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Health Care Disparities Among English-Speaking and Spanish-Speaking Women With Pelvic Organ Prolapse at Public and Private Hospitals: What Are the Barriers?

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Abstract

Objectives—The objective of this study was to compare perceptions and barriers between Spanish-speaking and English-speaking women in public and private hospitals being treated for pelvic organ prolapse (POP).

Methods—Eight focus groups, 4 in English and 4 in Spanish, were conducted at 3 institutions with care in female pelvic medicine and reconstructive surgery. Standardized questions were asked regarding patients' emotions to when they initially noticed the POP, if they sought family support, and their response to the diagnosis and treatment. Transcripts were analyzed using grounded theory qualitative methods.

Results—Thirty-three women were Spanish-speaking and 25 were English-speaking. Spanish speakers were younger ($P = 0.0469$) and less likely to have a high school diploma ($P < 0.0001$) than English speakers. Spanish-speaking women had more concerns that the bulge or treatments

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could lead to cancer, were more resistant to treatment options, and were less likely to be offered surgery. Women in the private hospital desired more information, were less embarrassed, and were more likely to be offered surgery as first-line treatment. The concept emerged that patient care for POP varied based on socioeconomic status and language and suggested the presence of disparities in care for underserved women with POP.

Conclusions—The discrepancies in care for Spanish-speaking women and women being treated at public hospitals suggest that there are disparities in care for POP treatment for underserved women. These differences may be secondary to profit-driven pressures from private hospitals or language barriers, low socioeconomic status, low health literacy, and barriers to health care.

Keywords

grounded theory; pelvic organ prolapse; qualitative research; English; Spanish

Pelvic organ prolapse (POP) is defined as the descent of the anterior or posterior vaginal wall, the uterus, cervix, or the apex of the vagina.[1] It is estimated that the number of women with at least 1 pelvic floor disorder (PFD) will increase from 28.1 to 43.8 million from 2010 to 2050, and that the number of women with POP will increase by 46%.[2] The prevalence of PFD seems to be higher among certain ethnic groups, with Latinas and white women having 4 to 5 times higher risk of symptomatic prolapse than African Americans.[3,4] In addition, Hispanics have a higher level of symptomatic bother at lower stages of POP than non-Hispanics.[4] Pelvic organ prolapse has a negative impact on quality of life, sexual function, and places a large socioeconomic burden on the health care system.[5–7] The authors' previous work has demonstrated that Hispanic and Native American women suffer a higher level of burden from POP than non-Hispanic white women.[4]

Surgical management of POP has been associated with higher patient satisfaction at 1 year than nonsurgical management.[8] According to the Cochrane review, up to 77% of providers offer pessaries, a nonsurgical management, routinely as first-line therapy for POP.[9] In addition, there is increasing evidence to support physiotherapy in the treatment of POP.[10] A study by Brazell et al[11] evaluated 3205 women and found that Hispanics are more likely than whites to seek treatment for POP ($P < 0.002$), and His-panics are also more likely to proceed with a surgical repair ($P = 0.027$). Despite Hispanics seeking surgical treatment for POP more often than whites or blacks, they still face barriers to receiving patient-centered medical care. This was demonstrated in a study that evaluated 125,369 English and Spanish speakers enrolled in Medicare.[11,12] One barrier that has been identified is mis-communication secondary to cultural and language differences.[13]

The aim of this study was to further define communication barriers by comparing common perceptions regarding prolapse and barriers to treatment between Spanish-speaking and English-speaking women with POP. Because many Spanish-speaking women seek care in public hospitals, a qualitative evaluation to compare the care provided to women in public and private hospitals was also performed. The authors hypothesized that there would be unique barriers to care identified in the Spanish-speaking populations and in the public hospitals.

Materials and Methods

This was a multicenter study, which included 3 referral centers, the University of New Mexico (UNM), a public university hospital in Albuquerque, NM; Olive View Medical Center (OVMC), a public university–affiliated hospital in Northern Los Angeles County, Calif; and Cedars-Sinai Medical Center (CSMC), a private university–affiliated hospital in Los Angeles, Calif. Institutional review board (IRB) approval was obtained at all the 3 institutions: CSMC (IRB No. Pro00025379), OVMC (IRB No. 10H-884300), and UNM (Human Research Review Committees No. 11-347).

A heterogeneous mix of women from the public and private domain, as well as different ethnic backgrounds, socioeconomic statuses, and religions were included. Women were recruited from female urology and urogynecology clinics at the time of their initial visit and were invited to participate in a single 1.5-hour focus group. All women were invited to participate if they qualified for the study and were given a small honorarium and meal for their participation. Women were eligible to participate if they had a diagnosis of POP based on physical examination findings and were aged 21 years or older. Participants were not required to solely speak English or Spanish but were placed in the appropriate group based on their native language and preferred language. Women were excluded if they had a diagnosis of pelvic pain, painful bladder syndrome, or a significant psychiatric disorder. Informed consent was performed before participating in focus groups.

A total of 8 focus groups were conducted, 4 in English and 4 in Spanish during a 1-month period. We have previously demonstrated that focus groups of this size are appropriate for schematic saturation of qualitative studies using grounded theory.[14,15] One female moderator trained in qualitative methods (C.S.) conducted all the focus groups. She was a physician who spent a year of research dedicated to this project and is fully bilingual in English and Spanish. Standardized scripts with open-ended questions were asked regarding patients' emotional response, knowledge and experience regarding their POP symptoms, evaluation, physician and staff interactions, and treatment. The Spanish-speaking groups were also questioned about their experience and comfort with interpreters. Full details of standardized questions are previously reported.[16] Focus group discussions were deidentified, recorded, and transcribed verbatim. Spanish focus groups were transcribed and translated into English by a qualified translator.

Transcripts were analyzed using grounded theory qualitative methods as described by Charmaz.[17] Grounded theory allows for data to be collected and analyzed in areas where little knowledge exists. The concept is used with interviews or focus groups to abstract data and identify common themes that can later be generated into a hypothesis and tested quantitatively. After interviews were transcribed, 3 independent investigators performed line-by-line coding of all transcripts. The codes were then further analyzed, and codes that appeared to be common and repetitive were categorized. The analyses of each investigator were then compared and combined. Analysis of these common concepts resulted in the final emerging theory, or final conclusion, that can be applied to clinical practice.

Statistical analysis was performed using JMP Pro Version 10 (SAS Institute, Cary, NC). Demographic data were calculated using mean (standard deviation [SD]). Numerical data were evaluated for normal distribution using a visual assessment of the histogram as well as a Shapiro-Wilk test. Differences in mean score values were calculated using a student *t* test for normal data. Categorical data were compared using a Fisher exact test for data containing 5 or less subjects per category. Statistical significance was considered with an alpha level of less than 0.05.

Results

A total of 58 women participated at the 3 sites, including 33 whose primary language was Spanish and 25 whose primary language was English. The OVMC included 2 groups of Spanish-speaking participants. The CSMC included 2 groups of English speakers. The UNM included 2 groups of Spanish speakers and 2 groups of English speakers. Spanish speakers were slightly younger (56.6 [9.6] years) than English speakers (63.8 [15.5] years, $P = 0.0469$). Spanish-speaking women were less likely to have a high school diploma, with 78.8% not completing high school versus 8% in the English-speaking group ($P < 0.0001$). Most Spanish speakers' country of origin was Mexico (70%) versus the United States for English speakers (83%). See Table 1 for complete demographic information.

There were several preliminary themes that emerged from the Spanish-speaking groups as well as several preliminary themes that were unique to the private hospital setting. See Table 2 for representative patient quotes.

Preliminary Themes in Spanish-Speaking Groups

Preliminary Theme 1: Fear of Cancer—There was less understanding of anatomy and more concern that the *ball* or *bulge* that was felt was colon or rectal cancer in the Spanish-speaking groups. Spanish-speaking women also had concerns that using a vaginal cream, pessary, or having surgery would cause cancer. Twenty-four percent (8/33) were concerned about cancer in the Spanish-speaking group versus 8% (2/25) in the English-speaking group. However, the percentages in the Spanish-speaking group may not be accurate because 1 group was not specifically questioned about cancer concerns. In contrast, English-speaking women had a higher understanding of POP, describing it as “similar to a hernia” and “not dangerous or worrisome”.

Preliminary Theme 2: Discrepancies in Treatment Options—Spanish-speaking patients reported that they were offered Kegel exercises and pessaries more often as a first-line treatment than English speakers. Many patients were told that they were “not a candidate for surgery because of too many medical problems” or “surgery won't help, and to try these exercises”. English-speaking women's “gynecologists recommended surgery right away” or the “only option given was surgery”. Discrepancies in treatments offered were noted in 21.2% (7/33) in the Spanish-speaking group versus 16% (4/25) in the English-speaking group.

Preliminary Theme 3: Resistance to Offered Treatments—Women in the Spanish-speaking groups (18.1%, 6/33) also expressed concern and resistance regarding treatment

options offered compared with the English-speaking groups (8%, 2/25). For example, “I was scared and anxious about pessary”, “scared to remove the pessary”, and “scared of anesthesia”. English-speaking women expressed that they were generally more comfortable using a pessary if it was offered.

Preliminary Theme 4: Preferred Spanish-Speaking Doctor Over Interpreter— Many of the Spanish speakers had negative experiences with a physician or medical staff member using an interpreter. These women had concerns that all their complaints or questions were not being addressed and that “the interpreter was doing it [the translation] incorrectly”. It was also found that Spanish speakers had “less confidence” in their care and physician when an interpreter was being used and “preferred to talk directly in Spanish with their doctor”.

Preliminary Themes Unique to Private Hospital Versus Public Hospitals

Preliminary Theme 1: Treatment Options Differed—Women in the private hospital setting had unique experiences not shared by those in the public hospitals. Table 3 contains patients' quotes for both groups. English-speaking women from the CSMC group were more commonly offered surgery as the only treatment option or were strongly encouraged by their physician that surgery would be the only option to be successful. Patients in the public setting were offered conservative therapy as first-line treatment or were told that surgery was not a reasonable first option 24.4% of the time (11/45) versus 0/13 patients in the private setting. They reported that it “took 2–3 visits to figure out what was wrong”, and then “told me to lose weight and exercise”. Both the English-speaking and Spanish-speaking groups were offered “pessaries for a while” before being offered or asking about surgery.

Preliminary Theme 2:Less Shame and Embarrassment in Private Sector— Women in the private hospitals were also more open to discussing their problems with their friends, husbands, and family and even “took them on appointments to help them understand”. This was not true for English speakers in public hospitals who felt ashamed because they were “too young” to have this problem. Spanish-speaking women also “felt ashamed” and would not “discuss with their husbands”. Twenty-four percent (11/45) reported feeling embarrassed or ashamed in the Spanish-speaking group compared with 7% (1/13) in the English-speaking group.

Preliminary Theme 3: Variation in Desire for More Information—Finally, patients in both hospital settings wanted more information from their physicians in the form of pamphlets, videos, or models. However, patients from the private setting desired more detailed information using more medical terminology. They commented that the use of “models was helpful, but the language was too simple” and that the “internet was helpful”. The English speakers in the public hospitals, however, found the “internet to be overwhelming”, and that the explanations were confusing because they “had not heard the names before”. Spanish speakers also found the information to be overwhelming and wanted more “simple language”. Fifteen percent (7/45) in the public hospitals found the information to be overwhelming and too detailed compared with zero percent (0/13) in the private setting.

Emerging Concepts

The preliminary themes identified differences in care provided to both Spanish-speaking (vs English-speaking) women as well as women treated in a public hospital setting (vs private). The concept emerged that patient care for POP varied based on both socioeconomic status and language and suggested the presence of disparities in care for underserved women with POP.

Discussion

The authors hypothesized that there would be unique barriers to care for women who were Spanish-speaking as well as those seeking care in public hospitals. From the data analysis, it was found that Spanish-speaking women faced unique barriers to their health care as did both English and Spanish speakers in public hospitals. The original study design was to compare patient experiences for the treatment of POP between Spanish-speaking and English- speaking patients. Patients from both the public and private domains were included to have a more heterogeneous mix. In addition, the Los Angeles groups were separated by public and private institutions to additionally capture possible differences in both language and socioeconomic status. The authors did not see these as confounders but rather factors to capture in the analyses. After applying grounded theory, it was clear that there were discrepancies in care between the public and private domain, not only discrepancies by language but also clear differences between the public and private hospitals in the qualitative analysis. These discrepancies were also suggested by our quantitative analyses.

In contrast to the authors' study where Spanish speakers were less likely to be offered or undergo surgery, Brazell et al[11] reported that women who were younger and were Hispanic were more likely to have POP and undergo surgical correction. They also found that socioeconomic status did not affect treatment-seeking behavior. However, this study was a retrospective review based on a single community hospital and their conclusions might not be applicable to hospitals that care for the uninsured or primarily Spanish-speaking patients because they evaluated only 1.9% who were Hispanic and noninsured.

For Spanish speakers, the lack of general knowledge of their condition led to misconceptions both in the condition itself as well as the treatments. This is supported by the findings that these women had concerns that their POP condition or its treatment could lead to cancer. These women also faced communication barriers, which have been shown in previous studies to contribute to their lack of understanding.[13]

In addition to facing language barriers, Spanish-speaking women tended to have less understanding of their condition, likely as a result of low literacy and possibly low health literacy. However, we did not formally assess language proficiency and literacy and can only comment that their lower understanding of their condition was secondary to low literacy because Spanish speakers wanted explanations in simpler terms with fewer words. Low literacy may lead to poor understanding of the different pelvic floor diagnoses and what the treatments are meant to improve. For example, a patient with low health literacy may not understand why surgery will not help treat overactive bladder whereas it may improve stress

urinary incontinence and prolapse symptoms. This may lead to dissatisfaction and confusion with treatments offered.

Not surprisingly, Spanish-speaking patients preferred speaking with their physician directly in Spanish because this has been shown to increase trust and confidence toward health care providers.[18] At the 3 hospitals, only trained interpreters were used, and many of the providers were fully bilingual and did not require the use of an interpreter for patient counseling. However, in the focus groups, patients described experiences they had at other facilities. These experiences included using a friend or family member as an interpreter, which could have increased patient anxiety. However, some patients still expressed concern with using trained interpreters. Further studies are needed to better understand patient distress associated with the use of interpreters as well as to help improve communication with Spanish-speaking women, especially when the condition is one associated with shame and embarrassment.[16]

Patients also expressed a desire for more educational aids such as pamphlets, models, and simple videos. These tools can assist them in understanding their condition(s), allowing for better patient decision making and higher patient satisfaction.[19,20] These educational aids, especially bilingual aids, may not be as readily available in the public hospital because private hospitals may have more resources available, thus continuing a cycle of misinformation. Future studies are needed to evaluate the value and accessibility of Spanish informational aids and determine if they lead to further understanding of patient conditions. In addition, understanding one's treatment plan may be even more important than understanding the details of their anatomic defects. It has previously been shown in patients with incomplete understanding of their diagnosis that a good understanding of one's treatment plan helps provide a sense of control and lessens the fear of treatment.[21]

Treatment options offered also differed in both the Spanish-speaking group and the public hospital setting. Women in a public hospital setting were more commonly offered conservative treatments such as Kegels, physical therapy, or a pessary as first line of treatment versus a surgical approach. These differences may be attributable to lower socioeconomic status, health insurance status, and ethnicity. Hargraves et al[22] demonstrated that disparities in health care were mainly secondary to lack of health insurance and resulted in medical needs not being met. These differences were most prevalent in the Hispanic population but were also evident in those with lower income and in certain geographical areas.[22] It is likely that the discrepancies found in the study are the result of the UNM and OVMC treating a higher number of underinsured and Hispanic patients. This is in contrast to CSMC, a private hospital in Los Angeles that typically treats privately insured patients. Unfortunately, data on insurance status were not collected, so further comment on the potential disparities by insurance status or type of insurance cannot be completed.

Another explanation for differences in care between the hospital systems is the use of a stepwise triage system for the care of patients in the public setting. These institutions have limited resources with often long wait times for services. There may also be lack of available primary care providers. This can lead to patients having poorly controlled medical comorbidities and thus being poor surgical candidates for prolapse procedures. Therefore,

these patients may be using pessaries or no treatment for their prolapse until their other medical conditions have been addressed. In addition, patients with low socioeconomic status who desire surgery may have additional economic barriers. For example, they may not be able to afford to take time off from work to recover from surgery. Furthermore, the wait time for surgery at public hospitals may be long because of limited resources. It is common in these settings to offer less invasive treatments as a temporary means until a desired surgical repair can be performed. This inequality of services has been documented to lead to treatment delay and even higher mortality in other medical conditions.[23,24] Another explanation may be that there is more financial incentive in a private hospital to offer surgical treatment over conservative therapy as a first-line treatment. Finally, patients in a private hospital are often managed by their primary care provider or gynecologist before being referred to a specialist. It is possible that these women previously failed conservative management, and that is why they were offered surgical correction more often.

The strengths of the study include its multicenter nature and inclusion of both English and Spanish speakers in 3 geographical areas. The population included a heterogeneous mix of women from diverse ethnic, religious, and socioeconomic backgrounds seen in both public and private domain. In addition, the same trained bilingual moderator was used at each focus group.

The weaknesses of the study include the fact that few quantitative comparisons between groups could be made, given the largely qualitative nature of the study. The authors have quantified the data as much as possible to support the preliminary themes and conclusions. However, because these data were collected in a group setting, the numbers might underestimate the actual total numbers, given that each participant was not directly asked the questions individually. In addition, even though the group was heterogeneous, it included women from referral centers who may not be representative of all women with POP in the community. Unfortunately, Spanish-speaking women in the private hospital settings as well as insurance status were not evaluated in this study. It is possible that the disparities found may have been due, in part, to other confounding variables. Future studies should be performed to evaluate care to Spanish speakers in the private versus public setting to evaluate if language is a confounder, as well as the effect that insurance has on care. Moreover, most of the Spanish-speaking women in the focus groups were from Mexico and therefore were not generalizable to all Spanish-speaking women. Finally, it is possible that the group interview setting (vs individual interviews) may have prevented some participants from answering personal questions. Although the authors have previously performed one-on-one interviews in the evaluation of women's experience with PFDs, it was found that these interviews are usually shorter with less discussion.[21] Focus groups provide a unique opportunity to allow people to share their experiences with other individuals with similar circumstances. The authors have performed several of these studies using group dynamics and have found that, oftentimes, patients will often make more comments after they hear others express their concerns.

In conclusion, the authors found that both Spanish-speaking women and women being treated in the public hospital setting face unique barriers that may lead to disparities in their health care. The findings of the study are important because they directly impact a large

proportion of patients in the Unites States, although it was recognized that these findings might not be generalizable to all patient populations. Physician awareness of these potential discrepancies and the provision of patients with additional educational aids may minimize misunderstanding and provide patients with equivalent care and treatment options.

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Table 1

Demographics

	Spanish-Speaking	English-Speaking	*P*
Total number	33	25	
Mean (SD) age *	56.6 (15.5)	63.8 (9.6)	0.0469
Birth country, n (%) †			<0.001
United States	0	20 (80)	
Mexico	23 (70)	0	
Belize	0	2 (8)	
El Salvador	5 (15)	0	
Guatemala	2 (6)	0	
Nicaragua	1 (3)	0	
Chile	1 (3)	0	
Dominican Republic	0	1 (4)	
Canada	0	1 (4)	
Not answered	1 (3)	1 (4)	
Religion, n (%) †			<0.001
Catholic	28 (85)	8 (32)	
Christian	4 (12)	8 (32)	
Jewish	0	3 (12)	
No affiliation	1 (3)	1 (4)	
Not answered	0	5 (20)	
Highest level of education, n (%) †			<0.001
< High school diploma	23 (69)	6 (24)	
High school or GED	2 (6)	1 (4)	
Some college	3 (9)	2 (8)	
Associate degree	1 (3)	6 (24)	
Bachelor degree	0	5 (20)	
Graduate or professional degree	0	1 (4)	
Not answered	4 (12)		
Total annual income, n (%) †			<0.001
<$10,000	15 (45)	2 (8)	
$10,000–19,999	5 (15)	3 (12)	
$20,000–29,999	1 (3)	3 (12)	
$30,000–39,999	1 (3)	4 (16)	
$40,000–49,999	0	3 (12)	
≥$50,000	0	8 (32)	
Not answered	11 (33)	2 (8)	
Employment status, n(%) †			0.1905
Unable to work	2 (6)	3 (12)	
Homemaker	8 (24)	1 (4)	

	Spanish-Speaking	English-Speaking	*P*
Looking for work	2 (6)	1 (4)	
Retired	4 (12)	6 (24)	
Employed	6 (18)	8 (32)	
Self-employed	3 (9)	3 (12)	
Not looking to work	2 (6)	2 (8)	
Not answered	6 (18)	1 (4)	

*Student *t* test;

†Fisher exact test.

GED, General Educational Development.

Table 2
Preliminary Themes in Spanish-Speaking Groups

Preliminary Themes	Spanish-Speaking Patient Quotes	English-Speaking Patient Quotes
Fear of cancer	"When you use the cream I heard you get cancer"	"Similar to a hernia"
	"Wanted to get rid of uterus...scared it would cause cancer"	"Not dangerous or worrisome."
	"Maybe having ring up there would cause cancer"	"I was not scared or worried about my condition, just concerned about treatment option"
Discrepancies in treatment options	"Waited long time for doctor to call me to schedule operation"	"Gynecologists recommended surgery right away"
	"Took pills for one year and did not help with prolapse"	"Only option given was surgery"
	"Told me to exercise, but made leaking and bulge worse"	
Resistance to offered treatments	"Scared and afraid of pessary"	"I wore the pessary for 10 years"
	"Couldn't stand the pain….didn't use it (pessary)"	"My decision was just to get it over with, just fix the problem..and have surgery"
	"Afraid to put my hand in there and take it out"	
	"Wasn't candidate for surgery because of my sickness… diabetes and high blood pressure"	
Preferred Spanish-speaking doctor over interpreter	"Ashamed to talk to different doctors each time"	
	"Ashamed when doctor not speaking Spanish… used interpreter"	
	"Have less confidence in doctors when they use an interpreter"	
	"Not sure interpreter doing it right"	

Table 3
Preliminary Themes Unique to Private Hospital Versus Public Hospitals

	Private Hospital Patient Quotes	Public Hospital Patient Quotes	
Preliminary Themes	**English-speaking**	**English-speaking**	**Spanish-speaking**
Treatment options differed	"Only option given was surgery"	" Wore pessary for a while… then had surgery"	"Took 2-3 visits to figure out what was wrong"
	"Not offered another option… they knew I just wanted it fixed"		"Told me to lose weight and exercise"
	"Offered pessary...but then surgeon said it would only be temporary fix and would need surgery anyway"		"Used pessary for 2 years then threw it out and wanted surgery"
Less shame and embarrassment in private sector	"Us women talk about this socially"	"Afraid to talk about since I am young"	"Felt ashamed, did not tell husband"
	"Talked to my friend for information"		"Did not talk about it,… it's shameful"
	"Took my husband and daughter with me to appointments… to help me understand"		
	"Told my sister and family"		
Variation in desire for more information	"I wanted more detail then the MD gave"	"Too much information, mainly since I had not heard the names"	"Using simpler words would have been helpful"
	"Internet was helpful"	"Internet was overwhelming"	
	"Wanted to know about different surgical options and specifics"		
	"The doctor used a model but the language was too simple"		