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Elder American Indian Women's Knowledge of Pelvic Floor Disorders and Barriers to Seeking Care

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Abstract

Objectives—To evaluate urinary incontinence and pelvic organ prolapse knowledge among elder Southwestern American Indian women and to assess barriers to care for pelvic floor disorders through Community Engaged Research.

Methods—Our group was invited to provide an educational talk on urinary incontinence and pelvic organ prolapse at an annual meeting of American Indian Elders. Female attendees 55 years anonymously completed demographic information and two validated questionnaires; the Prolapse and Incontinence Knowledge Questionnaire (PIKQ) and Barriers to Incontinence Care Seeking Questionnaire (BICS-Q). Questionnaire results were compared to historical controls from the original PIKQ and BICS-Q validation study.

Results—144 women completed questionnaires. The mean age was 77.7 ± 9.1 years. The mean PIKQ UI score was 6.6 ± 3.0 (similar to historic gynecology controls 6.8 ± 3.3 , $p=0.49$) and the mean PIKQ POP score was 5.4 ± 2.9 (better than historic gynecology controls 3.6 ± 3.2 , $p<0.01$). Barriers to care seeking reported by the elder women were highest on the BICS-Q subscales of “Cost” and “Inconvenience”.

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Conclusions—Urinary incontinence knowledge is similar to historic gynecology controls and pelvic organ prolapse knowledge is higher than historic gynecology controls among elder Southwestern American Indian women. American Indian elder women report high levels of barriers to care. The greatest barriers to care seeking for this population were related to cost and inconvenience, reflecting the importance of assessing socioeconomic status when investigating barriers to care. Addressing these barriers may enhance care seeking Southwestern American Indian women.

Keywords

American Indian; Barriers to care; Barriers to Incontinence Care Seeking Questionnaire; Pelvic Floor Disorders; Prolapse and Incontinence Knowledge Questionnaire

Introduction

Pelvic floor disorders (PFD) are common with a prevalence of 15.7% for urinary incontinence and 2.9% for pelvic organ prolapse [1]. Despite the prevalence of these disorders, multiple studies have shown that the majority of patients with urinary incontinence do not seek care from a healthcare provider [2-4]. In fact, only 25% of women surveyed from a primary care clinic knew the meaning of the three terms of urinary incontinence, pelvic organ prolapse, and pelvic floor disorder [5]. Providing education to increase knowledge and education about pelvic floor disorders may improve health seeking behavior for women with pelvic floor problems [6,7]. Using a validated questionnaire, Shat et al. reported that overall urinary incontinence knowledge is better than pelvic organ prolapse knowledge. White race and higher education were associated with better knowledge of urinary incontinence. However, race, education, and income did not have a significant effect on knowledge regarding pelvic organ prolapse [8].

Multiple barriers to care seeking for urinary incontinence have been identified including embarrassment and shame, the misperception that urinary incontinence is a normal part of aging, the view that urinary incontinence was less important compared to other medical problems and lack of knowledge of effective treatment options [9-13]. Factors that are associated with increased care seeking include increased age, prior surgery for urinary incontinence, increased severity of urinary incontinence, and having a regular doctor and routine pelvic exams [4].

While knowledge of barriers to care has improved and there has been an increased focus on the inclusion of minorities in the urogynecologic literature, very little is known about American Indians and pelvic floor disorders. This information gap includes lack of knowledge regarding its prevalence, barriers to care, health seeking behaviors and patient understanding of pelvic floor disorders. Prior work is limited to one study which describes the prevalence of urinary incontinence among women who were members of a South Dakota tribe [14] and another describing the level of bother American Indian women experience regarding pelvic organ prolapse compared to Hispanic and non-Hispanic white women [15].

The Centers for Disease Control and Prevention defines community engagement as, “the process of working collaboratively with and through groups of people affiliated by

geographic proximity, special interest or similar situations to address issues affecting the well-being of those people” [16]. Community based research is becoming increasingly recognized as important for collaborative work between the community and academia, especially with communities that may have had negative experiences with researchers in the past [17]. This project encompasses a community based approach.

Our objectives were to evaluate knowledge about urinary incontinence and pelvic organ prolapse among elder Southwestern American Indian women and assess knowledge by comparing questionnaire scores of these American Indian women to historic controls. We also sought to assess barriers to seeking care for pelvic floor disorders among elder Southwestern American Indian women.

Materials and Methods

Community Approach

The University of New Mexico (UNM) Urogynecology group was invited to provide an educational talk on urinary incontinence and pelvic organ prolapse at a regular meeting of Southwestern American Indian Elders. Health education, including health policy, was the focus for a two-year cycle (six sessions) for this long-standing, elder association. Attendees were primarily from the Pueblos in New Mexico and were mostly women. The purpose of the organization is to educate elders from member senior centers in the state. This study received IRB/HRRC exemption status (HRRC# 12-130).

Questionnaire Administration

Prior to the educational session, female American Indian attendees 55 years were invited to complete demographic information and validated questionnaires anonymously. This included the Prolapse and Incontinence Knowledge Questionnaire (PIKQ) [7] and Barriers to Incontinence Care Seeking Questionnaire (BICS-Q) [18]. The PIKQ is comprised of two 12-item questionnaires assessing knowledge of urinary incontinence (PIKQ UI) and pelvic organ prolapse (PIKQ POP). Respondents answer, “agree”, “disagree” or “don't know” to a series of statements on urinary incontinence or pelvic organ prolapse. Correct answers are given a score of one, incorrect or don't know answers are scored with zero, for a total score range of 0 to 12 points possible for each scale. Higher scores indicate greater knowledge of urinary incontinence and/or pelvic organ prolapse. Questionnaire results were compared to historical controls from the original PIKQ validation study, which studied a younger population of women presenting to either gynecology or urogynecology clinics. In the original validation study the urogynecology participants were recruited from a population of patients seen in urogynecologic follow-up. They were expected to have higher scores as they were assumed to have received some education regarding pelvic floor disorders. The mean age of the gynecology groups was 35.5 years $\pm$ 10.7, 55.0% had a college education, and 45.7% were white. In the urogynecology group, the mean age was 55.7 $\pm$ 17.4, 43.6% had completed college, and 89.7% were white [7].

The BICS-Q is a 14-item questionnaire which measures patient-reported barriers to care seeking for urinary incontinence. Subjects answer, “not at all”, “slightly”, “moderately”, or

“greatly” to describe the degree of barriers to care. These responses are scored from 0 to 3, with a total score ranging from 0 to 36 with higher scores indicate decreased likelihood of seeking care. The BICS-Q has several subscales, which include Inconvenience, Relationship, Site Related, Cost, and Fear. Results were again compared to historic controls from the original BICS-Q study [18]. The BICS-Q allows only for the ranking of the barrier, it does not have any space for additional space or clarification of questions.

Patient Outreach

The UNM Urogynecology team, which included two urogynecologists, one Urogynecology fellow, one pelvic floor physical therapist, one certified nurse midwife expert in pessary care, and two Urogynecology nurses, attended the elder's meeting which was located approximately 30 minutes outside of Albuquerque, New Mexico. All elder, American Indian women were invited to complete the questionnaires. We chose to exclude women of less than 55 years of age to avoid including data from the elder women's caregivers or family that may have accompanied them to the meeting. After completing questionnaires, meeting attendees received lectures on urinary incontinence, pelvic organ prolapse and an in depth discussion of treatment options. Treatment options discussed included both surgical and non-surgical treatments such as pessary and physical therapy and women had the opportunity to participate in physical therapy exercises.

Statistics Analysis

Data were analyzed using SAS v9.3 (Cary, NC). Descriptive statistics and Pearson correlations were performed to assess relationships between questionnaire scores and participant characteristics. One sided t-tests were used to compare American Indian Elder scores to historic controls.

Results

It was estimated that approximately 200 elders attended the meeting and approximately 10% were male. A total of 157 women completed the questionnaire. Nine were excluded as they reported their age as younger than 55 years and four were excluded, as they did not identify their race as American Indian. The mean age was 77.7 years $\pm$ 9.1 with a range of 55 to 90 years. The median parity was 3.5 (LQ 2, UQ 5) and ranged from 0 to 11. The majority of respondents (62%, 91/146) had a high school education or less, 47% (53/113) reported an annual income of less than \$10,000, and only 10.3% (15/145) had worked in the medical field. Sixty three percent (N=93) of women reported personal urinary leakage, and 20% (N=39) reported having pelvic organ prolapse based on self-reported symptoms. The mean score for the PIKQ UI was 6.6 $\pm$ 3.0 and the mean score for the PIKQ POP was 5.4 $\pm$ 2.9. Examples of questions and percentages of correct or incorrect answers for the PIKQ – UI and PIKQ- POP are shown in Table 1. Compared to historic gynecology controls, elder American Indian women had similar knowledge regarding urinary incontinence, see Table 2. They also had higher knowledge regarding pelvic organ prolapse when compared to the gynecology controls. In the original validation paper [7], it was expected that the Urogynecology group would have higher scores as they were all seen in follow-up and were expected to have received educational counseling at prior visits. This finding was confirmed

in our study. As expected, when compared to the Urogynecology controls, American Indian elders were found to have lower knowledge of both urinary incontinence and pelvic organ prolapse. (Table 2)

Barriers to care seeking reported by elder American Indian women via the BICSQ was significantly higher than that of historic controls (12.3 ± 9.6 , vs. 4.72 ± 6.28 , $p < 0.001$), indicating more barriers to care. The original validation paper did not include the mean scores for the subscales and are therefore not included. In the present study, the highest scoring subscales of the BICS-Q were Cost and Inconvenience. (Table 3) The most frequently cited barriers were long delays before copay reimbursement with 29.7% reporting that this “greatly” prevented them from seeking care, and prolonged wait times for appointments, with 19.7% reporting this “greatly” prevented them from seeking care.

Correlations were also examined to determine if patient characteristics were associated with PIKQ or BICS-Q scores. For the PIKQ UI there was a weak correlation between increasing age and decreasing score, $Rho = -0.20$, $p = 0.027$, i.e. as age increased urinary incontinence and prolapse knowledge decreased. There was also a weak correlation with the BICS-Q and income, $Rho = -0.25$, $p = 0.038$, i.e. as the respondents’ income increased the barrier to care seeking decreased. There were no significant correlations found with the PIKQ POP.

Discussion

Knowledge regarding urinary incontinence and pelvic organ prolapse among elder Southwestern American Indian women is similar to historic gynecology controls but lower than an urogynecologic controls. American Indian elder women reported greater barriers to care than the historical control group, despite the majority of American Indian elder women in this community having medical care coverage through Indian Health Service (IHS). However, this is complicated by underfunding of the IHS which according to 2011 data was only at about 50% of what was requested [19]. Also, contract health services (CHS) are frequently needed for subspecialty care and cases are prioritized based on “medical priorities of care” [20]. Therefore, IHS contract health care dollars are limited and care seeking may require significant individual investment, including time, transportation, and copays. The greatest barriers to care seeking for this population were related to cost and the inconvenience of prolonged wait times for appointments. This finding highlights the overall importance of poverty when assessing barriers to care as almost half of our population reported an annual income of less than \$10,000. It has been established that low socioeconomic status is associated with poorer health and a variety of medical conditions, including increased cardiovascular risk, type II diabetes, and cancer [21-24]. This study demonstrates that care seeking for pelvic floor disorders is also adversely affected by low socioeconomic status.

According to the US census data, American Indian or Alaska Natives comprise 1.2% of the population of the United States [25]. The state of New Mexico has a unique demographic make-up with the one of the larger population of American Indians in the United States comprised of 22 American Indian Tribes [26]. According to the United States Census

Bureau in 2012, 10.2% of the population in New Mexico reported themselves as American Indian or Alaskan Native [27].

The literature on American Indian women in the urogynecologic field is quite limited. One study specifically addressed urinary incontinence prevalence among women in a South Dakota tribe[14]. The authors reported a lower overall prevalence of urinary incontinence seen in this cross-sectional sampling of one American Indian tribe based on the Urogenital Distress Inventory. This study and ours take the first steps in assessing knowledge and identifying barriers that American Indian women face with pelvic floor disorders.

We began this research at the invitation of a community requesting more education on pelvic floor disorders for their elder population. Community engaged research has gained increasing popularity, especially when working with underserved or minority populations. This is especially pertinent as goals for community engagement include not only improved communication and trust building but also addressing health disparities and improving health outcomes [16]. Based on this first step, we now have preliminary data to move forward with the development of educational interventions. We will then evaluate the effect of these interventions on improving health understanding, reducing barriers to seeking care, and eventually improving outcomes.

Strengths of this study include the community based approach and the use of validated questionnaires for both knowledge and barriers to seeking care. Also, this is one of the few studies specifically addressing knowledge and barriers to care in an American Indian population related to pelvic floor disorders. Limitations include the small sample size and importantly, although the participants were from many New Mexican tribes, the results may not be generalizable to other American Indian communities. Also the PIKQ questionnaire used may not be culturally appropriate for all communities. It also does not capture the experience and knowledge that women may have gained from their community and groups. It may also not accurately reflect how American Indian women traditionally express their knowledge. Also, although almost 50% of the population reported their income of <\$10,000 this is a mainly retired population and this number may not accurately reflect other support as many women in this community have pueblo communal living resources that are not documented. Finally, comparisons using historic controls are problematic; understanding that the historic controls had many inherent differences than this study's population, such as age, limits the interpretability of the results. However, given that there are not yet normative data established for these questionnaires, we felt it was valuable to present historical comparison data for reference.

Future directions for this work include further development of our community partnership and further exploration of the prevalence of pelvic floor disorders among this population of American Indian women. From this we plan to develop culturally sensitive educational interventions. Paramount next steps include investigating ways to reduce barriers with the ultimate goal of improving health seeking behavior and treatment outcomes.

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Table 1

Examples of PIKQ-UI and PIKQ-POP Questions

PIKQ-UI Questions	Answered Correctly N (%)	Answered Incorrectly N (%)	Answered "Don't Know" N (%)
"Other than pads and diapers, not much can be done to treat leakage of urine."	78 (52.4%)	32 (21.5%)	39 (26.2%)
"Surgery is the only treatment for urinary leakage."	78 (51.7%)	20 (13.3%)	53 (35.1%)
PIKQ_POP Questions			
"A rubber ring called a pessary can be used to treat symptoms of pelvic organ prolapse."	50 (34.7%)	9 (6.3%)	85 (59.0%)
"People who are obese are less likely to get pelvic organ prolapse."	48 (34.0%)	30 (21.3%)	63 (44.7%)

Table 2

Comparison to Historic Controls

	Present Study	Historic Controls	
	Native American Population Mean Score $\pm$ SD N=157	Gynecology Population Mean Score $\pm$ SD * N=133	Urogynecology Population Mean Score $\pm$ SD * N=61
PIKQ UI	6.6 $\pm$ 3.0	6.8 $\pm$ 3.3 p = 0.49	8.8 $\pm$ 2.4 p <0.001
PIKQ POP	5.4 $\pm$ 2.9	3.6 $\pm$ 3.2 p <0.001	8.2 $\pm$ 3.4 p <0.001

* All comparisons are between Native American Elder women and historic controls.

Table 3

BISC-Q and Subscales with Example Statement

	Mean Score $\pm$ SD	Range (Minimum – Maximum)
BISC-Q Total Score	12.3 $\pm$ 9.6	0 -36
BISC-Q Subscales Inconvenience <i>"The wait is too long at the time of the appointment."</i>	3.23 $\pm$ 3.0	0 -9
Relationship <i>"The health care practitioner and his staff aren't interested in my worries about my health"</i>	2.32 $\pm$ 2.3	0 -9
Site-related <i>"There is no transportation to the office or clinic."</i>	1.31 $\pm$ 1.7	0 -6
Cost <i>"There are long delays before insurance repays out-of-pocket expenses."</i>	3.57 $\pm$ 3.2	0 -9
Fear <i>"I don't like to be examined or asked a lot of questions."</i>	2.48 $\pm$ 2.5	0 -9