



Improving Health Literacy Among Underserved Latinas with PFDs

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Abstract

Purpose of Review The goal of this review is to examine the current literature on existing health barriers and to propose interventions that would improve health literacy among underserved Latinas. Topics include barriers for Latinas with pelvic floor disorders (PFDs), health literacy, and interventions at multiple levels.

Recent Findings Current literature has identified barriers such as culture, misconceptions, and miscommunication as contributing to healthcare disparities among Latinas when it comes to PFDs. Salient in all barriers is language. Many Latinas also have low health literacy when it comes to understanding the causes and treatment options for PFDs. Interventions to improve health literacy among Latinas exist at the clinician-patient level, system patient-level, and community level.

Summary There is a lack of interventions used specifically for health literacy in PFDs. Interventions used to increase health literacy in other health conditions such as cancer, diabetes, mental health, and cardiovascular disease may be extended into PFDs in order to increase health literacy among Latinas. The use of social media as a platform for improving health literacy should be further researched since it has the ability to reach a large audience.

Keywords Health literacy · Latinas · Minorities · Pelvic floor dysfunction

Introduction

Epidemiologic evidence suggests that women have a 1 in 4 lifetime risk of experiencing a pelvic floor disorder (PFD) [1]. These include “urinary incontinence (UI), pelvic organ prolapse (POP), fecal incontinence, and other sensory and emptying abnormalities of the lower urinary and gastrointestinal tracts” [2]. It is estimated that the number of women in the USA with at least one PFD will increase from 28.1 million in 2010 to 40.3 million in 2050 [4, 5]. The proportion of affected women increases with age and parity [3]. Despite the common occurrence and burden of PFDs, women will often suffer in silence, choosing not to discuss

their problems with their healthcare provider or seek treatment [6]. It has been well established that PFDs vary among different ethnicities, with Latinas bearing a disproportionate burden of these symptomatic PFDs [7].

Latinos are the largest and fastest-growing minority group in the USA. By 2050, it is projected that the Latino population will comprise around 30% of the US population [8]. Latina and white women in particular were found to have a 4 to 5 times higher risk of developing symptomatic POP compared with African American women [9]. According to the Women’s Health Initiative Study, Latinas are at a higher risk of uterine and anterior vaginal wall prolapse compared with white women [10]. Latinas also maintain more secrecy about urinary incontinence and have longer delays in seeking care when compared to black and white women [11•]. Latinas have been found to harbor several misconceptions about PFDs and may have lower levels of health literacy, which pose obstacles to care-seeking behaviors [7, 12].

PFDs tend to be underdiagnosed and, when they are identified, undertreated [13]. It is vital to identify and understand the barriers that exist for Latinas when seeking care for PFDs, to measure the level of health literacy among Latinas, and to examine interventions that have been shown

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to improve health literacy in patients with other conditions such as cancer, diabetes, mental illness, and cardiovascular disease. The purpose of this review is to examine the current literature on existing barriers and propose various interventions to improve the health literacy among Latinas with PFDs.

Barriers for Latinas with PFDs

Latinas have identified barriers such as a fear of results, embarrassment of being touched, access to healthcare, and language issues as reasons for not obtaining regular health screenings [14]. In a qualitative study by Jackson et al., three common themes were derived from focus group discussions regarding the views and perceptions toward PFDs by Spanish-speaking Latinas living on the US/Mexico border: barriers, culture, and misconceptions [15••].

Language

One of the most prominent barriers Latinas face in obtaining healthcare revolves around language [20]. Often physicians lack a proficiency in Spanish and/or qualified interpreters may not be available to patients [21•]. Latinas tend to seek care in public hospitals and clinics which may not have the resources necessary to provide interpreters whether they are in person or on a tablet. Spanish-speaking patients often report having negative experiences with physicians or medical staff members when using an interpreter. Latinas also express concerns that all of their complaints or questions are not being addressed and interpreters are not doing the translations correctly [19••]. In our study in which we interviewed certified Spanish translators, they endorsed not being familiar with some of the terminology that they were asked to translate and reported having poor access to dictionaries or tools to assist them in learning the terms [16]. Some also assumed that the patients already understood the conditions and terms. Additionally, PFDs are sensitive topics and having an extra person such as an interpreter in the healthcare encounter may add to the level of embarrassment experienced. Often bilingual staff or the children of the patients act as their interpreter, which may inhibit the patients' ability to speak candidly [8].

Miscommunication

Miscommunication is a common occurrence. Spanish-speaking Latinas would prefer to speak directly in Spanish with their providers for fear of being misunderstood [16]. They tend to proactively seek a Spanish-speaking staff member in medical offices and clinics. It is common for physicians to use complicated language which is not understood

by the patient. Latinas may not understand their medical conditions and anatomy along with disease processes and treatment plans [12]. Spanish-speaking Latinas often feel overwhelmed with the amount of information being provided to them during consultations, especially when they have multiple PFDs. They are also afraid to ask their providers questions for fear of embarrassment, having had a poor understanding of their disease [16].

Culture

Culture encompasses the behaviors, beliefs, and values held by populations of common ancestry, language, and customs [51]. Culture is important to Latinas and can weigh heavily on how they view their bodies and healthcare beliefs. There is a focus on the family among Latino culture and thus Latinas tend to put their own healthcare needs last, behind their family and caregiving responsibilities [7]. There is also a high degree of influence from spouses and other family members. Latinas prefer to consult with a family member before seeking care and/or treatment.

The use of alternative medicine and certain religious beliefs may also contribute to delays in health-seeking behaviors. Patients may turn to religion and prayer for comfort when it comes to their conditions [16]. In a cohort study by Slavin et al., Latinas were more likely to try homeopathy for PFDs such as herbal supplements and oils before seeking conventional therapies [17].

Latinas recognize that PFDs such as POP and UI are abnormal conditions, but conditions that should be expected at some point in life [15••]. PFDs are frequently viewed as a normal part of aging. For some Latinas, it may also be taboo to talk about the vagina [18•]. In a study we conducted in which we interviewed Latina bilingual clinic staff members that grew up in Spanish-speaking households, many stated that PFDs were not something commonly discussed in their homes [16].

Misconceptions

Misconceptions about PFDs among Latinas have been identified in several studies. In focus group discussions with African American and Latinas, Hatchett et al. found that many of the women had several misconceptions related to the causes, symptoms, and treatments of common PFDs. They reported incidences of UI but did not classify them as a health problem [7]. Many of the participants saw UI as a normal part of life especially after having children; the participants also reported very little knowledge of PFDs. It appears that Latinas experiencing PFD symptoms do not recognize the symptoms as a treatable health problem, but just as a normal part of life.

In a study by Alas et al., Spanish-speaking participants may perceive POP (“ball or bulge”) as being indicative of cancer; there were also concerns that using vaginal creams, pessaries, or having surgery would contribute to cancer [19••]. Such concerns result in hesitancy and resistance to medical treatment of PFDs. In yet another study that focused on Spanish-speaking patients, some of the participants believed that their POP was an infection or evisceration, and it was found that the women would blame themselves for causing the prolapse by heavy lifting early in life or sexual intercourse [18•].

Health Literacy Among Latinas

Healthcare disparities and the barriers faced by Latinas are well established, but understanding these disparities among women with PFDs can help to guide programs for education, outreach, and treatment of women with these conditions [16, 22•]. Latinas tend to have lower levels of health literacy, understanding of medical conditions and anatomy, and lack knowledge of basic medical terminology [12]. Lack of health literacy is a barrier to seeking care, and interventions that increase health literacy have been shown to improve health outcomes [23•]. Forty-one percent of adult Hispanics lack basic health literacy and have lower health literacy averages than other ethnic groups in the country [24••].

Health literacy for Latinas means having the skills necessary to obtain, understand, and use information to make decisions regarding their healthcare [25•]. Individuals with lower health literacy are less likely to engage in preventative behaviors, may avoid help seeking and health information, and report greater barriers to healthcare [26••]. Research has also shown that poor health literacy is associated with higher healthcare costs and all-cause mortality rates [27••]. Latinas want more knowledge on PFDs but find it overwhelming and want simpler language [19••].

Measuring Health Literacy

By measuring health literacy among Latino patients, interventions can be selected that are both culturally and linguistically appropriate. Health literacy is usually assessed through the use of validated questionnaires. The majority of health literacy tools, ranging from brief screening tools to longer domain-specific instruments, were validated in samples largely comprised of US non-Hispanic whites and therefore were not geared toward the Latino population [28]. In a study by Estrella et al., it was found that to screen for health literacy among Hispanics/Latinos, it was more useful to obtain self-reported education attainment from the patient [27••].

Interventions to Improve Health Literacy Among Latinas

With the knowledge of the critical importance of health literacy in the management, outcomes, and delivery of care, there is a great need for interventions to improve health literacy among Latinas, specifically when it comes to common PFDs. These can be employed at multiple levels: with the clinician, within the system, and within the community. Common among Latinas is a language barrier which is present in all levels of interventions. The goal of health literacy interventions for Latinas with PFD symptoms is to improve the understanding of their conditions, lessen the feelings of embarrassment, and improve care-seeking and treatment. Patients with low health literacy tend to lack understanding of their diagnosis before and after the physician encounter [18•].

Clinician-Patient Level

At the clinician-patient level, communication needs to be tailored to the patient by asking what they already know or believe [29••]. Tailored patient engagement while taking into account the patients’ culture, beliefs, and barriers fosters shared decision making between physicians and patients especially in a situation in which there is already mistrust in the medical community [52, 53].

After a patient’s questions have been answered, the “teach back” method can be used to confirm patients’ understanding. “Teach back” methods have been shown to improve health outcomes [30]. Language plays a barrier in effective use of the “teach back” method when working with Latinas. When using an interpreter, the physician needs to address the patient directly and have the interpreter next to or slightly behind the patient [31].

Latinas often find PFDs to be embarrassing and may not bring them up during appointments. Providers should feel comfortable asking women about PFDs, with both medical terminology and as well as with vernacular terms within a cultural context [32]. If the clinician does not ask about PFDs, the patient may not disclose any associated symptoms. Pelvic floor information can be provided in simple terms along with depictions or pelvic models to demonstrate normal anatomy. For instance, physicians may forgo using the medical terminology associated with conditions such as “pelvic organ prolapse” but rather describe the condition such as the bladder falling down or the uterus falling [18•].

In communicating with Latino patients, physicians should first listen to the patients’ perception of a problem, explain his or her perception of the problem to the patient,

acknowledge and discuss any difference and similarities between the two views, recommend a treatment plan, and negotiate agreement [8]. Spanish-speaking Latinas tend to rely on their physicians to make decisions for them [12]. However, Latinas have also expressed that providers have downplayed the significance of symptoms associated with POP and UI, instructing patients to just wear incontinence pads. They were therefore more willing to seek prompt medical attention only if they had symptoms of severe pain and/or bleeding [15••].

The use of pictures and visuals, as well as videos combined with verbal counseling, improves understanding and adherence to treatment among low health literacy patients [30]. In a randomized pilot study, it was suggested that “a decision aid video intervention in Latinas with pelvic organ prolapse used at the time of initial evaluation may help the patient make a more informed treatment decision by increasing condition-related knowledge and lead to greater long-term satisfaction” [33•]. Physicians can also recommend internet sites with clear and accurate information on PFDs.

Patient Information Handouts

Ideally, physicians should be able to allow for additional time for patients with low health literacy, but there have been reductions in the length of average provider-patient visits and thus physicians rely on patient health literature for supplementation. Spanish-speaking patients in general require more time during appointments than English-speaking patients [16]. The National Institutes of Health (NIH) and the American Medical Association recommend that easy-to-read patient information handouts should be at or below sixth grade reading level. In a study by Robb et al., currently available PFD pamphlets and informational handouts in Spanish are at a corresponding eighth grade reading level, that is, within “average” to “difficult” reading levels. Higher reading levels limit the intended purpose of pamphlets to supplement patient understanding of medical conditions, terminology, female anatomy, PFD disease information, and treatment options [24••].

Effective patient information materials can potentially improve health outcomes, increase quality of care, and increase patient autonomy [34]. Education materials should also be culturally appropriate [35]. Pamphlets and other informational handouts for patients in accordance to WHO standards need to be translated in the desired language such as Spanish and then translated back into English by separate certified translators to make sure the material conveys the same information.

Decision aids should be in simple language for patients; they can be available either as brochures, videos, web programs, or decision tables. They need to incorporate relevant information and desired goals of the patient. For example,

one decision aid used in a study by Brazell et al., defined POP, provided details on nonsurgical and surgical options for the treatment of prolapse, described the risks associated with surgery, and briefly detailed postoperative expectations along with testimonials, both from women who chose surgery and those who opted for more conservative measures [36••, 37•].

System Patient-Level

Patient-related and system-related barriers to medical care for Latinas have been identified for various conditions such as follow-ups for abnormal Papanicolaou tests and mammograms [38, 39•]. Cultural competence training for physicians and staff may be beneficial in adequately serving increasingly diverse communities [40]. The National Standards for Culturally and Linguistically Appropriate Services (CLAS) published 14 guidelines which revolve around three central themes: culturally competent care, language access, and organization supports. Culturally competent care necessitates cross-cultural training, which is increasingly included in medical education, but developing cultural competence is a lifelong process [41••]. Culturally appropriate education for providers improves both health seeking and health outcomes for Latinas [14]. Other cultural competence interventions include minority recruitment of clinicians and staff into hospital and clinical settings, the development of interpreter services and language-appropriate educational materials, and provider education on cross-cultural issues [20].

It is well established that healthcare providers’ implicit biases are associated with reports of lower quality patient and provider communication among patients from minority groups [42•]. Clinic staff may assume that Spanish-speaking Latinas may not be able to understand the information provided or questions posed to them [16]. Implicit bias and cultural competency training will allow clinicians and other support staff to provide culturally competent care that would instill confidence in the medical system for patients.

Despite the low degree of health literacy found among a large number of Latinas, another barrier to seeking care often cited is lack of time and availability to see a healthcare provider. Telemedicine is a possible solution to this. Ghaddar et al. found that participants from underserved Hispanic Border Communities participants expressed positive attitudes toward telehealth despite low eHealth literacy [43••]. Telehealth interventions have shown benefit and improved outcomes among Latina breast cancer survivors [44•]. Similar interventions may be useful in the management of PFDs.

Community Level

A common theme seen among Latinas is a delay in health-seeking behaviors. At the community level, targeted public

health campaigns along with community engagement can be used for PFDs. Focus groups composed of both Spanish and English-speaking women with symptomatic POPs have shown that there is a general lack of public awareness about POP as a disease process. There is a reluctance to speak with healthcare professionals and family members [18•]. Health decisions such as family planning often occur outside of the clinic or hospital setting, and thus community-based interventions are important avenues to promote knowledge, awareness, and understanding of PFDs [45••].

Latinas are eager to learn more about PFDs and would feel more comfortable sharing private health issues within a small group of similar women in the community in areas such as health fairs, community centers, and churches [7]. Events may be coordinated between healthcare centers and the community to encourage Latinas to seek care for PFDs.

Flyers may be placed in predominantly Latino communities, in community health clinics, local churches, district offices, youth centers, and schools. Flyers and information packets can also be distributed to women who receive the Special Supplemental Nutrition Program for Women, Infants, and Children, WIC, which is aimed to safeguard the health of low-income pregnant, postpartum, and breastfeeding women, infants, and children up to age 5. Interventions delivered by lay providers have shown slightly larger effects than interventions delivered by medical providers. For example, interventions by lay providers resulted in longer breastfeeding durations for Latinas [46•].

Social Media

In a study by Hudnut-Beumler et al., findings suggest that Latinas would welcome information portrayed through mass media outlets such as television, Univision, Telemundo, or social media, Facebook, Twitter, Instagram, and Tik Tok [47••]. In Latino communities, where there is more secrecy about urinary incontinence, basic messaging about the presence and common nature of UI symptoms may be particularly important, especially when linked with information about treatment options [11•]. The internet and social media have become an increasingly popular platform for public health interventions since it has the distinct ability to communicate with, engage, and educate a large number of Latinas. Latinas are among the leading users of social media in the USA [47••]. In a study by Roy et al., it was reported that there were positive outcomes for help-seeking behaviors after Web-based interventions [48]. Influencers on platforms such as Instagram, Facebook, and Tik Tok may be helpful in bringing to light common PFDs through their stories.

Smartphones and tablets have become an integral part of people's daily lives. Apps on smart devices have the capability of reaching large populations as well as targeted populations such as Latinas. In a systemic review by Schoeppe

et al., it was found that 19 out of 27 studies identified significant improvement in behavioral and related health outcomes after using apps [49]. Integrating social media in health literacy programs needs to incorporate the same health literacy strategies used in patient education material such as the use of plain language [50••].

Discussion and Conclusions

Spanish-speaking Latinas appear to have a low level of health literacy when it comes to PFDs [12]. There is a limited knowledge of PFDs and a reluctance to speak about PFD symptoms with healthcare providers. As a result, Latinas tend to suffer from PFD symptoms such as POP and UI. It is a surprising finding that many Latinas are aware that PFDs are not normal conditions but that they are to be expected as a normal part of aging [15••, 18•].

The barriers to seeking care for PFDs are multi-factorial and include culture, language, misconceptions, and embarrassment. Family is important to Latinas, and they tend to care for themselves last. The family always comes first. Latinas are also more willing to try alternative therapies before conventional treatments. Some misconceptions identified were the belief that PFD symptoms were indicative of cancer, and that treatment of PFDs would contribute to cancer. Other common misconceptions were that POPs were infections or eviscerations and often Latina patients were embarrassed because they believed that they caused their own conditions.

Clinicians need to be sensitive to the unique needs of Latinas when it comes to PFDs. Staff and clinician training in cultural competency and implicit bias recognition at the system/clinic level is vital to helping patients with low health literacy navigate their care and put trust into providers. Latinas most often will not volunteer PFD symptoms, and it is the job of the clinician to ask the right questions and measure the patient's understanding of their condition. Miscommunication is common from both the physician and patient side. A patient's affirmative response or lack of questions does not convey understanding. Qualified interpreters should be used when executing the "teach back" method.

Health literacy interventions are continuously evolving. A common theme in communication with patients is the use of plain language along with visuals. Pamphlets and other supplemental documents should be at or below a 6 fifth grade reading level and culturally appropriate. Translated patient information for Latinas should be translated into Spanish first and then translated back into English to ensure that the information and messages remain intact. Interestingly, a study on disease understanding among Spanish-speaking women with PFDs demonstrated that patients had poor understanding of their diagnosis before

and after an encounter regardless of how extensive the physician's explanation or the level of Spanish-proficiency [12]. The same concept of plain language applies to social media.

More public education is needed. Promotion of health-seeking behaviors begins at the community level, community centers, local churches, and schools. Latinas have expressed that they would feel more comfortable discussing sensitive topics such as PFDs in small groups in a community setting. Since another common theme seen among Latinas is a lack of time or availability due to work and/or childcare, the use of telehealth interventions should be encouraged.

Mass media outlets on television or the radio are also a means to begin the conversation about PFDs. Latinos are among the largest user base of the internet and social media apps. While there are limited studies on social media use, it may play a vital role in normalizing the discussion of PFDs and encouraging Latinas to seek medical care and dispel any misconceptions.

Limitations

Latinos are a diverse ethnic group that includes many different cultures, races, and nationalities. Most of the studies reviewed focused on Mexican Americans and recent immigrants to the USA. Clinicians should not automatically assume that a Latina patient has low health literacy.

Many of the interventions identified were used for other health conditions such as diabetes, cancer, mental health, and cardiovascular diseases. Further studies need to be geared toward interventions used specifically for PFDs. The interventions reviewed were not directed toward Latinas but may be adapted to Spanish-speaking patients through the use of interpreters and translators and appropriate Spanish language documents.

While the use of social media to open the conversation on PFDs is an opportunistic venue, social media is also known for purporting false information. Patients are overwhelmed with the amount of information found on the internet and the same can be true with social media.

Declarations

Conflict of Interest Alexandra Chavez and Dr. Aqsa Khan declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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