel exercises. Most of the women had first learned of Kegel exercises early in adulthood.

Three main concepts emerged from our qualitative analysis. The first was that women often blamed themselves for their condition and attributed it to various experiences that they had in their lives. Self-blame has been shown to occur for many diseases, such as cancer and inflammatory bowel disease^{13, 14}. Although little data exists on the issue of self-blame with urinary incontinence, this finding leads us to ask whether women have the tendency to blame themselves for this condition. Such self-blame may be due to lack of information about the etiology of overactive bladder symptoms. Providing information about the etiology of OAB to patients newly diagnosed with the condition may help alleviate symptoms of self-blame and associated anxiety.

The second emergent concept was a desperate quest for both a cause and a cure for OAB. Although various treatment modalities often improved the symptoms of OAB among these women, actual cure did not occur. This finding suggests that older women with OAB might greatly benefit from a chronic disease model in which the focus is shifted from curing a disease ("cure") to optimizing symptom management ("care"). Expecting a cure of OAB symptoms may be unrealistic. Providing patients with an understanding of the reality that OAB is unlikely to be cured may lead to better management of expectations.

The third concept was that there was an overall failure of conventional strategies, and, as a result of this failure, the women became self-reliant and developed personalized strategies to alleviate their symptoms. That patients developed their own solutions is consistent with models of chronic care^{15, 16}. Patient self-management is crucial in maximizing both the effectiveness and efficiency of chronic disease care. Since chronic disease cannot be cured, the patient needs to play an active role in a combination of different health care practices. Holman and Lorig reported that patients with chronic disease have different needs than those with acute illness. These include access to information about disease diagnosis, treatments, and consequences, continuity of care and coordination of care, ways to cope with symptoms, and ways to adjust to the consequences of disease¹⁵. Treating OAB as a chronic condition may positively impact patients with OAB by allowing them to take a more active role in their care.

The data from these focus groups gives us the impetus to encourage health care workers to shift their treatment of OAB patients from a curative approach to a chronic care approach applying symptom-management strategies, including those strategies that patients learned themselves. Although most participants had been prescribed medications for their OAB symptoms, not all had been instructed on how to manage their symptoms. Many participants were unaware of effective symptom management strategies, such as the use of incontinence pads and proper performance of Kegel exercises. We propose that patients should be instructed in the various ways that they can help themselves to manage their incontinence. This includes pelvic muscle rehabilitation and behavioral therapies such as those recommended by the Agency for Healthcare Research and Quality (AHRQ)¹⁷. Behavioral therapies include bladder training (teaching people to resist the urge to void and gradually expand the time intervals between voiding), and scheduled toileting. AHRQ also specifies behavioral therapies for the chronically incontinent, such as scheduled toileting, prompted voiding, improved access to toilets, and fluid management. Medical and minimally invasive surgical treatment options are useful adjuncts. However, expecting a cure from them may be unrealistic. By giving patients more tools to control their symptoms, physicians have the ability to present patients with more control over their condition, which in turn gives the patients more freedom to live their lives.

Our focus group findings shed light on some inherent problems in measuring OAB outcomes with questionnaires. For example, a common symptom-management approach for the OAB wet patient is preventive toileting. Such toileting will result in an increased number of voids per day, and decreased voided volumes, as measured by a voiding diary. However, the frequency in this case is not a true symptom, but rather a symptom-management strategy. Also, we found that all women denied episodes of enuresis. However, on further questioning, many acknowledged leaking into pads at night. Hence, our focus group findings demonstrate the inherent difficulties in accurately measuring incontinence through the use of questionnaires, and even through voiding diaries.

This study has limitations that are inherent in the study design. The first was referral bias. As the participants were recruited from specialty urology clinics, many were patients who had been referred because of failed treatment with their general practitioner. Hence, the women in our focus groups may have had more severe symptoms than the general OAB population, and were less likely to respond to simple medical or surgical interventions. The second limitation was that participants were recruited via telephone during business hours and the focus groups were held during those hours. As a result, the majority of those who participated were retired, and therefore represent an older group of OAB patients. Therefore, this data may not reflect the experiences of a younger woman with OAB. The last limitation is that discrepancies and biases in data analysis may arise when analyzing qualitative research. The data was analyzed separately by four investigators to minimize this limitation.

Conclusions

The majority of women who participated in the focus groups reported only a partial response to medical and other treatments for OAB. As a result, they developed personalized self-management strategies to improve their quality of life. Although most studies addressing the treatment of OAB aim at curing the condition, such a strategy may be unrealistic. We propose that a patient-centered symptom management approach using a chronic care model will optimize patient outcomes and improve quality of life.

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Appendix 1

Focus Group Topics and Sample Questions

Topics	Sample Questions
Symptoms	<ul style="list-style-type: none"> • Describe your experience with frequency. • In what situations does it bother you the most? • Do you go to the bathroom frequently to prevent leakage? • When you experience urgency, is it the discomfort from fullness or the fear of leakage that makes you want to go to the bathroom? • What triggers make you want to go to the bathroom? • Do you ever leak on the way to the bathroom? • What bothers you most about nocturia? • Has your nocturia affected other people in your household? • Do you wear a pad? • Have you ever wet the bed? • Is there something that you no longer do because of OAB? • Has OAB had any implications for intimacy?
Experience with OAB workup	<ul style="list-style-type: none"> • When you were diagnosed, what information did you receive about OAB and who gave you that information? • Was your condition appropriately addressed by your primary care provider? • Once you were diagnosed with OAB, were you better able to cope with the condition? • Describe the diagnostic tests you received for your OAB symptoms.i
Experience with Treatment	<ul style="list-style-type: none"> • How did you decide on your OAB treatment and what influenced your decision? • Describe your treatment as well as side effects that may have resulted from treatment. • Which medications have you taken, which have you found helpful? • Have you tried bladder training? • Have you tried fluid restriction?

Table 1

Focus Group Participant Demographics

Participant Characteristics		Number of Patients
Race	Asian	2
	Black	6
	Caucasian	25
Marital Status	Divorced	7
	Married	14
	Single	6
	Widowed	6
Previous Procedures	Interstim	4
	Botox	1
Total patients		33
Mean Age (range)	67 (39–91)	
Median Age	70	

Table 2

Preliminary themes and illustrative quotes pertaining to those themes

Preliminary Themes	Quotes
Triggers for incontinence: <ul style="list-style-type: none"> • Running water • Standing from sitting • Putting the house key in the door • Sleeping longer than usual • Undoing pants in preparation for using the bathroom 	"If I have been sleeping extra long, I can't make it to the bathroom." "There is something about turning the key in the latch, and I am 10 feet from the bathroom."
Medications and Side Effects: <ul style="list-style-type: none"> • Ineffective in controlling wetness • Unpleasant side effects 	"I was taking the pills, and no, it didn't meet my expectations at all. Actually I stopped it because it didn't seem to be helping that much." "Cause you get to the point where all of a sudden you can't say the next word and your mouth won't move. That's bad."
Impact of OAB on Quality of Life <ul style="list-style-type: none"> • Movies, airplane trips, car trips • Nocturia • Inability to fall back asleep • Fatigue during the day 	"It controls my life." "Going on car trips, long car trips, airplane trips. I mean it doesn't stop me but you have to think where am I gonna sit, where am I gonna stop, where's the next bathroom." "It [OAB] definitely interferes... just remember, if I'm not here I am in the bathroom." "I haven't slept through the night in years. I think that is a profound impact on my life."
Strategies to Control Wetness: <ul style="list-style-type: none"> • Preventive toileting • Fluid restriction • Altering type of drinks • Kegel exercises • Wearing pads 	"Don't ever pass a toilet without stopping." "I know every bathroom in Southern California, practically the world." "I try not to drink coffee after noon." "I'm thankful for the pads because this problem is controlling my life, and this is my life saver so I can go wherever I want to go." "That is our legacy. Pads, I mean. Carrying it with us." "I buy the underwear, I buy the little pads, I buy the bigpads... I am just, as they say, I am the best buyer of pads."

Table 3

Emergent Concepts and quotes pertaining to those concepts

Emergent Concepts	Exemplar Quotes
Self responsibility and self blame for their condition	<p>"I had a hysterectomy. Did that help with this? I could never get any answers."</p> <p>"I was wondering if a serious tear that I had during childbirth [is the reason for OAB]."</p> <p>"I thought I had an anatomical problem."</p>
A desperate quest for a cause and for a cure	<p>"Is there one specific thing that causes it or is it the number of years you're here?"</p> <p>"I just thought that it was a process of getting older and that you can't do anything for it."</p> <p>"That's what bothers me. They don't come out and say what is causing this."</p> <p>"I don't understand why the medical field hasn't been able to solve this problem for us. They can take care of men's erectile dysfunction, but they don't care about us. Period."</p> <p>"We are so desperate we will try anything."</p>
Self-reliance (personalized self-management strategies)	<p>"First you go to the doctor for advice and if that doesn't work you start playing doctor yourself doing what you think should be done. I mean what can you do?"</p>