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Urinary incontinence and health seeking behavior among White, Black, and Latina women

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Structured Abstract

Objective—Fewer than half of women with urinary incontinence (UI) seek care for their condition. Our objective was to qualitatively assess themes surrounding treatment seeking behaviors.

Methods—We conducted 12 focus groups in women, and using purposive sampling we stratified by racial or ethnic group (White, Black, Latina) and by UI frequency. All sessions were transcribed and coded for common themes. Comparative thematic analysis was used to describe similarities and differences among groups.

Results—In total, 113 (39 White, 41 Black, and 33 Latina) community dwelling women participated in focus groups. There were no differences in treatment seeking themes between groups with different UI frequency. However, certain themes emerged when comparing racial/ethnic groups. Women from all groups shared experiences of embarrassment and isolation due to UI, which were impediments to care seeking. White and Black women described discussions with close friends or family that led to normalization of symptoms, and prevented care seeking. Latina women maintained more secrecy about UI and reported the longest delays in seeking care. Women articulated a higher likelihood of seeking care if they had knowledge of treatment options, but White women were more likely to seek UI-related knowledge compared to Black or Latina women. Physician communication barriers were identified in all groups.

Conclusions—Despite similar experiences, there are different perceptions about care seeking among White, Black, and Latina women. Culturally relevant educational resources that focus on a

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range of treatment options may improve knowledge and thus improve care seeking behaviors in women with UI.

Keywords

Care seeking; disparities; focus groups; treatment seeking; qualitative research

Introduction

Urinary incontinence (UI) represents a major public health burden due to its prevalence and impact on quality of life.(1–3) Approximately 16% of adult women in the US report weekly or more frequent UI,(4, 5) but fewer than half of those women seek care.(6–9) Furthermore, despite comparable prevalence of UI amongst racial and ethnic groups,(1, 6, 10) there are conflicting reports of whether racial and ethnic factors play a role in which women endorse seeking care.(11, 12)

Health-seeking behavior depends on multiple factors. The “grounded theory of health seeking behavior” is a theoretic model that explains the processes that underlie care seeking.(13) This theory states that for chronic conditions, decision-making goes through several stages culminating in a judgment of impact on quality of life versus costs of therapy. At this point, an individual might seek care, but that decision is highly influenced by the individual’s knowledge of treatment options. For women with UI, 37% are unaware of types of UI therapy.(6) This proportion is likely higher in minority women since White women demonstrate more knowledge of UI treatments compared to their non-White counterparts.(14, 15) However, it is unclear if there are additional racial or ethnic differences that contribute to the variability in seeking care.

An improved understanding of care seeking behavior is necessary in order to optimize access to care. In contrast to observational techniques, qualitative research can help to assess attitudes, perceptions, and decision-making processes that underlie behaviors.(16) Thus, our objective was to qualitatively assess the themes surrounding treatment seeking behaviors in White, Black, and Latina women.

Materials and Methods

This study, approved by the Duke University Medical Center (DUMC) Institutional Review Board, employed qualitative research methods to examine care seeking behavior and UI. We used purposive sampling to recruit adult community-dwelling women to participate in a two-hour focus group with a trained moderator. Since we were interested in distinguishing sociocultural perspectives, focus groups were stratified by race/ethnicity (White, Black, and Latina). To gather varying perspectives about care-seeking, the focus groups were further stratified by UI frequency (at least weekly versus less than once per week). Over a period of 6 months we held 12 total focus groups; two per racial/ethnic group for each level of UI frequency. Though there are little data on the number of focus groups required per sub-sample, a common guideline suggests a minimum of two focus groups per defining demographic group, with 4–12 participants each, to obtain thematic variation.(16)

Women were recruited via flyers and outreach in DUMC and local community centers. Potential study candidates were screened by a trained research coordinator in the woman's native language. Women were excluded if they were pregnant, up to 3 months postpartum, mentally incapable of completing self-administered questionnaires, or if they did not fall into pre-defined categories for the focus groups. Candidates were asked to self-identify their racial and ethnic categories, and to self-quantify the presence and frequency of UI (daily, weekly, monthly, rarely or never). Based on these responses, they were invited to participate in a focus group corresponding with their race/ethnicity and frequency of UI. Women were considered eligible for the groups with "frequent UI" if they reported UI occurring daily or weekly. Women were considered eligible for the "infrequent UI" groups if they reported UI monthly, rarely or never. Women did not require a physician's visit prior to enrollment and thus we did not further stratify groups based on type of UI.

Focus group sessions with White and Black women were conducted in English. Groups with Latina women were conducted in Spanish. All groups were conducted by moderators with expertise in facilitating focus groups. After providing individual informed consent, participants were asked to complete questionnaires regarding demographic information, the Questionnaire for Urinary Incontinence Diagnosis (QUID),(17) and the Sandvik Incontinence Severity Index.(18) The moderators then led the groups in discussions about UI and care seeking behaviors according to a semi-structured focus group guide.

Sessions were recorded using digital audio recorders, transcribed verbatim, and Spanish-language transcripts were translated by the session moderator or a bilingual physician into English. All transcripts were uploaded into Atlas.ti (Scientific Software Development GmbH, Chicago, Illinois) to facilitate analysis. All session transcripts were reviewed and a codebook was created(19) that included a number of *a priori* codes related to the aims of the study, and codes created during our initial transcript review.

Each session transcript was then separately coded for theme content by two investigators, one a qualitative researcher and one a content-area expert. Code definitions were created to ensure consistency in coding. The codebook was refined during the coding process with further transcript review and discussion by the two primary coders (NS, NA). A third investigator (JW) reviewed two coded transcripts to check reliability in coding and to ensure all themes were identified. Using code frequencies, we performed a comparative thematic analysis to assess for similarities and differences in our participants.(20)

Results

We included 113 women (39 White, 41 Black, and 33 Latina); baseline characteristics are displayed in Table 1. We separately analyzed some of the specific barriers to care seeking using quantitative methods, and those results are reported elsewhere.(21) Here we report the results of our qualitative analysis. Based on transcript review, we did not identify differences in themes between the women with frequent versus infrequent UI. Thus we focused on comparisons between racial and ethnic groups. Four focus groups were conducted in each racial/ethnic category, and we consistently achieved thematic saturation in each racial/ethnic category. During transcript review, we created 84 codes and after thematic analysis, these

themes were grouped into 4 overarching categories: 1) Experiences; 2) Understanding; 3) Behaviors; and 4) Context.

Experiences

This category addressed triggers and experiences of UI, along with general feelings related to UI. Experiences were similar among groups with dominant themes including: challenges in social situations, shame, fear, and isolation. Impairments in sexual activity were a common theme among White and Black women's focus groups, related both to embarrassment and to physical functioning. Women with UI spoke about their lack of sexual activity or lack of sexual desire due to the condition. Women without UI recognized the potential for interference with sex as well. However, some Latina women tended to frame UI as a consequence of sexual acts ("*I think this happens when the husband touches you too much*") or potentially as a result of sexual abuse. Across groups, women tended to talk about these experiences of embarrassment, shame, and isolation as impediments to seeking care for UI. Many women spoke of enduring symptoms for some period of time before the negative consequences of UI in their daily lives outweighed the emotions that prevented them from seeking care.

Understanding

The "understanding" category included attitudes, perceptions, and overall knowledge of UI. Attitudes were discussed by all groups and were divided into two subthemes: attitudes of women themselves and those they perceived in others. The most dominant subtheme, present across all groups, was a negative attitude from spouses and family members that translated into a lack of support for women with UI. One White woman with UI stated:

"My husband will get in the car and drive...and I get in the car and we stop every hour. And he just has a fit about it."

A Latina woman said:

"They will not receive the support...from their partner. I imagine if you think you don't have your partner's support..they may think that no one else will support them."

Across all racial/ethnic categories, women perceived that childbirth was associated with UI, and women were divided between beliefs that UI was normal with aging and perceptions that UI happens with age but is not normal.

Within the category of "understanding", awareness or knowledge of the condition of UI differed among racial/ethnic groups. White women expressed an early awareness of this condition, perhaps starting in childhood, as something overheard in discussion with female family and friends. In contrast, Black women remarked that there was a lack of awareness in younger age groups:

"For me, I never heard of it when I was coming up with my mom -- and we were close and she would talk about things -- I never heard of that one. I heard of menopause and stuff. I never heard about any further like the leakage of urine."

Latina women also expressed a lack of awareness, but this seemed to persist into older adults:

“I talk to my coworkers about it ... and I got the feeling that they have no idea that this is a disease. And things like this are happening I think they even ignore the possibility of this disease...”

Both White and Black women expressed the belief that treatment options exist for UI, though this was not expressed in Latina focus groups. Women mentioned that if they had some knowledge that treatment options exist, they may be more likely to seek care.

Awareness of UI was also affected by women’s ready access to information and choice of media, which varied by racial/ethnic group. For White women in our focus groups, the Internet, blogs, and web-based resources were the dominant means of gathering information about UI. Compared to other groups, White women more commonly discussed researching treatment options for UI. For example one White woman said:

“Well I think a lot of health issues today are really left for us to become self-educated. And that we are expected to challenge some of the things our doctors tell us because we research it ourselves and get some information.”

This is in contrast to Black women who more often expressed a desire for mass media and social outlets to gather information:

“I think the conversations are helpful. And I think there need to be more services and conversations...support groups”;

“have commercials like [what they do] for breast cancer”.

In Latina women there was very little discussion about seeking information, and more emphasis on the need for resources, with the belief that medical providers should provide information. Latina women also believed that television advertisements would be a good medium to convey information, as long as the messages were in Spanish.

Behaviors

Themes in this category addressed adaptive behaviors and ways that women deal with UI. Aside from seeking help or treatment, dominant themes were: ignoring symptoms, maintaining secrecy, and normalization of symptoms. All groups talked about ignoring symptoms and living with their condition; this was especially emphasized if UI symptoms were not yet very severe. All groups talked about some level of maintaining secrecy regarding UI. However, White and Black women tended to develop small circles of people with whom they would discuss their symptoms. In many instances these were close female friends or mothers, and not necessarily spouses. Women discussed their symptoms to seek advice or reassurance. These discussions often led to normalization of symptoms and thus inhibited care seeking. For example:

“Less likely to seek care because you’re just ... you’re having it, I’m having it. Part of growing older or something”;

“...there’s a lot of people who know about it but there’s not a serious conversation about it... I mean I guess in a way I don’t have anybody to really have a serious conversation with except for my doctor. And...my mom doesn’t give me any advice.”

Latina women tended to maintain more secrecy around UI compared to other women as exemplified in this quote:

“in the Hispanic culture... people feel shy to talk about certain things. And from what I have seen, not only our culture but in different cultures too, they are concerned about what people may think or say. This stops them from asking anything, and if they don’t say anything or ask they will not receive the necessary help”;

“I think the same thing she [said]... And we think that we can fix all the problems by ourselves and sometimes is very difficult to fix the problems all by yourself.”

Women from all groups expressed a desire to have health professionals screen for UI symptoms:

“I think that if your doctor asks you during a physical, ‘Do you have any issues with this?’ you’re more likely to say actually yes, than you having to bring it up on your own.”

This desire for screening from health care professionals was especially dominant in the Black and Latina focus groups.

The relationship with the doctor and lack of useful information that women received from doctors was identified as a barrier. Women expressed frustration that when they finally decided to talk to their doctors about UI, they did not receive adequate information or might not have been taken seriously. Women discussed that when they did not receive a serious response it was especially frustrating, since it usually took some time and level of courage to bring up the issue in the first place. Many women felt that concerns regarding UI are better dealt with by a specialist than a general primary care or OB/GYN provider because they do not receive adequate information from non-specialty providers:

“You go to the doctor, first of all you’ve got to talk to the people that you know so you can get information, then you have to get on the internet and do research, because they don’t present information to you. And there can be stuff out there that can help you, and they don’t even tell you about it.”

Context

Themes such as gender, financial concerns, and racial/cultural differences were additional circumstances that contextually influenced care seeking. Financial concerns were often portrayed as a barrier with treatment seeking, particularly regarding co-pays and prices of medications. In Latina women, there were substantial economic concerns. The Latina focus group participants in our study were generally under-resourced and sometimes did not have basic medical insurance, which made seeking care for quality-of-life issues very difficult.

Regarding racial/cultural differences, Latina women pointed out many differences in their cultural expectation of care seeking compared to other racial/ethnic groups. They also felt that the lack of conversation and added level of secrecy was more unique in their population. One Latina woman summed up numerous unique barriers:

“I believe the Latinas are the least ones to go out and seek support. First because they are more shy to talk about this topic, second because they see it as something normal, and third because they don’t want to pay attention so they won’t have to go to the doctor and spend money...”

Gender roles came up as a very strong theme across women from all racial/ethnic groups. Gender issues came up in many contexts, and there were numerous discussions about how gender may play a role in the patient-physician relationship:

“I was sent to a urologist first...so not saying that a man really shouldn’t know how you feel, but he really didn’t understand”;

“... I don’t hate men by any means, but there is something different to me in a woman’s understanding of another woman.”

Women of all races and ethnicities also expressed particular embarrassment and discomfort if urinary leakage occurred around men.

Discussion

Through comparative analysis of focus group transcripts, we identified similarities and differences in how White, Black, and Latina women consider UI. We found that the experiences related to UI were similar, but awareness about UI was different among White, Black, and Latina women. Differing knowledge about UI and treatment options led to differences in care seeking. Gender-related and financial barriers were identified in all groups, and there was an increased level of secrecy in Latina women that was an additional barrier.

A strength of our study is that participants were recruited from the community, and not already presenting for UI treatment. Thus we could qualitatively assess perceptions in a more generalizable population. However, our study also corroborates findings from other qualitative studies in populations of women with UI. Anger *et al.* qualitatively assessed patient perceptions and treatment goals in women seeking urologic care for UI; they identified similar experiences of UI as those identified in our study.(22) Hatchett *et al.* qualitatively explored knowledge and perceptions of pelvic floor disorders among African American and Latina Women. Similar to our findings, they identified embarrassment about pelvic health as a barrier to care seeking, and Latina women indicated that cost/insurance factors were additional barriers.(23) A questionnaire-based study assessing UI knowledge specifically found that African American and other women of color (including Latinas) were less likely to know that certain exercises can help control leakage, and women of color were more likely to think that surgery is the only treatment for leakage.(24) These misperceptions about treatment options are similar to the knowledge discrepancies that we found among our

study participants. We further used comparative analysis to determine how these thematic differences may influence care seeking behaviors in White, Black, and Latina populations.

In other studies, age, impact on quality of life, symptom severity and bother have been identified as determinants for care seeking behavior.(25) Among these determinants, it is possible that certain racial or ethnic groups may perceive more UI bother or impact on quality of life despite the same UI severity, though this association has not been consistently demonstrated in the literature.(26–27) When reflecting on the grounded theory of health seeking behavior, decisions about care seeking are not only based on cost, bother, and quality of life impact, but these decisions are also highly influenced by an individual's knowledge of treatment options. Our findings corroborated knowledge disparities regarding UI treatment in different racial and ethnic groups, and further exposed differences in ways that women seek to overcome those knowledge gaps.

Weaknesses of our study mainly relate to the inherent socioeconomic skew of our study population. White participants reported higher average incomes and higher levels of education than Black and Latina participants; Latina participants were significantly younger than the White and Black women. Thus in some instances, it is unclear if the racial/ethnic differences that we identified may actually be more related to age, education, or socioeconomic status. For example, we found that White women were more likely to seek web-based resources and to be proactive seeking knowledge about their health conditions. These characteristics may be attributed to different learning styles or levels of health literacy in a more educated or mature population. We also identified very specific financial barriers in the Latina women, which would be expected in a group reporting annual household incomes less than \$40,000. Though we attempted to recruit very broadly, our study participants are likely reflective of the demographic characteristics of women living in the Southeastern United States. Notably, Hatchett et al. identified similar barriers in Latina women living in the Chicago, Illinois area.(23) Thus, it is likely that many Latina women around various geographic areas of the United States struggle with these same barriers. It is unclear, however, if Latina women of higher socioeconomic background or those who have attained a higher level of education would demonstrate the same results. By design, the Latina women in our study spoke Spanish as their first language, and focus groups were conducted in Spanish. These study design characteristics may also skew our results to be more reflective of immigrant populations compared to Latina women who speak English as a first language or grow up in a bilingual home.

Despite efforts to increase screening for UI and despite having a range of therapeutic options, women continue to express dissatisfaction with the level of information they receive about UI. It is possible that primary care providers simply lack knowledge about various treatment options, and thus feel uncomfortable discussing treatment strategies. In fact, from a provider perspective, a study of primary care providers determined that the lack of familiarity with treatment algorithms was the most common barrier to care.(28) Continuing education, particularly regarding non-medication therapies for UI such as pelvic floor physical therapy, incontinence pessaries, intradetrusor Botox injections, and neuromodulation may aid in reducing the patient/physician communication barriers that were noted in our study. Certain issues, such as racial/cultural differences and gender,

became relevant in discussions of care seeking, and providers may currently underestimate the barriers involved, particularly for minority women. Providers may consider pre-emptive screening questions, open lines of communication, and taking additional steps to provide education when queried about UI. Focus group participants who encountered male providers using these methods expressed that they felt very comfortable and did not perceive gender to play a significant role in their care.

Our study has revealed some differences in perceptions, understanding, and care seeking behaviors for women with urinary incontinence. These findings can be incorporated into targeted educational strategies to increase knowledge about UI, which seems to be a key impediment to care seeking. Our study findings suggest that Black and Latina women would welcome information portrayed through mass media outlets such as television or social media. In Latina communities, where there was more secrecy about UI, basic messaging about the presence and common nature of UI symptoms may be particularly important, especially when linked with information about treatment options. Efforts such as these should be further tested in targeted populations before being deployed on a large scale, but ultimately may be helpful in reducing disparities in treatment for this troublesome public health condition.

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Table 1

Subject characteristics

	White (n=39)	Black (n=41)	Latina (n=33)	P value
Age ^{a,b}	48.1 ± 16.9	47.12 ± 9.9	38.4 ± 14.4	<0.01 ^c
College/professional degree ^a	31 (82)	18 (53)	5 (16)	<0.01 ^d
Household Income > \$40,000 ^a	19 (50)	4 (12)	0 (0)	<0.01 ^d
Any urinary incontinence (UI)	30 (77)	33 (81)	30 (91)	0.28 ^d
Weekly or Daily UI	17(44)	20 (49)	10 (30)	0.26 ^d
QUID Total Score	4 [1–13]	4 [1–15]	6 [1–22]	0.77 ^e
QUID-Stress	2 [0–6]	3 [0–6]	3 [0–8]	0.85 ^e
QUID-Urge	2 [0–6]	2 [0–9]	3 [1–11]	0.97 ^e
ISI Scores ^f				
Infrequent UI	1 [1–1]	1 [1–2]	1 [1–1]	0.28 ^e
Frequent UI	4 [2.5–7]	4 [2–8]	3.5 [2.5–6]	0.87 ^e

^aInformation summarized for n=38 White, n=34 Black, n=33 Latina women

^bData presented as mean ± standard deviation, median [interquartile range], or n(%)

^cOne-way ANOVA

^d χ^2 test

^eKruskal-Wallis one-way ANOVA

QUID: Questionnaire for Urinary Incontinence Diagnosis (Stress and Urge subscales scored from 0–15; subscales summed for Total score which ranges from 0–30)

ISI: Incontinence Severity Index

^fInformation summarized separately for women with infrequent UI (n= 22 White, 19 Black, 17 Latina) and with frequent UI (n= 17 White, n= 20 Black, n=10 Latina).