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Variation in Cervical Cancer Screening Preferences Among Medically Underserved Individuals in the US: A Systematic Review

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Abstract

Underutilization of effective screening is one driver of disparities in cervical cancer incidence and mortality. Consideration of patient preferences could help to improve screening rates in populations facing substantial barriers to preventive care. We conducted a systematic review of the literature on cervical cancer screening preferences among medically underserved patients in the United States. We searched six electronic databases (PubMed, Web of Science, EMBASE, Scopus, CINAHL, and PsycINFO) for articles published through February 2019 [Prospero ID: CRD42019125431]. Among the forty-three articles included, 23 reported screening modality preferences, 11 reported preferences related to provider demographics and attributes, 6 reported screening scheduling and results delivery preferences, and 9 reported preferences related to health education and communication. This review demonstrates the wide variety of medically underserved patient preferences related to cervical cancer screening. It also draws attention to two key preference trends that emerged despite heterogeneity in study design, populations, and preference assessment. Consistent preferences for HPV self-testing over traditional Pap testing highlight a key potential mechanism for increasing cervical cancer screening uptake among medically underserved populations. Additionally, preferences for gender- and language-concordant providers underscore the need for continued efforts toward expanding diversity among medical professionals.

Keywords

Early Detection of Cancer; Patient Preference; Systematic Review; Uterine Cervical Neoplasms

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Conflicts of Interest

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Introduction

Cervical cancer incidence in the United States (US) has declined by over 70% since the introduction of routine preventive screening in the 1940's, including Pap testing and, more recently, human papillomavirus (HPV) testing (1–4). Recommended screening protocols, when administered appropriately, are effective in decreasing cervical cancer incidence and mortality through early detection and treatment of pre-cancerous lesions (5).

Despite the success of preventive measures, cervical cancer remains a leading cause of cancer-related death in medically underserved individuals (6). Cervical cancer incidence and mortality are marked by disparities in the US (7, 8). Notably, the hysterectomy-adjusted overall mortality rate from cervical cancer among African-Americans, 10.1 per 100,000 individuals with a cervix, is almost double the rate for White individuals (9). Heightened mortality rates have also been documented among Hispanics, American Indians/Alaskan Natives (AI/AN), individuals without a usual source of care, and residents of geographically remote locations (7, 8, 10).

As over 50% of new cervical cancer cases are estimated to be due to insufficient screening (11), disparities in cervical cancer outcomes stem, in part, from disparate screening uptake across groups. Lower screening rates have been documented among Hispanic (79.4%), AI/AN (79.0%), and Asian (75.3%) women compared to Black (85.6%) and White (85.0%) women (12). Additionally, a disproportionate number of recent immigrants to the US, uninsured individuals, and individuals without a usual health care source remain unscreened (12, 13). Evidence shows that patient perceptions of low cancer risk and high screening barriers (e.g., cost, access, embarrassment) are associated with low screening uptake (14, 15). Lack of consideration of patient preferences surrounding screening, particularly in medically underserved populations, is another important factor contributing to disparate screening rates (16).

With the introduction of HPV testing, in addition to Pap testing, as a recommended primary screening mechanism, patient preferences surrounding screening modality must be considered. Various HPV testing modalities have proven to be effective, including clinician-administered HPV testing and HPV self-testing, in which the patient collects their own vaginal sample, either by direct mail or in-person delivery. The specificity and sensitivity of HPV self-testing is comparable to clinician-administered HPV testing for the detection of HPV infection and high-grade cervical lesions (17, 18). Additionally, studies have documented high patient acceptability of HPV self-collection, particularly among under-screened individuals, suggesting this may be a potentially effective and preferred method to increase screening uptake (19–21). Despite these advances, however, the US Preventive Services Task Force (USPSTF) only recommends provider-administered HPV tests, rather than self-tests, leading to limitations in HPV self-test dissemination and uptake (5, 19). In addition to screening modality, preferences for other aspects of cervical cancer screening should be assessed, including preferences about certain provider attributes, scheduling, and reminders – in the case of in-clinic screening – as well as about communication of results and delivery of screening education interventions.

To date, cervical cancer screening preferences among medically underserved individuals in the US have not been systematically reviewed. Huynh and colleagues (2010) conducted a systematic review of articles published through October 2008 about individual perceptions of HPV self-testing (22). Additionally, two studies have systematically reviewed self-sampling acceptability (23, 24). While these reviews found self-testing to be generally well received by patients, none have specifically reviewed preferences across the full range of approved screening delivery options or focused on medically underserved populations. Other systematic reviews have assessed barriers to and facilitators of cervical cancer screening among specific populations, such as immigrants, Latinas, and other racial/ethnic minorities (7, 15, 25, 26). Building on these reviews, this systematic review is unique in its assessment of medically underserved patients' preferences for cervical cancer screening attributes and delivery, including test modality (particularly important in the era of HPV self-testing), provider demographics and attributes, scheduling and results delivery, and health education and communication efforts. This work can be used to inform future interventions, policies, and research targeting screening uptake.

Materials and Methods

We conducted a systematic review of patient preferences related to cervical cancer screening among medically underserved individuals, according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (27, 28). The protocol for this review is registered with the International Prospective Register of Systematic Reviews (PROSPERO, ID: CRD42019125431) (29).

We developed the inclusion and exclusion criteria for this review using an adapted version of the PICOTS (Population, Intervention, Comparison, Outcome, Timing, and Setting) framework commonly used for clinical research questions (30, 31). The Intervention criterion was not considered since we did not limit this review to studies with an experimental component. Instead, we added a Study Design criterion to capture observational and experimental studies that assessed patient preferences using quantitative, qualitative, or mixed method research designs (Supplementary Table S1).

We developed an initial list of “medically underserved” populations by consulting the Department of Health and Human Services' National Stakeholder Strategy for Achieving Health Equity. The National Stakeholder Strategy defines “medically underserved” as groups or individuals subject to social factors known to increase the risk of adverse health outcomes, including low socioeconomic status, low educational attainment, racism, and inadequate access to quality health care (32). We then expanded this definition to include any additional groups that face economic, cultural, or linguistic barriers to accessing health care, given that these populations often have disparately low rates of cervical cancer screening (7, 8, 10, 12). Because cervical cancer screening guidelines differ internationally (33), we only included studies conducted in the US in this review to ensure consistency in the recommended screening guidelines that may shape patients' preferences and screening behaviors. As for outcomes, studies had to include a patient-reported preference related to cervical cancer screening to be considered for inclusion; however, preference was not

required to be the primary outcome assessed. The specific inclusion and exclusion criteria are outlined in Supplementary Table S1.

We searched the following databases for articles published through February 2019: Medline (PubMed), Science Citation Index (Web of Science), EMBASE, Scopus, CINAHL, and PsycINFO (Figure 1). The following basic search string was used to identify relevant articles: *(HPV OR Pap OR papillomavirus OR human papillomavirus OR Papanicolaou OR cervical OR cervix OR endocervix OR endocervical) AND (Test* OR screen* OR self-test OR self-tests OR self-testing OR self-tested) AND (Preference OR perception OR perceptions OR (discrete AND choice*) OR attitude OR attitudes) AND (Neoplasms OR neoplasm OR neoplasia OR neoplasias OR neoplastic OR dysplastic OR dysplasia OR dysplasias OR cancer OR cancers OR cancerous OR malignant OR malignancy OR malignancies) AND NOT (vaccine) (Title only) AND NOT (vaccination) (Title only)*. Detailed search terms specific to each database can be found in the supplementary materials (Supplementary Table S2).

In total, 6,442 articles were identified across the six databases and imported into F1000 Workspace (Faculty of 1000 Ltd, 2019), a reference management database (Figure 1). After the removal of duplicates, 2,693 unique articles remained and were transferred to Covidence (Veritas Health Innovation Ltd, 2019) for screening. Two reviewers (CBB and MCO) independently screened all titles and abstracts, initially reviewing and comparing 20 articles to ensure screening consistency. For the review of all remaining articles, the reviewers resolved any discrepancies through discussion with one another, and with a third reviewer (LPS) when consensus could not be reached.

During the title/abstract screening, we focused on excluding articles that were not conducted in the US or not related to cervical cancer screening, such as studies related to other health conditions or cervical cancer studies related to HPV vaccination or treatment. Additionally, we excluded studies that were not conducted among patients and studies without an outcome derived from patient experience, such as studies reporting screening uptake only. During the title/abstract screening process, 2,428 articles were removed, leaving 265 articles for full-text review.

During full-text review, the two reviewers (CBB and MCO) assessed whether each record met the inclusion criteria, with discrepancies resolved by the third reviewer (LPS) as necessary. Reviewers specifically focused on excluding articles that did not include a medically underserved population or preference outcome. Assessing these criteria in full-text review allowed us to capture the broad range of cervical cancer screening preferences across diverse populations who meet our definition of medically underserved but were not included in our initial list of target populations. Of the 265 articles reviewed, 222 were excluded, 193 of which did not include a preference outcome. An additional 25 articles were excluded due to not including a medically underserved population, and the remaining 4 were excluded due to being conducted outside of the US. The remaining 43 articles identified for inclusion were abstracted using structured fields.

As a final step, we conducted a risk of bias assessment using a template designed specifically for preference studies by Purnell and colleagues (2014) (34). Each of the 43 included studies were evaluated for low versus high bias in the following six categories: (1) well-defined study question, (2) well-described inclusion criteria, (3) comprehensive description of alternatives, (4) appropriate measure of preferences, (5) appropriate analysis, and (6) pre-specified analysis.

Results

We included a total of 43 studies assessing cervical cancer screening preferences among medically underserved patients in the US. Twenty-three of these studies used a quantitative design, 17 qualitatively assessed preferences, and 3 employed mixed methods. Of the quantitative studies, 22 administered a cross-sectional survey, and 1 elicited patient preferences as a part of a randomized controlled trial (RCT). The majority of qualitative studies (n=11) conducted focus groups, and the other 6 studies conducted one-on-one interviews. Among the mixed method studies, 2 used a combination of interviews and surveys, while 1 paired focus groups and surveys.

Medically underserved populations are categorized broadly as racial and ethnic minorities in 30 studies, low-income populations in 7 studies, LGBTQ populations in 4 studies, rural residents in 3 studies, homeless women in 1 study, and women residing in domestic violence shelters in 1 study. Three of these studies reported preferences for intersectional populations, such as individuals who self-identified as being Black or African American, as well as lesbian, gay, or bisexual.

Tables 1–4 organize results by the type of preference outcome assessed. Table 1 includes 23 studies assessing preferences regarding screening modality (e.g., Pap test, HPV test, co-testing, HPV self-test). Table 2 includes 11 studies reporting preferences for provider demographics and attributes (e.g., gender, ethnicity, type of training). Table 3 presents 6 studies about screening scheduling and results delivery (e.g., reminders, timing) preferences, and Table 4 identifies 9 studies that report preferences regarding health education and communication (e.g. information source, educational material attributes). Studies reporting preferences falling into more than one category are included in each of the relevant tables. Variables associated with preference were only consistently reported across screening modality preference studies; therefore, associations are only reported in Table 1. Associations with other preference outcomes are reported in the text.

Screening Modality (n=23)

A total of 23 studies reported preference outcomes related to cervical cancer screening modality, specifically assessing patient preference between HPV self-testing and traditional cytology (Pap test) (Table 1). Various study designs were used to elicit this preference, including 15 cross-sectional survey studies (35–49), 6 qualitative studies (4 focus group studies (50–53), 2 interview studies (54, 55)), 1 RCT (56), and 1 mixed methods study (57).

All non-focus group studies reported the percentage of participants who preferred the HPV self-test to the Pap test (35–49, 54–57). Percentages ranged from 10% (45) to over 90% (54).

Only 2 studies reported a greater percentage of participants preferring the Pap test compared to the HPV self-test (42.3% vs. 9.9% (45); 67.6% vs. 32.4% (35)). While about half of these studies posed the preference question as a dichotomous choice between the two modalities (36–41, 57), the remaining 9 studies provided additional options, such as “no preference” (35, 42–45, 47–49, 55, 56), “would refuse either” (48), and “do not know” (46). Preference for HPV self-testing over Pap testing ranged from 6% (55) to 45% (56) in these studies. Of note, Galbraith and colleagues (2014) assessed preference differently than the studies discussed above in that participants were asked which test they believed provides the highest level of protection. Only 6% believed the HPV self-test offered greater protection than the Pap test; however, 75% of participants believed the tests protected them equally well, and the remaining 19% favored the Pap test (49).

On the whole, low-income populations (35, 44) and women staying in domestic violence shelters (45) preferred the HPV self-test over the Pap test less than other groups. The majority of rural residents studied (89% (39), 66% (40)) preferred the HPV self-test to the Pap test. The percentage of individuals who preferred the HPV self-test among Hispanic populations ranged from 30% among individuals residing along the US-Mexico border (47) to 89% (42). Similarly ranging estimates were seen across studies assessing the preferences of non-Hispanic Black individuals and African-Americans, among other racial/ethnic minorities. Both studies assessing AI/AN populations reported just over 60% of individuals preferring self-testing over the Pap test (37, 41).

The remaining studies (n=4) used focus groups to probe on reasons individuals may prefer one test over the other. In focus groups of low-income, minority individuals, Anhang and colleagues (2004) found that most participants preferred that the physician administer the HPV test, rather than performing a self-test, due to fear of performing the test incorrectly (53). Alternatively, Scarinci and colleagues (2013) and Katz and colleagues (2017) found that the majority of low-income and minority participants preferred HPV self-testing over Pap testing due to convenience and privacy (50, 52). The focus groups conducted by Penaranda and colleagues (2014) with 21 individuals residing along the US-Mexico border did not reach a clear preference consensus, reflecting both the negative and positive self-testing attributes posed by the other three focus group studies (51). Two studies probed further regarding participant preferences for HPV self-testing device instructions. Trans-masculine individuals preferred both video and written instructions tailored to trans-masculine individuals (54). Similarly, African-American individuals echoed the preference for take-home video instructions; however, participants indicated a preference for in-person instructions as well (52).

Of the quantitative studies included, 11 used bivariate and multivariate regression analyses to identify variables associated with a preference for HPV self-testing over Pap testing. Variables identified as significantly associated with a preference for HPV self-testing included: more education (35), older age (49), less frequent screening history (40, 45, 48), and self-reported avoidance of preventive care due to cost or discrimination (48). Additionally, lack of health insurance was associated with preferring HPV self-testing among transgender men (48), whereas having health insurance was associated with preferring HPV self-testing among low-income women (49). Race and ethnicity were

significantly associated with HPV self-testing preference in 4 studies, with the following groups having a higher likelihood of preferring self-testing to Pap testing: Hispanics versus Haitians (42), Blacks versus Hispanics (43), Blacks versus Whites (44), and non-Hispanics versus Hispanics (35).

Across the 23 screening modality preference studies, study designs varied regarding whether participants performed the HPV self-test, received a Pap test, or completed both tests prior to stating their preference. Participants underwent both HPV self-testing and a provider-administered Pap test at the time of the survey in only 6 studies (35, 43, 44, 46, 54, 55). In 8 studies, participants received descriptions of the HPV self-test and Pap test but did not undergo either screening procedure (40, 45, 48, 50–53, 57). In the remaining 9 studies, participants self-administered an HPV self-test but did not have a Pap test (36–39, 41, 42, 47, 49, 56). However, in synthesizing study results by test(s) performed, it does not appear that significant differences in preferences existed based on whether participants performed either or both screening modalities prior to being assessed.

Provider Demographics and Attributes (n=11)

Eleven studies reported patient preferences for provider demographics and attributes (Table 2). All 11 studies assessed preferences related to provider gender. Additional outcomes assessed included preferences for the type of examiner (n=3) (58–60), language spoken by the provider (n=3) (58, 61, 62), provider's communication style (n=3) (60, 61, 63), and provider's race or ethnicity (n=1) (60).

Gender—All but one study found a preference for female providers over male providers. Of the 5 studies that elicited patients' preference for a female rather than male provider quantitatively, percentages ranged from 41% (59) to 77% (64). Three of these studies included the option of “no preference”, with between 34% (59) and 50% (65) of respondents selecting this option. Lanier and colleagues (1999) also found that 18% of the AI/AN respondents would refuse a male provider (65), while Nguyen and colleagues (2002) reported that 53% of Vietnamese, Vietnamese-American, or Vietnamese-Chinese participants would prefer to have a female standby if a Pap test was performed by a male provider (62).

Qualitative research provided some insight into the reasons for the female provider preference in select groups. Participants in rural Appalachian Ohio reported trusting female physicians more, and expressed discomfort with male physicians (63). Among Bhutanese refugees, preference for a female provider was the result of negative experiences with male doctors in refugee camps (66). Somali women identified a preference for both female providers and interpreters, in part, due to their sensitivity to female issues (67). In the single study that reported a preference for male over female providers, Hispanic participants often described doctors as male and nurses as female, with most preferring to receive information from a doctor than a nurse. However, Hispanic participants still expressed comfort in speaking to another woman about women's health issues (58).

Type of Examiner—A clear consensus for preferred examiner type (e.g. physician, nurse, etc.) when being screened for cervical cancer was not found. Alexander and McCullough

(1981) provided Mexican-American and low-income women with a choice between the following examiner categories: female physician, male physician, nurse or nurse practitioner, female person, no preference. Forty-eight percent of Mexican-Americans and 39% of low-income study participants preferred a physician (with the majority preferring a female over a male), whereas just 10% of Mexican-Americans and 12% of low-income participants preferred a nurse or nurse practitioner. Of note, 34% of Mexican-Americans and 40% of low-income participants reported no preference (59). Torres and colleagues (2013) also found that Hispanic interviewees typically preferred receiving information from a doctor instead of a nurse (58). In contrast, Agénor and colleagues (2015) reported that Black lesbian, bisexual, or queer (LBQ) focus group participants preferred to receive care from a physician's assistant, registered nurse, or nurse practitioner, who they felt were more likely to have increased time and attention available (60).

Language—Three studies assessed whether ethnic minority women preferred to have a provider who speaks their own non-English language. In a cross-sectional survey study of Vietnamese, Vietnamese-American, and Vietnamese-Chinese individuals, nearly two-thirds (64%) preferred having a provider who spoke Vietnamese when completing a Pap test (62). Torres and colleagues (2013) similarly found that the majority of Hispanics interviewed preferred a Spanish-speaking healthcare professional (58). Although Kim and colleagues (2017) found that the majority of Korean immigrant women interviewed preferred a female provider who spoke Korean, their provider language preference changed if seeing a male doctor, preferring a male provider who did not speak Korean out of concern for privacy (61).

Communication Style—Among the three studies reporting communication style preferences, McAlearney and colleagues (2012) conducted focus groups and found that patient-centered communication is preferred among individuals residing in rural Appalachian Ohio (63). Kim and colleagues (2017) found that, instead of receiving the results of their Pap test by letter or phone, most Korean immigrant women preferred to receive their results through in-person conversations with their doctor (61). Black LBQ individuals, in particular, articulated the importance of having an examiner with a calm demeanor who described the process of the Pap test before and during the exam (60).

Race/Ethnicity—Only one study examined preferences related to the provider's race or ethnicity. The majority of Black LBQ participants preferred providers who shared similar characteristics and backgrounds, stating preferences for clinicians who are persons of color, female, and/or from the LGBTQ community. These participants also noted their preference for providers who have had experience with and feel comfortable serving LBQ patients, even if they do not identify as LBQ (60).

Associations with Provider Preferences—Variables associated with preferences for provider demographics and attributes were reported in three studies. Ma and colleagues (2012) found that Vietnamese survey participants who preferred male providers over female providers, as well as those who had no gender preference, were more likely to report a prior Pap test (67). Nguyen and colleagues (2002) reported that older study participants, defined as 65 years of age and above, were more likely to prefer a doctor of the same ethnicity

(Vietnamese) but less likely to prefer a female provider (62). Alexander and McCullough (1981) found that Mexican-American and low-income participants were more likely to prefer a female physician over a male physician, nurse, or nurse practitioner compared to other participants attending the free Pap test clinics (59).

Screening Scheduling and Results Delivery (n=6)

A total of 6 studies reported preference outcomes related to cervical cancer screening scheduling and results delivery (Table 3). Outcomes assessed related to logistical aspects of the screening appointment, including reminder delivery (n=3) (63, 68, 69), appointment time (n=1) (40), and results delivery (n=2) (50, 70)).

Reminder Delivery—In their assessment of screening reminder preferences, Brandzel and colleagues (2016) found that African-American participants most often preferred that reminders, whether mailed or sent electronically, came from community-based advocates over health care professionals. Latina participants did not express a preference regarding who the reminder came from but preferred smart phone reminders over mailed letters (68). In contrast, McAlearney and colleagues (2012) reported that rural residents preferred to receive provider encouragement in the form of mailed, versus electronic, reminders (63). Though Greaney and colleagues (2014) did not find a preference consensus on reminder medium among study participants, when asked about interactive voice response (IVR) messages, Latina women preferred brief messages left by a member of their community to more detailed messages recorded by an outside health care professional, and believed that screening details should be limited for confidentiality reasons (69).

Appointment Time and Results Delivery—Only one study assessed patient preferences regarding screening appointment time. Hatcher and colleagues (2011) reported that 36% of rural residents surveyed preferred weekend appointments over weekday appointments, with recently screened individuals more likely to report this preference than individuals who had not been screened in the past five years (40). Lastly, two studies reported preferences related to the delivery of screening results. Both found that participants preferred comprehensive descriptions of results, with Mexican women preferring that images of cell changes accompany their results compared to having no images with their results (70), and low-income women preferring to receive results outside of the doctor's office as opposed to in the clinic due to anxiety associated with office waiting rooms (50).

Health Education and Communication (n=9)

A total of 9 studies reported preferences related to health education and communication efforts aimed to increase screening uptake in underserved communities (Table 4). Whereas all prior preference results related to the screening encounter, the studies presented in Table 4 considered patient preferences when developing interventions to increase screening uptake. Outcomes assessed related to three broad categories: information source (n=5) (66, 71–74), health education class location (n=1) (75), and printed material attributes (n=4) (70, 74, 76, 77).

Information Source and Education Class Location—Among the 5 studies that assessed preferences related to the source of health information prior to screening, two studies indicated informational preferences in favor of printed materials. Sharpe and colleagues (2013) documented that members of the Cherokee tribe preferred to receive printed educational materials over in-person information since printed materials can be taken home and read in private (72). Similarly, Yemane and colleagues (2016) found that women who have sex with women (WSW) preferred to receive information through the media and pamphlets over conversations with health care providers or community workshops (71).

Three studies noted patients' preferences to receive information about screening within their community as compared to health care settings. Haworth and colleagues (2014) demonstrated that Bhutanese refugees preferred to learn about screening from community health workers who spoke their native language over other information sources (66), and Kenya and colleagues (2015) found that Haitian focus group participants preferred community health workers to HIV case managers for the delivery of information about screening benefits and guidelines (74). Lee and colleagues (2015) specifically studied preferences and acceptability related to screening information delivery in Vietnamese-American and Korean-American beauty salons; preferences for videos and one-on-one conversations over websites, workshops, and pamphlets were shared by both cosmetologists and customers (73). Relatedly, Yu and colleagues (2001) assessed participant preferences for the location of a health education class, finding that Chinese participants most often preferred community service centers, followed by schools and churches (75).

Printed Material Attributes—Four studies provided participants with sample printed educational materials and probed on preferred attributes. Participants in all four studies emphasized the importance of visual components, including realistic pictures and diagrams, particularly in the case of limited literacy (70, 74, 76, 77). More specifically, Hunter and Kelly (2012) found that Mexican immigrant women preferred screening descriptions and pictures focused on prevention rather than cancer (70), and Christopher and colleagues (2009) noted that, though Apsáalooke women preferred realistic pictures to unrealistic illustrations, they urged against depicting medical procedures in realistic detail (76).

Quality Assessment

The supplementary materials present the results of the quality assessment, identifying either low or high bias for each of the six evaluated categories: (1) study question well-defined, (2) inclusion criteria well-defined, (3) comprehensive description of alternatives, (4) appropriate measure of preferences, (5) appropriate analysis, and (6) pre-specified analysis (Supplementary Table S3). Of the 43 studies, 14 (33%) were identified as having high bias in one category, 7 (16%) as having high bias in two categories, and 3 (7%) as having high bias in three categories.

Among the 24 studies with some type of bias identified, 14 were reported as having high bias specifically related to the appropriateness of the analysis, most commonly due to having an unknown or low (less than 60%) participation rate among quantitative studies. Twelve studies had high bias with respect to the description of alternatives provided to participants.

Generally, these studies assessed participants' preference for screening modality after only administering one of the modality options as part of the study (i.e. self-testing was completed prior to evaluating preferences, but Pap testing was not completed as part of the study). Six studies had potential for bias due to providing minimal description of the primary inclusion criteria, and 5 studies were identified as biased with respect to the appropriateness of the preference measure employed (e.g. acceptability vs. preference). None of the studies were identified as having high bias related to the study question or pre-specified analysis categories.

Of note, many of the studies included did not assess patient preferences as their primary objective but rather to supplement other results. Thus, the results of the quality assessment should not be assumed to apply to the study as a whole, but rather to the assessment of preferences specifically.

Discussion

This systematic review highlights several themes in cervical cancer screening-related preferences among medically underserved populations, including documented preferences for HPV self-testing over Pap testing and providers who share patient socio-demographic characteristics, such as gender and language spoken. This review also demonstrates the variation in patient preferences related to screening scheduling, results delivery, and the communication of health information across the medically underserved populations studied. These findings can be utilized in the development of programs and policies designed to increase screening uptake and reduce disparities in cervical cancer incidence and mortality.

A preference for HPV self-testing over Pap testing emerged as a primary theme, with more participants preferring the HPV self-test in over 90% of screening modality studies. This overwhelming preference for self-testing over Pap testing is consistent with findings in prior systematic reviews of self-testing acceptability, which all found that participants in the majority of included studies preferred self-testing (22–24). The consistency of these results, viewed in concert with other reviews, has important implications for the incorporation of HPV self-testing into primary screening practice. In 2018, the USPSTF approved provider-administered HPV testing as a primary screening strategy, but self-testing was not included (5, 78). The majority of studies that we reviewed assessed patient preferences before HPV testing had been approved as a primary screening mechanism. As such, the novelty of self-testing may have contributed to patient concerns about test accuracy and inability to properly perform the test, which were expressed consistently across study populations. Similar concerns were also identified by prior reviews of self-testing acceptability (22–24). Particularly, Morgan and colleagues (2019) found that participants in 42% (8/19) of studies preferred provider-administered sampling, primarily due to concerns about correctly conducting the test independently (24). These concerns highlight the importance of communication, particularly related to device instructions, as the HPV self-test is increasingly studied, disseminated, and incorporated into national screening guidelines.

A second theme that emerged, of particular relevance to medically underserved populations, was that individuals generally preferred providers who share their demographic

characteristics and life experience. In the absence of available providers with gender, racial/ethnic, sexual orientation, and language concordance, individuals valued providers with experience and who demonstrated comfort in serving patients like them. Participants in multiple studies commented on the difficulty of finding providers with whom they felt comfortable (60, 61), underlining the need for increased diversity among the full range of healthcare professionals, including physicians, nurses, medical assistants, and community health workers. These findings are in line with a prior review of perceived psychosocial barriers to cervical cancer screening, which identified unsatisfactory experiences with physicians, particularly male physicians, as common barriers (15).

Additionally, this review documents the heterogeneity of patient preferences relating to screening communication, which may be attributed to varying degrees of English language ability, comfort with providers, and familiarity with technology among different populations and individuals. This variation highlights the importance of assessing patient preference prior to designing screening intervention programs or adapting evidence-based interventions to new populations (79). It is also important to recognize the individual nature of preferences and the difficulty of generalizing the preferences of one group of patients to the larger population of interest.

It is possible that the introduction of the HPV vaccine in 2006 may have affected cervical cancer screening preferences through changes in risk perception, and thus attitudes toward screening. However, given the age range of participants in the studies reviewed (21–65 years) and the fairly recent introduction of the HPV vaccine, most participants would not have received the HPV vaccine within the recommended age interval of 10–12 years. Additionally, we did not find differences in preferences between participants of studies conducted pre-2006 and those of studies conducted post-2006. As vaccination rates increase over time, though, it may be interesting to assess the influence of vaccination on attitudes toward screening, particularly among underserved groups.

There are several limitations of this review, including the inability to fully characterize the populations studied. The population categorizations reported in Tables 1–4 reflect the population groups identified in each study's inclusion criteria; however, in many cases, a large majority of patients could be classified as medically underserved along other axes as well, such as being uninsured, having low educational attainment, or having immigrated to the US. Additionally, due to the heterogeneity of patient preferences among individuals, few results could be generalized to medically underserved populations as a whole. This review thus serves, not to draw conclusions about the preferences held by underserved groups but rather to document the variety of preferences reported in the literature to date. It also must be mentioned that studies of cervical cancer screening-related preferences are not currently available for several notable medically underserved groups, such as veterans, individuals with disabilities, and the uninsured. This dearth in the literature represents areas for future research.

This review also demonstrates a need for standardized preference elicitation studies to better capture trends in patient preference and assess potential differences between underserved populations. Of note, no studies utilized formal preference elicitation methods, such as

discrete-choice experiments or best-worst scaling (80). Additionally, almost half of cross-sectional survey studies across all preference outcomes did not offer participants a “no preference” option or the ability to not prefer any of the options presented, which is a legitimate preference that is important to consider. A formalized preference elicitation approach recognizing all potential preference options could help various stakeholders - including providers, policy-makers, and researchers - to understand why screening rates remain so much lower among underserved populations, informing future interventions and policies. Interventions that fail to account for the wide range of patient preferences regarding screening will fall short of effectively improving cervical cancer screening uptake, and thus health outcomes, for medically underserved individuals.

This systematic review provides a compilation and synthesis of medically underserved patient preferences relating to cervical cancer screening documented in the current literature. Findings suggest that there is significant heterogeneity of patient preferences across populations and individuals, pointing to the importance of assessing preferences among individuals designed to benefit from a given intervention. That being said, synthesis of the 43 studies included in this review revealed two overarching themes: preference for HPV self-tests over Pap tests and preference for providers who reflect patient gender, language, and life experience. These preferences must be recognized and leveraged by relevant stakeholders in the development of programs and policies to increase cervical cancer screening uptake among individuals most at risk. Failing to account for the specific preferences of medically underserved individuals will allow the disparities in cervical cancer incidence and mortality to continue widening.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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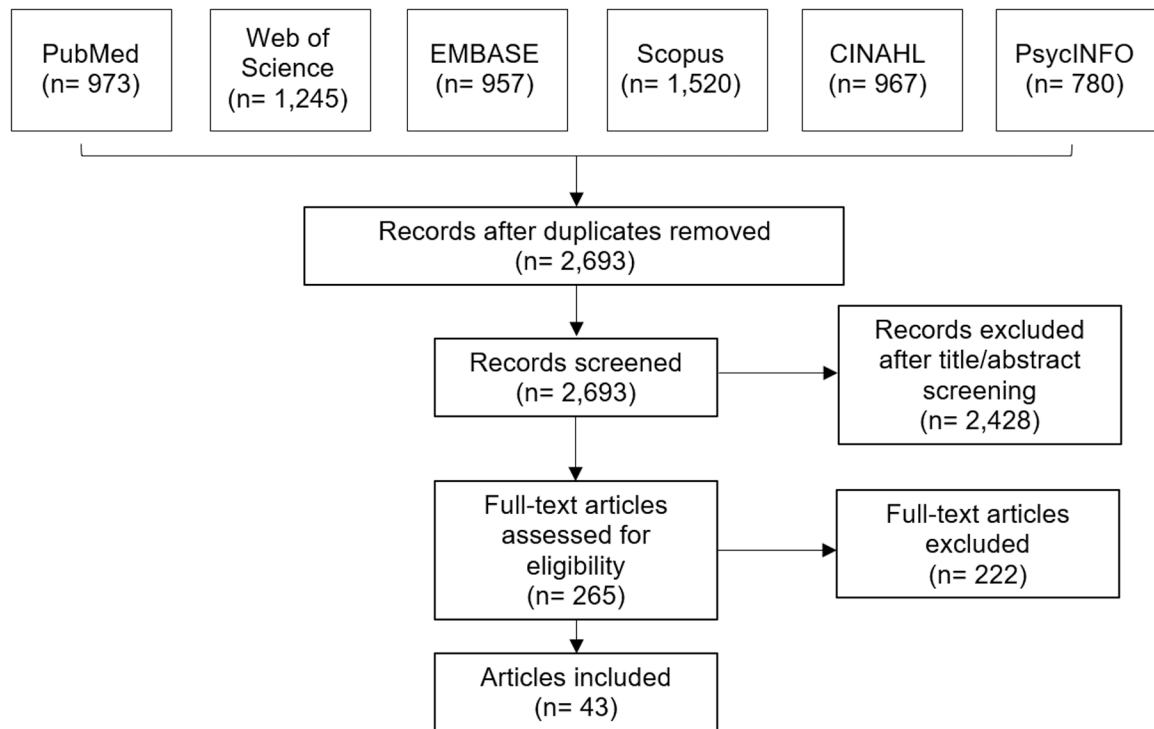


Figure 1. PRISMA flow diagram:

Figure 1 represents the PRISMA flow diagram, which depicts the flow of studies reviewed throughout the systematic review.

Table 1.

Characteristics of studies assessing screening modality preference (n=23)

Study	Medically Underserved Population	Study Design	Sample Size	Findings	Factors Associated with Screening Modality Preference
Anhang 2005	Low-income populations ^a	Cross-sectional Survey	172	32% preferred HPV self-test to Pap test "Which would increase screening likelihood..." Pap test (47%), HPV self-test (21%), HPV self-test + pelvic exam (19%), none (12%)	Those recruited at a STD clinic (versus a cancer screening clinic), non-Hispanics (versus Hispanics), and those with at least some college education (versus less than college education) were more likely to prefer the HPV self-test.
Barbee 2010	Racial/ethnic minorities	Cross-sectional Survey	189 (Haitian)	87% preferred HPV self-test to Pap test	--
Cina 2017	Racial/ethnic minorities	Cross-sectional Survey	93 (AI/AN)	63% preferred HPV self-test to Pap test	--
Crosby 2015 ^b	Rural residents	Cross-sectional Survey	400 (Appalachian Kentucky)	89% preferred HPV self-test to Pap test	--
Crosby 2017	Racial/ethnic minorities	Cross-sectional Survey	88 (non-Hispanic Black Mississippians)	78% preferred HPV self-test to Pap test	No associations with preference for HPV self-test.
Hatcher 2011	Rural residents	Cross-sectional Survey	345 (Appalachian Kentucky)	66% preferred HPV self-test to Pap test	Rarely or never screened individuals (versus recently screened individuals) were more likely to prefer the HPV self-test.
Winer 2016	Racial/ethnic minorities	Cross-sectional Survey	306 (Hopi Tribe members)	62% preferred HPV self-test to Pap test	Those without a Pap test within the past 3 years and individuals not employed full-time were more likely to prefer the HPV self-test.
Ilangovan 2016	Racial/ethnic minorities	Cross-sectional Survey	121 (Haitian: 40 Hispanic: 81)	77% preferred HPV self-test, 20% had no preference, 2% preferred Pap test, 1% did not respond	Hispanics (versus Haitians) were more likely to prefer the HPV self-test.
Jones 2012	Racial/ethnic minorities	Cross-sectional Survey	197 (Hispanic: 166 Black: 25 Other: 6)	79% preferred HPV self-test, 14% reported no preference, 8% preferred Pap test ^c	Black individuals (versus Hispanic individuals) were more likely to prefer the HPV self-test.
Kilfoyle 2018	Low-income populations ^d	Cross-sectional Survey	227	51% preferred HPV self-test, 27% had no preference, 19% preferred Pap test ^c	Black women and other women of color (versus White women) were more likely to prefer the HPV self-test.
Levinson 2016	Women staying in domestic violence shelters	Cross-sectional Survey	142	10% preferred HPV self-test, 39% had no preference, 42% preferred Pap test ^c	Women not up-to-date on screening were more likely to prefer the HPV self-test.
Litton 2013	Racial/ethnic minorities	Cross-sectional Survey	516 (AA)	43% preferred HPV self-test, 25% preferred Pap test, 15% preferred HPV test at doctor's office, 17% did not know	Women who had recently received a colposcopy or Pap test were more likely to prefer a Pap test.
Molokwu 2018	Racial/ethnic minorities	Randomized controlled trial	195 (Hispanic)	32% preferred HPV self-test, 45% had no preference, 23% preferred Pap test	--

Study	Medically Underserved Population	Study Design	Sample Size	Findings	Factors Associated with Screening Modality Preference
Penaranda 2015	Racial/ethnic minorities	Cross-sectional Survey	110 (Hispanic)	30% preferred HPV self-test, 43% had no preference, 26% preferred Pap test ^c	--
Seay 2017	LGBTQ populations	Cross-sectional Survey	91 (transgender men)	57% preferred HPV self-test, 21% preferred Pap test, 14% had no preference, 7% would refuse both tests ^c	Individuals who reported avoiding preventive health care due to cost and/or discrimination were more likely to prefer the HPV self-test. Individuals with health insurance and a history of screening were less likely to prefer the HPV self-test.
Galbraith 2014	Low-income populations ^d	Cross-sectional Survey	199	When asked which protects women's health better... 75% had no preference, 19% preferred Pap test, 6% preferred HPV self-test	--
McDowell 2017	LGBTQ populations	Mixed Methods (Interviews + Surveys)	63 (transmasculine individuals) ^f	79% preferred HPV self-test to Pap test (across survey and interviews)	Self-test benefits: less invasive, more comfortable, less likely to provoke gender discordance, greater agency Pap test benefits: more thorough The degree of comfort participants felt with their providers influenced their willingness to have Pap test. (n=31, interviews only)
Pieters 2013	Homeless women	Qualitative (Interviews)	17	65% preferred HPV self-test, 29% preferred Pap test, 6% reported no preference	Self-test benefits: easy, comfortable, unintrusive Cytology still seen as necessary.
Katz 2017	Low-income populations ^f	Qualitative (Focus Groups)	15	Majority preferred HPV self-tests	Self-test benefits: convenience, cost, no doctor's office visit Self-test concerns: pain
Penaranda 2014	Racial/ethnic minorities	Qualitative (Focus Groups)	21 (Hispanic ^g)	No clear preference consensus	Participants value: choice, ease, accuracy, cost Self-test benefits: ease, convenience, practicality, less embarrassment, not needing child care Self-test concerns: performing test incorrectly
Reisner 2018	LGBTQ populations	Qualitative (Interviews)	131 (transmasculine individuals) ^f	>90% preferred HPV self-test to Pap test	Self-test benefits: ease, privacy, self-empowerment Self-test concerns: performing test incorrectly, distrust of accuracy, gender dysphoria triggered by interacting with genitals
Scatinci 2013	Racial/ethnic minorities	Qualitative (Focus Groups)	96 (AA)	Most women would be willing to perform HPV self-test	Self-test benefits: convenient, private Self-test concerns: performing test incorrectly, cost
Anhang 2004	Low-income populations ^h & Racial/ethnic minorities	Qualitative (Focus Groups)	48 (Hispanic, AA, AI/AN, White)	Most women preferred physician-administered HPV test or preferred physician examination in addition to self-test	--

^aDefined as women attending inner-city publicly funded health clinics in New York City^bPreference measured as which type of test participants would be more likely to complete on a regular basis^cDue to rounding and/or missing data, percentages do not add up to 100%

^dDefined as individuals who had children in federal school lunch program, had Medicaid or Medicare Part B, were uninsured, or had income <200% of the federal poverty level

^eDefined as those assigned female at birth who identify with a gender other than female

^fIncome <\$20,000 (87% of individuals had incomes less than \$10,000)

^gResiding on the US-Mexico border, majority Hispanic

^hMajority had income <\$15,000, not otherwise defined

Abbreviations: African American (AA); American Indian/Alaskan Native (AI/AN)

Table 2. Characteristics of studies assessing preferences for provider demographics and attributes (n=11)

Study	Medically Underserved Population	Study design	Sample Size	Provider Preference Assessed	Findings
Carey Jackson 2000	Racial/ethnic minorities	Mixed Methods (Survey + Interviews)	455 (Cambodian-American)	Gender	77% preferred a female provider, 73% preferred a female interpreter. (n=413, survey only)
Haworth 2014 ^a	Racial/ethnic minorities	Mixed Methods (Survey + Focus Groups)	69 (Bhutanese refugees ^b)	Gender	Women almost unanimously preferred female doctors. (n = 27, focus groups only)
Lanier 1999	Racial/ethnic minorities	Cross-sectional Survey	481 (AI/AN ^c)	Gender	48% preferred a female provider, 2% preferred a male provider, 50% had no preference. 18% would refuse a male provider.
Ma 2012	Racial/ethnic minorities	Cross-sectional Survey	1416 (Vietnamese)	Gender	60% preferred female provider, 3.5% preferred male provider, 36.5% had no preference.
Reed 2002 ^d	Racial/ethnic minorities	Qualitative (Focus Groups)	26 (Somalia: 10, Central America: 6, Vietnam: 10)	Gender	Somali women preferred female providers and interpreters.
Nguyen 2002	Racial/ethnic minorities	Cross-sectional Survey	1566 (Vietnamese, Vietnamese-American, or Vietnamese-Chinese ^d)	Gender Language	57.2% preferred a female doctor for a Pap test. 52.9% preferred a female standby if male doctor performs a Pap test. 64.4% preferred a Vietnamese-speaking doctor for a Pap test.
Kim 2017	Racial/ethnic minorities	Qualitative (Interviews)	32 (KIW)	Gender Communication style Language	Majority preferred a female doctor. Some KIW wanted more dialogue with their doctors about Pap test results, rather than a letter or phone message. Majority preferred a Korean-speaking doctor.
Torres 2013	Racial/ethnic minorities	Qualitative (Interviews)	45 (Hispanic)	Gender Language Examiner type	Most expressed comfort in speaking to another woman about women's health issues but preferred a doctor, who was generally perceived to be male, over a nurse, who was perceived as female, for screening. Majority preferred healthcare professional who speaks Spanish. Preferred receiving information from a doctor versus a nurse.
McAlearney 2012	Rural residents	Qualitative (Focus Groups)	36 (Appalachian Ohio)	Gender Communication style	Majority preferred female providers. Preferred patient-centered communication.
Alexander 1981 ^e	Racial/ethnic minorities Low-income	Cross-sectional Survey Cross-sectional Survey	509 (Mexican-American) 1956	Gender, Examiner type Gender, Examiner type	44% preferred female physician, 4% male physician, 10% nurse or nurse practitioner, 8% female person, 34% no preference. 33% preferred female physician, 6% male physician, 12% nurse or nurse practitioner, 9% female person, 40% no preference.
Agénor 2015	Racial/ethnic minorities & LGBTQ populations	Qualitative (Focus Groups)	18 (Black or AA and LBO)	Gender, Race/Ethnicity Examiner type Communication style	Majority preferred providers who identified as a woman, person of color, and/or LGBTQ. Many preferred to receive care from a physician's assistant, registered nurse, or nurse practitioner.

Study	Medically Underserved Population	Study design	Sample Size	Provider Preference Assessed	Findings
					Preferred providers who had experience and felt comfortable serving LBQ patients and were willing to explain the Pap test process with a “calm demeanor and gentle touch.”

^aIncluded in more than one results table

^bSurveys: 42, Focus groups: 27

^cMembers of a federally recognized AI/AN group or tribe

^dEthnic Chinese who were born or had lived in Vietnam

^eStratified results by racial/ethnic minority and income

Abbreviations: Korean immigrant women (KIW); African-American (AA); Lesbian, bisexual, or queer (LBQ); AI/AN (American Indian/Alaskan Native)

Table 3. Characteristics of studies assessing preferences related to screening scheduling and results delivery (n=6)

Study	Medically Underserved Population	Study design	Sample size	Delivery Preference Assessed	Findings
Brandzel 2016	Racial/ethnic minorities	Qualitative (Focus Groups)	39 (Black: 24 Hispanic: 15)	Screening reminder delivery	No consensus on screening reminder timing. Black women preferred reminders from community-based advocates (versus HCPs). Hispanic women preferred smart phone reminders.
Greaney 2014	Racial/ethnic minorities	Qualitative (Focus Groups)	40 (Hispanic)	Screening reminder delivery	No consensus on screening reminder source (IVR, personal call, letters). Preferred IVR messages recorded by member of clinic staff, native speaker, and community representative. Preferred brief messages emphasizing screening importance.
McAlearney 2012	Rural residents	Qualitative (Focus Groups)	36 (Appalachian Ohio)	Screening reminder delivery	Preferred timely reminders in the form of a letter or postcard in the mail.
Hatcher 2011	Rural residents	Cross-sectional Survey	345 (Appalachian Kentucky)	Appointment time	63.8% did not prefer weekend appointments.
Hunter 2012	Racial/ethnic minorities	Qualitative (Interviews)	45 (Mexican ^a)	Results delivery	Preferred detailed explanations of Pap test results accompanied by images of cell changes.
Katz 2017	Low-income populations ^b	Qualitative (Focus Groups)	15	Results delivery	Mixed preferences on how to receive HPV self-test results (phone, mail, in person). Preferred to avoid receiving results in an office visit.

^aBorn in Mexico, lived in the US for five years or less, completed nine grades or less of formal education, and speak predominantly Spanish

^bThose assigned female at birth who identify with a gender other than female

Abbreviations: Healthcare Professional (HCP); Interactive Voice Response (IVR)

Table 4. Characteristics of studies assessing preferences related to health education and communication (n=9)

Study	Medically Underserved Population	Study design	Sample size	Delivery Preference Assessed	Findings
Yu 2001	Racial/ethnic minorities	Cross-sectional Survey	332 (Chinese)	Class location	Preferred community service center (54.7%), local school (21.3%), church (20.9%), home (6.2%); senior centers, hospitals, clubs, and work places (all <3%).
Yemane 2016 ^a	LGBTQ populations	Cross-sectional Survey	28 (WSW)	Information source	Preferred media (46%), pamphlet (21%), personal conversation with healthcare provider (18%), workshop at a community center (7%).
Haworth 2014	Racial/ethnic minorities	Mixed Methods (Survey + Focus Groups)	69 (Bhutanese refugees) ^b	Information source	Preferred community health workers who spoke native language over other information sources.
Shaope 2013	Racial/ethnic minorities	Qualitative (Interviews)	32 (Cherokee)	Information source	Preferred receiving information from a health care provider; reading HPV educational information in private; printed materials available to take home that include informational websites.
Lee 2015	Racial/ethnic minorities	Cross-sectional Survey	62 (Vietnamese American: 30 Korean American: 32)	Information source (within the context of ethnic beauty salons)	Cosmetologists preferred videos (31.3%) and 1-on-1 talks (25%) for receiving health information, and 1-on-1 talks (47.1%) and pamphlets (29.4%) for information delivery. Customers preferred videos (20.5%) and 1-on-1 talks (23.1%) for receiving health information. Customers were interested in talking about cervical cancer (75%) and willing to learn about it from cosmetologists (89%).
Kenya 2015	Racial/ethnic minorities	Qualitative (Focus Groups)	21 (Haitian) ^c	Screening information source Printed material attributes	Preferred community health workers to HIV case managers for information delivery. Preferred communication of cervical cancer and HPV information through Haitian radio. Preferred flip-charts to written materials.
Christopher 2009	Racial/ethnic minorities	Qualitative (Focus Groups)	68 (Apsaalooke – Crow Nation)	Printed material attributes	Preferred English brochure with native words interspersed; pictures (not drawings); pamphlets with white space.
Reed 2002	Racial/ethnic minorities	Qualitative (Focus Groups)	26 (Somalian: 10, Central American: 6, Vietnamese: 10)	Printed material attributes	Preferred visual presentations of health care information (including pictures, diagrams, and stories) and group educational sessions.
Hunter 2012	Racial/ethnic minorities	Qualitative (Interviews)	45 (Mexican) ^d	Printed material attributes	Preferred written descriptions focused on prevention and finding early changes instead of cervical cancer (98%); preferred more realistic illustrations of pelvic exam.

^aLetter to the editor

^bSurveys: 42, Focus groups: 27

^cBorn in Haiti

^dBorn in Mexico, lived in the US for five years or less, completed nine grades or less of formal education, and speak predominantly Spanish

Abbreviations: African American (AA); Women who have sex with women (WSW); American Indian/Alaskan Native (AI/AN)