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# Shame and Embarrassment in Human Papilloma Virus (HPV) Screening for Cervical Cancer: A Narrative Literature Review

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*La vergüenza<sup>1</sup> en la detección del Virus del Papiloma Humano (VPH) en el cáncer cervical: Una revisión de literatura narrativa*

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## Abstract

The Human Papillomavirus (HPV) is a common and asymptomatic sexually transmitted infection (STI). Prolonged infection with the virus is considered the main component that can cause cervical cancer. To detect HPV, cervical cytology (Pap smear or Papanicolaou) is usually used. It has been found that women feel shame and embarrassment when undergoing cervical cancer screening and after receiving a positive HPV diagnosis, because of its association with STI's. The purpose of this Narrative Literature Review (NLR) is to present studies and literature reviews in which shame and embarrassment<sup>2</sup> influence women's decision to undergo cervical cancer screening. To carry out this review, texts published between 2006-2021 in Google Scholar were used. The inclusion criteria were: 1) articles that mentioned shame and embarrassment as a factor that decreases HPV detection, 2) articles that included self-sampling for HPV detection, and 3) publications (studies, meta-analyses, and systematic reviews) written in English. A total of 4,585 articles were found and 24 met the inclusion criteria. The findings in this NLR show that women feel shame and embarrassment during cervical cancer screening; however, there is a lack of studies focused on embarrassment, HPV, and why women do not attend cervical screening appointments.

*Keywords:* HPV, self-sampling, shame, embarrassment, cervical cancer screening

## Resumen

El Virus del Papiloma Humano (VPH) es una infección de transmisión sexual (ITS) asintomática y muy común. El tener el virus por un tiempo prolongado es considerado como el componente principal que puede provocar cáncer de cuello uterino. Para detectar el VPH, generalmente, se utiliza una citología cervical (prueba de Papanicolaou). Se ha encontrado que las mujeres sienten vergüenza al realizarse exámenes para la detección de cáncer de cuello uterino y al recibir un diagnóstico positivo de VPH, ya que se relaciona con una ITS. El propósito de esta Revisión de Literatura Narrativa (NLR) es reportar estudios y revisiones de literatura en los que la vergüenza influya la decisión de las mujeres para someterse a un examen de detección de cáncer de cuello uterino. Para realizar esta revisión se utilizaron textos publicados entre 2006-2021 en Google Scholar. Los criterios de inclusión fueron: 1) artículos que mencionaron la vergüenza como un factor que disminuye la detección de VPH, 2) artículos que incluían el auto-muestreo para la detección de VPH y 3) publicaciones (estudios, metaanálisis y revisiones sistemática) escritas en inglés. Se encontraron un total de 4,585 artículos y 24 cumplieron con los criterios de inclusión. Los hallazgos en esta NLR presentan que las mujeres sienten vergüenza durante los exámenes para la detección de cáncer de cuello uterino, sin embargo, hay una carencia de estudios enfocados en la vergüenza, el VPH y el por qué las mujeres no asisten a sus citas para la detección de cáncer cervical.

*Palabras claves:* VPH, auto-muestreo, vergüenza, detección de cáncer de cuello uterino

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<sup>1</sup> We used vergüenza as synonymous to refer to both concepts of "shame and embarrassment"

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According to the World Health Organization (WHO, 2020a), the human papillomavirus (HPV) is the most common and asymptomatic sexually transmitted infection (STI). At some point, it will infect most sexually active women and men (Lugović-Mihic et al., 2021; WHO, 2020a). Despite HPV being sexually transmitted, penetration is not required for transmission; skin-to skin genital contact and genital mucosa are common ways of transmission (Hernandez et al., 2019; Lugović-Mihic et al., 2021). HPV is responsible for a portion of oropharyngeal, vaginal, vulvar, penile, anal, and cervical cancer; the latter being the most common cancer caused by HPV (Dube Mandishora et al., 2017; Lugović-Mihic et al., 2021). HPV oncogenic infections, which can cause cancer cells to develop, usually clear up within 14 months without intervention and five to six months for non-oncogenic infections (Lugović-Mihic et al., 2021). To test for HPV, many women attend a clinic to have a Papanicolaou test performed (Thompson et al., 2020). As a result, some report shame and embarrassment during the process of HPV screening (Rees et al., 2017). As an alternate method, studies have assessed the feasibility of utilizing self-sampling techniques to reduce these feelings (Thompson et al., 2020; Yeh et al., 2019). This Narrative Literature Review aims to identify which studies and literature reviews reported shame and embarrassment as a factor for lack of HPV screening and the use of self-sampling as an alternative to test for HPV. By identifying this, we add another purpose: to present studies in Puerto Rico regarding HPV self-sampling and entice researchers to study existing gaps regarding shame and embarrassment in the Puerto Rican population.

### **HPV Prevalence**

According to the Center of Disease Control and Prevention (CDC, 2021a), 80% of sexually active persons are usually exposed to HPV during their lifetime. HPV

is the most common sexually transmitted infection (STI) and an infectious agent related to cancer (CDC, 2021a). HPV is responsible for 90% of anal and cervical cancers, 70% of vaginal and vulvar cancers, 60% of penile cancers, and 70% of oropharynx cancers (CDC, 2021b). Two of the most common types of HPV (16 and 18) are more high risk and known to cause approximately 70% of cervical cancers (WHO, 2022). Because of the high burden of cases, the WHO adopted a global strategy (e.g., vaccination) to decrease the number of new cervical cancer cases. There are currently four vaccines, all aimed at protecting against HPV16 and HPV18 types (Torres-Roman, et al., 2022; WHO, 2022). The rapid rise of HPV cases and cervical cancer among women can be attributed to changes in sexual behaviors (e.g., early sexual activity), increase in the risk of HPV infection and limited access of the health system to preventative measures such as vaccination, screening, and treatment (Torres-Roman et al., 2022; WHO, 2022).

### **HPV in Puerto Rico**

Studies have shown that in Puerto Rico, HPV infection rates may go up to 79% (Medina-Laabes et al., 2018). Puerto Ricans have the highest indecency rate of cervical cancer compared to the United States and other territories (Acevedo-Fontánez et al., 2018). Moreover, there is a high burden of other HPV-related cancers, such as: anal, oral, pharyngeal, and penile (Colón-López et al., 2013; Colón-López et al., 2012; Ortiz et al., 2016; Suárez et al., 2009). A study among Puerto Rican women between the ages of 16-64 identified that 32% of women are HPV positive with strands 16 or 18, which are responsible for most HPV-related cancer (Ortiz et al., 2018). This same study identified a relationship between positivity rate and having three or more sexual partners in their lifetime. Moreover, the highest positivity rate is among women between the

ages of 16-19. (Ortiz et al., 2018). Puerto Rican women have also reported low knowledge about HPV, cervical cancer, and susceptibility to HPV infection (Fernández et al., 2014).

## **Cervical Cancer**

In 2020, The World Health Organization (WHO, 2022), ICO/IARC Information Centre on HPV and Cancer (HPV Information Centre, 2021) and Global Cancer Observatory (GLOBOCAN, 2021) data showed that cervical cancer is the 4th most common cancer among women worldwide with approximately 604,127 new cases and 321,831 deaths in 2020. HPV is the major component that leads to cervical cancer (Hu & Ma, 2018). Even though an HPV infection does not cause cervical cancer by itself, being infected for a prolonged period can lead to cervical cancer (Hu & Ma, 2018). Cervical cancer can be prevented if there is proper and routine screening (Benard et al., 2021).

## **HPV Testing**

In many countries, the standard way to screen for HPV is to use cervical cytology (Papanicolaou or Pap smear; Thompson et al., 2020). A pap smear is a routine procedure where tissue is scraped from the cervix and tested for abnormalities (CDC, 2021c). Since its implementation in the 1950's, cervical cancer rates among U.S women declined by over 50% (Thompson et al., 2020). However, HPV testing is being used alongside cervical cytology or by itself; therefore, eliminating the Pap smear (O'Connor et al., 2018; Onuma et al., 2020; Wentzensen et al., 2017). This shift is happening because HPV testing can identify abnormal cell growth earlier and with more precision (Ogilvie et al., 2018). Contrary to PAP intervention, self-sampling collection, where a person collects their own sample, has been reported to be more acceptable and enhances women's participation in regular

cervical and anal screenings (Yeh et al., 2019). A study of 812 women revealed that 55% of them were willing to get the HPV test instead of the PAP (Thompson et al., 2020).

If the Pap smear results show a smaller amount of cell abnormality (CIN1/ASCUS), women are then asked to have another Pap done alongside HPV testing. If these results show a biopsy diagnosis of CIN1, CIN2 or ASCUS (results could also appear negative at this stage), women are referred to a colposcopy (Castle et al., 2011). If a moderate amount of abnormality (CIN2+) is detected during the initial Pap smear, women are directly referred for a colposcopy (Castle et al., 2011). A colposcopy is a procedure in which a microscope, equipped with a light, is used to examine the tissue in the cervix. During this procedure, a speculum is used to keep the area open for an extended period (John Hopkins Medicine, 2019). Because of what a colposcopy procedure entails, investigators in the United Kingdom (Swancutt et al., 2011) wanted to study women's experiences with the procedure. Some of their findings show some women feel embarrassment and distress because of prolonged exposure to strangers (Swancutt et al., 2011).

If any of the tests come back negative, women are asked to screen as they normally would (Mayo Clinic, 2022). Different from a Pap smear, the HPV test is more sensitive and identifies hrHPV types (high-risk HPV) that lead to cervical cancer; also, the testing gives a simple positive or negative result (American Cancer Society, n.d.; Koliopoulos et al., 2017). If the results are positive, women are referred for a colposcopy and a Pap smear (Aarnio et al., 2020). Because of the simplicity and accessibility of an HPV test, this is the preferred choice for self-sampling (WHO, 2020b).

## Shame & Embarrassment

Emotions can arise when discussing or getting tested for STIs; two of which are shame and embarrassment (Scheinfeld, 2021). According to the American Psychological Association (APA, 2015), the term shame means “a highly unpleasant self-conscious emotion arising from the sense of there being something dishonorable, immodest, or indecorous in one’s own conduct or circumstance”. The term embarrassment refers to “a self-conscious emotion in which a person feels awkward or flustered in other people’s company or because of the attention of others, as, for example, when being observed engaging in actions that are subject to mild disapproval from others” (APA, 2015).

There are some limitations in the Spanish language since the terms shame and embarrassment are encompassed in one word: *vergüenza*. To understand what a person is specifically referring to, one must understand the context of what is being spoken or written. Up to date, only one investigation has been found whose sole focus was shame and embarrassment and the process of HPV screening (Teng et al., 2014). This investigation also underscored the importance of language. Like Spanish, in the Luganda language, shame and embarrassment can be described as ‘personal embarrassment’ which is related to one’s feelings of shame and ‘community embarrassment’ which refers to the social aspect or embarrassment (Teng et al., 2014). According to Teng et al. (2014), “embarrassment in gynecological screening is a well-known but ill-defined phenomenon”.

### Shame and Embarrassment in HPV Screening

Recent studies have shown that women feel shame and embarrassment when getting a Papanicolaou test or Pap smear

(Rees et al., 2017). Because of this, some women avoid going to gynecological screening altogether (Polman et al., 2019). In a study conducted in the southeastern Asian country of Brunei (Chaw et al., 2022), researchers wanted to understand the reasons why women were not attending cervical cancer screenings. The result showed that the second highest percentage (14.9%) reported they did not want to get screened because of embarrassment (Chaw et al., 2022). Comparable results were seen in England; 29% of women did not want to get tested for HPV due to embarrassment (Waller et al., 2009). HPV can be seen worldwide; however, the data show that over 80% of HPV cases and HPV related cervical cancer cases can be seen in low- and middle-income countries and minority populations (Allen-Leigh et al., 2017; Arbyn et al., 2020). Because of this, there has been a small rise in investigations to find the reasons and to offer alternatives (Allen-Leigh et al., 2017; Rees et al., 2017; Teng et al., 2014; Vahabi & Lofters, 2016).

In Nicaragua, only 10% of the entire female population go to clinics to have a Pap smear done (Rees et al., 2017). Because of this, a study was developed to find out how women in a specific area in Nicaragua felt about HPV screening. The results underscored that one of the five main reasons to not get a Pap smear was embarrassment and shame (Rees et al., 2017). They felt that the screening was too intimate, and it causes them shame to have it done so often. Out of all participants, 74% also voiced that the doctor’s gender plays a key role, and they feel more comfortable with a female doctor. Also, some of them expressed that their health is too important, so they are willing to let go of the shame, but the embarrassment is still present (Rees et al., 2017). A study whose focus is shame and embarrassment and the role it plays on cervical cancer screening showed that there is not a clearly stated reason as to what causes shame and/or embarrassment during screening. However, Teng et al., (2014)

state that, “there are several factors associated with embarrassment: community embarrassment, confusion of human papillomavirus (HPV) or HIV, place of recruitment, location of self-collection, relationship with healthcare worker, gender of the physician performing screening, handling of swab, personal embarrassment, age of participant, novelty of the test and lack of knowledge”. It was also mentioned that the possibility of a positive result already causes them to develop a sense of shame and fear of death. Additionally, the study revealed that, after receiving education, embarrassment and shame were seen in smaller proportions (Teng et. al., 2014).

### **Shame and Embarrassment after HPV Diagnosis**

Shame and embarrassment are not limited to screening, it can also be seen when women receive a positive HPV diagnosis (McBride et al., 2020; Rees et al., 2017). Women feel shame because this creates an association to STI’s and fear their family and friends would not accept them; therefore, they would rather not share their test results (McBride et al., 2020). Additionally, there is the fear that this will affect the process of finding a romantic and/or sexual partner (Flynn et al., 2017). Some women outright refuse to have sexual intercourse to avoid any type of embarrassment (Pereira-Caldeira et al., 2020). Because of this, shame is more prominent amongst single rather than married women (O’Connor et al., 2018). Another instance of shame was shown in the Nicaraguan study (Rees et al., 2017), where a participant shared her aunt’s story. Her aunt had a positive HPV diagnosis, which led to cervical cancer, and the shame she felt was so substantial that she informed her family of her diagnosis five days before her death.

Studies also show that shame is seen across all age groups, however, it is seen

more amongst younger women, and it can also be present at a higher rate amongst women with lower levels of education, religious women, and non-white women (McBride et al., 2020; O’Connor et al., 2018). As of 2022, only one published investigation has been found in Latin America that has explored the psychosocial aspects of HPV positive women. The results show that amongst other psychosocial factors, women felt shame when thinking about their results (Arrossi et al., 2020). To help women cope with their positive test results, a team of investigators in Hong Kong attempted to offer education and support. The results were not favorable, because shame was still present in women six months after HPV education (Ngu et al., 2018). The lack of favorable results could be explained by the results of another study where knowledge about HPV and emotional response varied throughout a sample of HPV-positive women. The authors suggest that stigma and emotions associated with an HPV diagnosis may affect how women comprehend the disease, leading to more negative emotions and behaviors (Daley et al., 2010).

### **Self-sampling, Shame, and Embarrassment**

One way to diminish or eliminate shame and/or embarrassment is by introducing self-sampling (Allen-Leigh et al., 2017; Camara et al., 2021; Polman et al., 2019). In recent years, HPV prevention and testing has shifted to HPV DNA testing (HPV test) and self-sampling (Aranda et al., 2021). HPV self-sampling is just as accurate as if the test were being administered by a physician or health care worker (Arbyn et al., 2018; Bakiewicz et al., 2020; Leinonen et al., 2018; Polman et al., 2019a; Toliman et al., 2018). The WHO recommends self-sampling because of its ability to reduce barriers women face; these include fear, cultural factors, accessibility problems, embarrassment, and shame (WHO, 2020a).

With self-sampling, women receive a kit in the mail (or personally pick it up) and gather a vaginal sampling for no longer than 30 seconds. After gathering the sample, the tip is then added to a tube, and they should send it through the mail or dropped at a clinic or pharmacy. Afterwards, they will receive their results (WHO, 2020a).

With self-sampling, women feel little to no pain, less nervousness and little to no shame and embarrassment (Camara et al., 2021; Polman et al., 2019; Williams et al., 2017). Furthermore, women reported the ease of instructions and administration, and underscore the importance of privacy (Bakiewicz et al., 2020; Hermansson et al., 2020; Polman et al., 2019). Because self-sampling is easy and makes women feel comfortable, there has been an increase in screening and acceptability among women and they would rather self-sample than go to a physician (Chaw et al., 2022; Mao et al., 2017; Polman et al., 2019; Shin et al., 2019; WHO, 2020a). However, the cost of the test is an important topic for many. Some women would choose to not use self-sampling if health insurance does not cover it (Vahabi & Lofters, 2016).

As of the development of this NLR, only two published studies conducted in Puerto Rico regarding self-sampling and HPV were found. Said studies were conducted in 2012 (Ortiz et al., 2012) and 2010-2013 (Ortiz et al., 2016), almost 10 years ago. The purpose of one of these investigations was to determine the acceptability of HPV self-sampling amongst women (Ortiz et al., 2012). Vaginal testing results showed that 58% felt less pain, 71% felt less embarrassment, and 94% felt they had more privacy (Ortiz et al., 2012). However, 67% of women stated they would rather have the HPV test done by a clinician; 85% felt that they could get better results when done by a healthcare professional (Ortiz et al., 2012). With anal self-sampling, the results were comparable. Literature regarding the

availability of self-sampling in Puerto Rico was not found.

## **Method**

During a general HPV literature review, the primary author (LRR) observed how the themes of shame and embarrassment were discussed within some of the literature. This NLR aims to identify which studies and literature reviews reported shame and embarrassment as a factor for the lack of HPV screening and the use of self-sampling. We performed an NLR without any specific framework. We chose to use an NLR because of its individuality and flexibility and for allowing us to cover a wide range of issues without discussing the validity of the studies (Collins & Fauser, 2005).

### **Eligibility criteria**

The eligibility criteria included articles where shame and embarrassment were mentioned as a factor for diminished HPV screening. Additionally, articles which discussed self-sampling as an option were utilized. Eligible publications included studies, meta-analysis and systematic reviews written in English.

### **Exclusion criteria**

Articles excluded from this NLR were articles where HPV vaccination and its association as an STI was the cause for shame and embarrassment. Articles which only mentioned shame and embarrassment but did not include it as part of their analysis were excluded as well.

### **Information sources**

A search was conducted in Google Scholar database. The selected articles ranged from 2006-2021, or 15 years. This NLR was conducted in Google Scholar due to its range and versatility as a database for finding articles. However, we recognize

that using only one database can be considered a limitation for this NLR.

### **Search Strategy**

The search for this NLR was conducted only in English. The keywords used during the article search were: 1) shame and embarrassment AND HPV, 2) HPV and self-sampling AND shame and embarrassment, and 3) shame and embarrassment AND HPV screening. To conduct this literature review, the primary author searched for articles published between 2006-2021.

### **Selection Process**

To select which articles met the inclusion criteria for this NLR, the primary author reviewed each title to identify if they discussed HPV, self-sampling, emotional process, screening, shame, or embarrassment. Articles that met this first screening passed to a second screening in which the primary author and one team member evaluated each abstract and full text with the inclusion criteria for their selection and further analysis. Finally, abstracts and full texts that did not meet the inclusion criteria were excluded.

### **Data Collection Process**

Articles were selected based on the inclusion criteria through the assessment of the selection process. After a search of all keywords, Google Scholar produced 4,585 articles. By conducting the first screening of each article, 81 articles met the inclusion criteria. A second screening was conducted to identify abstracts and full text, in which a total of 42 articles were further considered after reading each abstract and full text meticulously. As a final process, we identified a final sample of 24 articles that met the eligibility criteria.

## **Results**

After the initial process, 24 articles met the eligibility criteria. Excluded articles identified shame and embarrassment in relation to HPV vaccination. Twenty-one publications were studies and three were reviews (meta synthesis, meta-analysis, and systematic review) Two articles were selected based on their abstract and 22 were fully text reviewed. Only one article's primary focus is on shame and embarrassment, its impact on cervical cancer screening, and explored self-sampling as an option. See Table 1 for more information on articles used for the literature review.

**Table 1***Shame, embarrassment, and self-sampling articles used for literature review*

Author	Title	Design	Participants	Findings
Allen-Leigh et al. (2017)	Barriers to HPV self-sampling and cytology among low income indigenous women in rural areas of a middle-income setting: A qualitative study	Qualitative	Individual interviews ( $n = 29$ ), focus groups ( $n = 7$ ) and discussion groups ( $n = 2$ )	Women had a limited understanding of HPV's role in cervical cancer. In addition, the study highlights organizational barriers like distance to clinics and lack of clear communication by healthcare personnel.
Arbyn et al. (2018)	Detecting cervical precancer and reaching under screened women by using HPV testing on self samples: Updated meta-analyses	Quantitative, Meta Analysis	Accuracy studies ( $n = 56$ ) and participation trials ( $n = 25$ )	The results of the HPV self-sample were similarly accurate as those of clinician samples, and it is a more effective way to reach under-screened women.
Arrossi et al. (2020)	Psycho-social impact of positive human papillomavirus testing in Jujuy, Argentina results from the Psycho-Estampa study	Quantitative, Cross-sectional	$n = 163$	The highest psychosocial impact was related to worries about cancer and treatment, followed by sexual aspects and limited information provided by healthcare providers about testing HPV positive.
Bakiewicz et al. (2020)	"The best thing is that you are doing it for yourself" – perspectives on acceptability and feasibility of HPV self-sampling among cervical cancer screening clients in Tanzania: A qualitative pilot study	Qualitative	$n = 21$	Women preferred self-sampling over provider sampling due to privacy. However, women experienced uncertainty about their capability to collect the self-sample correctly.
Camara et al. (2021)	Self collection for HPV-based cervical screening: A qualitative evidence meta-synthesis	Qualitative, Meta synthesis	$n = 1889$	To increase the acceptability of HPV self-collection, the healthcare system needs to ensure access to self-collection kits, culturally sensitive programs of health literacy, the importance of values and self-efficacy, and the impact on social relationships.



Author	Title	Design	Participants	Findings
Chaw et al. (2022)	Reasons for nonattendance to cervical cancer screening and acceptability of HPV self-sampling among Bruneian women: A cross-sectional study	Quantitative, Cross-sectional	$n = 174$	Reasons for not attending the pap-test screening were: fear of a positive result, embarrassment, and lack of time to attend. However, the acceptability of self-sampling kits was positive due to their ease and convenience.
Flynn et al. (2017)	High trait shame undermines the protective effects of prevalence knowledge on state shame following HPV/CIN diagnosis in women	Quantitative, Cross-sectional	$n = 80$ ,	HPV diagnosis can lead to a persistent experience of acute shame and guilt, increasing the risk for depression.
Hermansson et al. (2020)	Elderly women's experiences of self-sampling for HPV testing	Mixed-methods	$n = 868$	Women preferred self-sampling because it was easy to perform, less embarrassing, and less time-consuming than a visit to a clinic. On the other hand, women with better knowledge about HPV infection were more worried about having a positive HPV test.
Leinonen et al. (2018)	Safety and acceptability of human papillomavirus testing of self-collected specimens: A methodologic study of the impact of collection devices and HPV assays on sensitivity for cervical cancer and high-grade lesions	Quantitative, Cross-sectional	$n = 187$	Evalyn Brush self-collection for high-risk HPV was more sensitive, easier, and comfortable than FLOQSwabs. Collection kit devices may have an impact on disease detection and the acceptability of self-sampling.
Mao et al. (2017)	Clinician and patient acceptability of self-collected human papillomavirus testing for cervical cancer screening	Quantitative, Randomized trials	$n = 1,769$ women; $n=238$ physicians and mid-level healthcare providers	Women preferred HPV self-collected testing because it was less time-consuming, embarrassing, or uncomfortable. In addition, physicians and mid-level healthcare providers would recommend self-collected HPV tests if the test had qualities such as high sensitivity and cost-effectiveness.

Author	Title	Design	Participants	Findings
McBride et al. (2020)	Emotional response to testing positive for human papillomavirus at cervical cancer screening: A mixed method systematic review with meta-analysis	Systematic Review	$n = 33$	Anxiety and distress about test results, sexual relationships, and feelings of disgust, shame, and fear about cancer were the common emotional responses for testing positive for HPV.
Ngu et al. (2018)	Impact of different educational interventions on psychosocial well-being of women with a positive high-risk human papillomavirus and normal cervical cytology: A randomised trial	Quantitative, Randomized trials	$n = 121$	Educational interventions about cervical screening and HPV can lead to short-term higher knowledge, relieving adverse HPV-related psychosocial effects such as worry, anxiety, and depression.
O'Connor et al. (2018)	Socio-economic variations in anticipated adverse reactions to testing HPV positive: Implications for the introduction of primary HPV-based cervical screening	Quantitative, Cross-sectional	$n = 3,470$	Testing positive for HPV can lead to adverse psychosocial responses such as shame, anxiety, stigma, and worry. It can be seen in different aspects of life: socio-economic, religion, marriage/partners, employment.
Ortiz et al. (2012)	Acceptability of cervical and anal HPV self-sampling in a sample of Hispanic women in Puerto Rico	Mixed-methods, Cross-sectional	$n = 100$	Cervical HPV self-sampling has a higher acceptability than clinician sampling; however, clinician sampling acceptability was higher in anal sampling.
Ortiz et al. (2016)	Prevalence, genotyping, and correlates of anogenital HPV infection in a population-based sample of women in Puerto Rico	Qualitative, Cross-sectional	$n = 564$	Anal HPV infection is prevalent in Puerto Rican women (38.6%). Anogenital HPV infection can be a burden in women, and its relationship with sexual behavior.
Pereira-Caldeira et al. (2020)	Quality of life for women with human papillomavirus induced lesions	Qualitative, Cross-sectional	$n = 20$	HPV impairs women's quality of life. It impacts physical, emotional, sexual, social, and affective relationships.

Author	Title	Design	Participants	Findings
Polman et al. (2019)	Experience with HPV self-sampling and clinician-based sampling in women attending routine cervical screening in the Netherlands	Qualitative, Cross-sectional	$n = 3,835$	Women reported lower levels of shame, nervousness, discomfort, and pain during self-sampling compared to clinician-based sampling (71.6 to 79.4%). On the other hand, trust in sampling was higher during clinician-based sampling.
Rees et al. (2017)	Knowledge and beliefs regarding cervical cancer screening and HPV vaccination among urban and rural women in León, Nicaragua	Mixed-methods, Cross-sectional	Quantitative sample ( $n = 229$ ) qualitative interviews ( $n = 20$ )	Knowledge of Pap smears, HPV, and cervical cancer is associated with screening-promoting beliefs. Some determinants were: the gender of the exam provider, beliefs of sexual promiscuity, knowledge of cervical cancer limited prevention, and time spent in clinics.
Scheinfeld, (2021)	An exploration of emerging adult students' felt shame and stigma towards getting tested for and disclosing sexually transmitted infections	Quantitative, Cross-sectional	$n = 462$	Stigma and shame were associated with STI communication, the perception of STI knowledge, and getting tested.
Shin et al. (2019)	Evaluation of satisfaction with three different cervical cancer screening modalities: Clinician-collected Pap test vs. HPV test by self-sampling vs. HPV test by urine sampling	Quantitative, Cross-sectional	$n = 732$	Psychological distress, such as embarrassment, pain, anxiety, discomfort, and stress, were significantly lower with self-sampling than with a Pap smear.
Teng et. Al. (2014)	Understanding the role of embarrassment in gynaecological screening: A qualitative study from the ASPIRE cervical cancer screening project in Uganda	Quantitative, Cross-sectional	$n = 22$	Embarrassment was a barrier to screening at the outset and diminished over time through education and knowledge.
Vahabi & Lofters, (2016)	Muslim immigrant women's views on cervical cancer screening and HPV self-sampling in Ontario, Canada	Mixed-methods	$n = 39$	There is limited knowledge about cervical cancer and screening guidelines, and a need for providing culturally appropriate sexual health information.

Author	Title	Design	Participants	Findings
Waller et al. (2009)	Barriers to cervical cancer screening attendance in England: A population-based survey	Mixed-methods, Cross-sectional	$n = 580$ , 26-64	Common barriers to cervical screening were: embarrassment, intending to go but not going, fear of pain, and worry about the results.
Williams et al. (2017)	Women's perspectives on human papillomavirus self-sampling in the context of the UK cervical screening programme	Quantitative, Cross-sectional	$n = 194$ , 20-64; subsample of $n = 19$	There is a perception of lower efficacy of self sample, lower education, and lower perceived importance of HPV as a cause of cervical cancer due to the lack of knowledge about HPV self-sampling. Women's low confidence in their ability to self-sample correctly resulted in low confidence in the results.

## Discussion

This narrative literature review aims to present shame and embarrassment as a factor that influence women's choice on whether to undergo HPV screening for cervical cancer. Said screening is paramount because HPV is the most common STI worldwide, and it causes the fourth most common cancer among women (Aranda et al., 2021; Lugović-Mihić et al., 2021; WHO, 2020a). Across multiple studies (Chaw et al., 2022; Rees et al., 2017; Waller et al., 2009), shame and embarrassment were present during routine cancer screenings, and it is mentioned as one of the main reasons women choose not to attend HPV screening (Polman et al., 2019). As a result, self-sampling is presented as an option, because of the benefits it may bring to women (Allen-Leigh et al., 2017; Camara et al., 2021; Polman et al., 2019). Additionally, HPV carries a stigma due to it being an STI and because of this, women may also feel shame and embarrassment after receiving a positive HPV diagnosis (McBride et al., 2020).

There is a lack of studies whose focus is embarrassment and shame during cervical cancer screening, which include the Papanicolaou test (Rees et al., 2017; Teng et al., 2014). Some women would rather not attend cervical cancer screening, and there is a need to know why. Some reasons identified include pain, accessibility, privacy, shame, and embarrassment (Camara et al., 2021; Polman et al., 2019; Williams et al., 2017). As a result, some studies have tried to identify alternatives to help mitigate these feelings. Self-sampling has been shown to be a feasible alternative because not only does it minimize the feeling of shame and embarrassment, but it also makes self-sampling an accessible option (Chaw et al., 2022; Mao et al., 2017; Polman et al., 2019; Shin et al., 2019; WHO, 2020a). Because of this, self-sampling is being introduced as an alternate

method, so women may still get screened for cervical cancer and hopefully reduce cervical cancer rate (WHO, 2020a). Currently, there is a lack of studies in Puerto Rico which study shame and HPV (Ortiz et al., 2012; Ortiz et al., 2016). A study of this nature could analyze if cultural factors interfere in adherence, or lack thereof, to HPV screening. Additionally, there should be a discussion towards the availability of self-sampling in Puerto Rico and if health insurance agencies would cover the cost.

## Limitations

Due to the nature of a Narrative Literature Review, there were limitations. Firstly, only Google Scholar was used due to its accessibility, range, and versatility; however, not every publication indexed in Google Scholar. This review's sole focus was shame, embarrassment, Pap smears and their role in HPV screening and prevention. As such, vaccinations were excluded from this NLR. Additionally, there are other factors which could interfere in a lack of HPV screening, such as: lack of transportation, access to care, socioeconomic status, or doctor availability. Self-sampling is presented as an option to reduce lack of adherence, however if this is not covered by health insurance, some might not be willing or able to pay for it.

## Compliance with Research Ethics Standards

### Financing

This NLR did not receive any funding.

### Declaration of conflict of interest

The authors have no conflict of interest to report.

### Institutional Review Board for Human Subjects (IRB)

This NLR does not require IRB approval.

## Informed Consent/Assent

This NLR does not require informed consent.

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