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Health Literacy and Disease Understanding among Aging Women with Pelvic Floor Disorders

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Abstract

OBJECTIVES—Few studies on health literacy and disease understanding among women with pelvic floor disorders have been published. We conducted a pilot study to explore the relationship between disease understanding and health literacy, age, and diagnosis type among women with urinary incontinence and pelvic organ prolapse.

METHODS—Study subjects were recruited from urology and urogynecology specialty clinics based on a chief complaint suggestive of urinary incontinence or pelvic prolapse. Subjects completed questionnaires to assess symptom severity and health literacy was measured using the Test of Functional Health Literacy in Adults. Patient-physician interactions were audiotaped during the office visit. Immediately afterwards, patients were asked to describe diagnoses and treatments discussed by the physician and record them on a checklist, with follow-up phone call where the same checklist was administered 2–3 days later.

RESULTS—A total of 36 women with pelvic floor disorders, aged 42–94, were enrolled. We found that health literacy scores decreased with increasing age; however, all patients had low percentage recall of their pelvic floor diagnoses and poor understanding of their pelvic floor condition despite high health literacy scores. Patients with pelvic prolapse appeared to have worse recall and disease understanding than patients with urinary incontinence.

CONCLUSIONS—High health literacy as assessed by the TOFHLA may not correlate with patients' ability to comprehend complex functional conditions such as pelvic floor disorders. Lack of understanding may lead to unrealistic treatment expectations, inability to give informed consent for treatment, and dissatisfaction with care. Better methods to improve disease understanding are needed.

Keywords

pelvic floor disorders; health literacy; incontinence; pelvic organ prolapse

Introduction

The US **Institute of Medicine (IOM)** defines health literacy as: “The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.”^{1, 2} Health literacy is important in navigating the healthcare system, communicating with healthcare providers, managing chronic disease, and making informed treatment decisions^{2, 3}. Nutbeam described a comprehensive model of health care in which low health literacy has an adverse impact on clinical care². According to the model, health literacy is an identifiable risk factor that needs to be appropriately managed in health care. It begins with assessment of relevant prior knowledge and/or individual reading literacy. If knowledge is included as a part of the definition of health literacy, then this too must be measured, and few commonly used screening tools achieve such an assessment^{2, 4}.

Many factors are known to influence health literacy. Although education mediates the observed association between increasing age and decreasing health literacy, older adults remain the most vulnerable group to have low health literacy^{5, 6}. According to the National Assessment of Adult Literacy in 2003, 29% of adults over the age of 65 had lower than basic health literacy⁷. One study found that in older adults, inadequate health literacy was a mediator to disparities in utilization of preventative services including influenza vaccines, mammograms, and dental care⁸. Health literacy also plays a role in health-promoting behaviors: adults with higher health literacy were found to be more likely to consume more fruits and vegetables, be non-smokers, and have higher self-rated health⁹.

PFDs encompass a range of conditions affecting aging women, including POP, UI, and **fecal incontinence (FI)**. POP is defined by the **International Continence Society (ICS)** as “the descent of the anterior vaginal wall (cystocele), posterior vaginal wall (rectocele), or apex of the vagina (uterine or vaginal vault prolapse)”¹⁰. The ICS defines UI as “the complaint of any involuntary leakage of urine.” UI may be classified into **stress urinary incontinence (SUI)**, leakage on effort, exertion, sneeze or cough or **urgency urinary incontinence (UUI)**, leakage that occurs with an urge to void. UUI is part of a constellation of symptoms referred to as **overactive bladder (OAB)**, which includes urinary frequency and urgency, with or without incontinence^{11, 12}. Among all PFDs, SUI and POP represent conditions that are most often surgically treated.

Twenty three percent of all community-dwelling women in the United States are currently affected by one or more symptomatic pelvic floor disorders, with the prevalence increasing to nearly one-half of women above the age of 80 years¹³. Pelvic floor disorders negatively impact quality of life, incur significant costs, and are likely to become increasingly prevalent as the population ages. To date, there has been little research on health literacy and disease understanding among patients with pelvic floor disorders. This study aims to correlate health literacy, age, and diagnosis among aging women with urinary incontinence and pelvic organ prolapse. We sought to better understand the impact of health literacy on patient understanding of their pelvic floor dysfunction. We focused on disease understanding as a clinical outcome that is strongly influenced by health literacy.

Materials and Methods

Institutional IRB approval was obtained and patients were recruited from outpatient urology and urogynecology specialty clinics at UCLA. Treating physicians identified eligible study subjects based on a chief complaint suggestive of urinary incontinence or pelvic organ prolapse listed in patient medical charts. Other inclusion criteria were female gender,

English fluency, and age 21 or older. Exclusion criteria were significant psychiatric history or cognitive impairment.

Women gave written informed consent and patients completed the Incontinence Severity Index (ISI), Questionnaire for Urinary Incontinence Diagnosis (QUID), and Pelvic Floor Distress Inventory (PFDI). To assess health literacy, the Test of Functional Health Literacy in Adults (TOFHLA) was administered by research staff. The TOFHLA contains a reading comprehension and numeracy section and is scored out of 100 points, with higher scores indicating better health literacy¹⁴. A score of 75 or greater indicates adequate health literacy. The patients' office visits were audiotaped to document patient-physician interactions as well as diagnoses and treatments discussed. Though no formal script was used, patients were consistently provided with adequate verbal information during their office visit to allow a realistic assessment of knowledge following the visit. Immediately following their appointment, patients were asked to orally describe diagnoses and treatments discussed by the physician. Care was taken to assure that patients felt comfortable discussing private matters before the one-on-one interviews. Patients were then asked to record their diagnoses and treatments on checklist containing several possible diagnoses and treatments (Appendix 1). No written material was given to patients. Two or three days later, patients were contacted by telephone and again asked to describe the diagnoses and treatments given to them by the physician, with prompting provided as necessary. Audiotapes were reviewed and the number of diagnoses and treatments actually discussed with women was recorded. Understanding was measured by calculating the number of items correct as a percentage of the total items that the physician discussed with the patient as documented on the audiotapes. The patient's diagnosis was a checklist and the patient's treatment was also a checklist. For percentage recall (immediate and follow up) calculated, both diagnosis and treatment were combined for a total score. Student's t-test was conducted, and a $p < 0.05$ was considered significant.

Descriptive statistics were used to describe patient characteristics. We recruited a convenience sample of women presenting for care and planned these exploratory analyses to better define the relationship between health literacy and patient understanding of their pelvic floor condition. This study therefore served as a pilot to generate data for a formal power calculation.

Results

Thirty six women, aged 40–94 (mean age 62) were enrolled. The women were highly educated (26/36 had above a high school education) and Caucasian race was most frequently represented (Table 1). The types of pelvic floor disorders represented in our study were urinary incontinence (stress urinary incontinence, urgency urinary incontinence) and pelvic organ prolapse (cystocele, rectocele, vaginal vault prolapse/enterocele, uterine prolapse).

Fourteen patients had urinary incontinence (UI) only, 6 had pelvic organ prolapse (POP) only, and 11 had both UI and POP. Five out of 36 women who presented with pelvic floor disorders were given additional diagnoses including vaginal atrophy, urinary frequency, urinary tract infection, incomplete emptying. As expected, UI-only patients had higher scores on the ISI than the POP-only patients, indicating more severe urinary incontinence symptoms. Within the UI patients, scores for the stress urinary incontinence section of the QUID were higher than for urgency urinary incontinence. Women with both UI and POP had the highest scores on both the ISI and the PFDI, suggesting that patients with both types of pelvic floor disorders have the most severe symptoms (Table 2).

Overall the women had high health literacy; the mean TOFHLA score was 93 on a scale of 100, and 29 out of the 36 subjects had a score of 90 or greater. All but one woman had adequate health literacy as defined by a TOFHLA score of 75 or greater. Despite high TOFHLA scores, we did note variation in patients' degree of disease understanding and their ability to recall diagnoses and treatments discussed by the physician, as queried on the checklist. Patients with POP only had the lowest percentage recall and disease understanding (70%, Table 3; $p > 0.05$). Patients with both POP and UI had intermediate percentage recall and disease understanding (82%). Patients with UI only had the highest percentage recall and disease understanding (94%). Recall did not vary by age group (Table 4; $p > 0.05$). Representative quotes reflecting patient understanding after their consultation are listed in Table 5.

Discussion

This pilot study identified a poor association between high health literacy and disease understanding among a highly health literate population. The findings from this study suggest that urinary incontinence and pelvic prolapse represent uniquely complex conditions to understand. Women with POP often have one or more compartment defects that occur simultaneously, yet different vaginal wall defects present with the same symptom of a vaginal bulge. This might explain the fact that women with pelvic prolapse in this study had less understanding of their pelvic floor dysfunction than those with urinary incontinence. Diagnosis of the specific compartment prolapse can be difficult for even physicians to discern. In fact, we previously showed that female Medicare beneficiaries who underwent sling surgery for stress urinary incontinence had a high rate of re-operation for prolapse within one year of sling surgery, suggesting a failure on the part of the treating surgeons to accurately diagnose prolapse pre-operatively¹⁵. In addition, PFDs are associated with silence and shame. Since PFDs are not discussed freely in communities, even highly educated women may remain uninformed about them.

Lack of understanding may result in the inability to understand treatment options and give informed consent, and also result in dissatisfaction with care. In addition, women who lack disease understanding may experience fears regarding therapy so that they do not seek treatment, resulting in longstanding discomfort and poor quality of life. Alternatively, patients may seek care, yet may lack a basic understanding of the risk and benefits and alternatives of various interventions and have difficulty in weighing the risks and benefits of surgical versus medical therapy. This may result in unmet expectations of therapy and lower satisfaction with care. Our pilot data suggests that even high health literacy may not be sufficient to achieve understanding of complex conditions such as pelvic organ prolapse and urinary incontinence. Further work is needed to better understand what educational tools may enhance patient understanding.

This study was designed as a pilot study to shed light on the relationship between health literacy, age, and patient understanding of pelvic floor dysfunction. Our study was not powered to detect quantifiable differences in disease understanding based on patient diagnosis, age, or health literacy status. Though this population was health literate, our findings will guide an appropriately powered study that includes patients of varying health literacy levels. Future exploratory work is needed to better understand sources of shame surrounding pelvic floor disorders. In addition, our pilot data involved a simple measure of understanding based on a checklist. According to D.W. Baker, knowledge must be measured, but is not assessed adequately with the TOFHLA or other commonly used screening tools⁴. We are aware that such an assessment tool may measure the ability to recall items but may not be a true measure of comprehension. A standardized script for physicians will also assure consistency in patient education. Nonetheless, for purposes of

this pilot study, completion of such an assessment tool should serve as an adequate surrogate for disease understanding.

High health literacy as assessed by the TOFHLA may not correlate with patients' ability to comprehend complex conditions such as pelvic floor disorders. Despite high health literacy and high educational status, patients with pelvic organ prolapse had poor recall of their diagnoses and less understanding of their disease and treatment plan than women with urinary incontinence. Lack of understanding may lead to unrealistic treatment expectations and disappointment; the use of appropriate educational tools may help improve patients' disease understanding.

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Appendix 1: Checklist

Please check any diagnoses you were given by your doctor today:

1. Overactive Bladder	_____
2. Urinary incontinence	_____
a. Stress-type	_____
b. Urge-type	_____
3. Urinary tract infection	_____
4. Vaginal atrophy	_____
5. Pelvic Prolapse	_____
a. Cystocele	_____
b. Rectocele	_____
c. Uterine Prolapse	_____
d. Enterocele/apical vaginal prolapse	_____
6. Other	_____

Please Describe _____

Please check any treatments you were offered today:

1. Fluid restriction	_____
2. Kegel exercises	_____
3. Caffeine restriction	_____
4. Physical therapy/ Biofeedback	_____
5. Prophylactic (preventive) antibiotics	_____
6. Vaginal estrogen	_____
7. Surgery	_____

Please describe the surgery you were offered _____

8. Other	_____

Please Describe _____

References

1. Health Literacy: A Prescription to End Confusion. Institute of Medicine; 2004. US Institute of Medicine 2004 report.
2. Nutbeam D. The evolving concept of health literacy. *Social Science & Medicine*. 2008; 67:2072–2078. [PubMed: 18952344]
3. Paasche-Orlow MK, Wolf MS. The causal pathway linking health literacy to health outcomes. *American Journal of Health Behaviour*. 2007; 31:S19–S26.
4. Baker DW. The meaning and measure of health literacy. *J Gen Int Med*. 2006; 22:1:878–83.
5. Carthery-Goulart MT, Anghinah R, Areza-Fegyveres R, et al. Performance of a Brazilian population on the test of functional health literacy in adults. *Rev Saude Publica*. 2009; 43:631–638. [PubMed: 19488667]
6. Cutilli CC, Bennett IM. Understanding the health literacy of America. *Orthopaedic Nursing*. 2009; 28(1):27–32. [PubMed: 19190475]
7. Kurtner, M.; Greenberg, E.; Jin, Y., et al. Institute of Education Science, National Center for Education Statistics. U.S. Department of Education; Sep. 2006 The Health Literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy.
8. Bennett IM, Chen J, Soroui JS, et al. The contribution of health literacy to disparities in self-rated health status and preventive behaviors in older adults. *Annals of Family Medicine*. 2009; 7(3):204–211. [PubMed: 19433837]
9. Von Wagner C, Knight K, Steptoe A, et al. Functional health literacy and health-promoting behaviour in a national sample of British adults. *J Epidemiol Community Health*. 2007; 61:1086–1090. [PubMed: 18000132]
10. U.S. Department of Health and Human Services. Healthy People 2010. U.S. Government Printing Office; Washington, DC: 2000. Originally developed for Ratzan SC, Parker RM. 2000. Introduction. In National Library of Medicine Current Bibliographies in Medicine: Health Literacy. Selden CR, Zorn M, Ratzan SC, Parker RM, Editors. NLM Pub. No. CBM 2000-1. Bethesda, MD: National Institutes of Health, U.S. Department of Health and Human Services
11. Abrams P, Cardozo L, Fall M, et al. The standardisation of terminology in lower urinary tract function: report from the standardisation sub-committee of the International Continence Society. *Urology*. 2003; 61:37–49. [PubMed: 12559262]
12. Abrams P, Cardozo L, Fall M, et al. The standardisation of lower urinary tract function: report from the standardisation sub-committee of the International Continence Society. *Am J Obstet Gynecol*. 2002; 187:116–126. [PubMed: 12114899]
13. Nygaard I, Barber MD, Burgio KL, et al. Prevalence of symptomatic pelvic floor disorders in US women. *JAMA*. 2008; 300(11):1311–1316. [PubMed: 18799443]
14. Parker RM, Baker DW, Williams MV, et al. The test of functional health literacy in adults: a new instrument for measuring patients' literacy skills. *J Gen Intern Med*. 1995; 10:537–41. [PubMed: 8576769]
15. Anger JT, Litwin MS, Wang Q, et al. Complications of sling surgery among female medicare beneficiaries. *Obstet Gynecol*. 2007; 109(3):707–714. [PubMed: 17329524]

Table 1

Characteristics of Study Population

Characteristic	Number	% of study sample*
Age Group		
40–60	18	50%
60–80	10	28%
80–100	8	22%
Self-Identified Race		
Caucasian	22	61%
Asian/Pacific Islander	4	11%
African American	4	11%
Hispanic	3	8%
American Indian	1	3%
Other	1	3%
Highest educational level		
Unreported	1	3%
Grade school	1	3%
High school	8	22%
Some College	11	25%
College graduate +	15	47%
Pelvic Prolapse	17	47%
Cystocele	12	33%
Rectocele	14	39%
Vault/Enterocele	3	8%
Uterine	5	14%
Urinary Incontinence	25	69%
Stress	17	47%
Urge	12	33%
Number of patients having both Pelvic Prolapse and Urinary Incontinence	11	30%

* Rounded to the nearest percentage.

Table 2

Severity of Pelvic Floor Symptoms

Diagnosis Type	Mean Age	Mean score		
		ISI	QUID (stress/urge)	PFDI
UI only (n=14)	66.2	7.1	4.9/6.8	62
POP only (n=6)	58.0	1	0.5/1.8	66
Both (n=11)	61.4	7.8	5.3/7.1	125

UI = urinary incontinence, POP = pelvic organ prolapse, ISI = Incontinence Severity Index (score range 0–12), QUID = Questionnaire for Urinary Incontinence Diagnosis (score range 0–15 for each, stress and urge), PFDI = Pelvic Floor Distress Inventory (score range 0–300)

Table 3

Health Literacy by Diagnosis Type

Diagnosis Type	Mean Age	TOFHLA score	Immediate Recall	Follow-up Recall
UI only (n=14)	76.2	94	94%	90%
POP only (n=6)	58.0	95	70%	97%
Both (n=11)	61.4	90	82%	87%

UI = urinary incontinence, POP = pelvic organ prolapse, TOFHLA = Test of Functional Health Literacy in Adults

Table 4

Health Literacy by Age Group

Age Group	Mean Age	TOFHLA score	Immediate Recall	Follow-up Recall
21–60 (n=18)	48.6	94	90%	92%
60–79 (n=10)	68.0	94	76%	85%
80–100 (n=8)	84.8	88	93%	94%

TOFHLA = Test of Functional Health Literacy in Adults

Table 5

Disease Understanding, as reflected by patient quotes

Physician's Words	Patient's Understanding
Rectocele	"Bulge in the bowel area" "Rectum pushing in"
Cystocele, rectocele, uterine prolapse, urge urinary incontinence	"Vagina, things falling out"
Rectocele repair	"Vaginal cut and reattach"
Sling surgery	"Tighten bladder"
Estrogen, urodynamics, antibiotics, stress urinary incontinence	"Plans to fix it"