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Efficacy and acceptability of self-collected versus provider-collected HPV samples among the transmasculine population

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Abstract

Background: The vast majority of cervical cancers are caused by high-risk strains of human papillomavirus (HPV). Conventional screening by Papanicolaou (Pap) smear can effectively prevent the development of cervical cancer, but transmasculine (TM) individuals (those assigned female at birth, but who do not identify as female) utilize screening less frequently than their cisgender counterparts. Self-collected HPV samples may be viewed as more acceptable by TM patients and may be an equally effective screening method, which could ultimately increase cervical cancer screening uptake in this underserved population.

Methods: An exhaustive search of the literature using MEDLINE-PubMed, CINAHL, and Web of Science with the terms transmasculine, screening, self, and HPV. The resulting studies were appraised and assessed for quality using GRADE.

Results: Three studies met eligibility criteria and were included in this review. One observational study surveyed 91 transmasculine subjects and found that over 50% preferred self-collection methods for cervical cancer screening. An additional observational study collected information from 62 TM participants and found that a clear majority preferred self-collected frontal swabs, or at least provider-collected frontal swabs, over traditional Pap testing. The final article described a mixed methods study, including both an observational and RCT portion. The authors found that most of the participants expressed similar preferences to those in the previous two studies. They also found substantial concordance between self-collected vaginal swabs and provider-collected cervical swabs, which is the current gold standard.

Conclusion: Self-collected vaginal HPV samples are seen as highly acceptable among TM patients, show substantial concordance with Pap testing, and appear to be an efficacious alternative. This is especially true in patients who refuse conventional screening or are not utilizing preventative care. Offering self-collection as a primary HPV screening method would likely increase cervical cancer screening uptake among the TM population.

Keywords: Transmasculine, screening, self-collected, HPV, cervical cancer, perceptions, acceptability, efficacy, concordance
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Efficacy and Acceptability of Self-Collected Versus Provider-Collected HPV Samples Among the Transmasculine Population

Jenna Stevens

A Clinical Graduate Project Submitted to the Faculty of the School of Physician Assistant Studies Pacific University Hillsboro, OR
For the Masters of Science Degree, August 10th, 2019
Faculty Advisor: Brent Norris, MPAS, PA-C
Clinical Graduate Project Coordinator: Annjanette Sommers, MS, PA-C
Biography

Jenna Stevens is a native of California, but quickly moved to Oregon for much of her primary education. In 2014, she majored in Psychology with an emphasis in Neuroscience at Pacific University in Forest Grove, OR. She went on to spend two years working in the Portland Metro on a medical-surgical hospital floor as a CNA. This was followed by a short stint as an autopsy assistant before returning to Pacific University for her PA education. She plans to stay in the Pacific Northwest as she moves forward in her career.
Abstract

Background: The vast majority of cervical cancers are caused by high-risk strains of human papillomavirus (HPV). Conventional screening by Papanicolaou (Pap) smear can effectively prevent the development of cervical cancer, but transmasculine (TM) individuals (those assigned female at birth, but who do not identify as female) utilize screening less frequently than their cisgender counterparts. Self-collected HPV samples may be viewed as more acceptable by TM patients and may be an equally effective screening method, which could ultimately increase cervical cancer screening uptake in this underserved population.

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Keywords: Transmasculine, screening, self-collected, HPV, cervical cancer, perceptions, acceptability, efficacy, concordance
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<tr>
<td>ACOG</td>
<td>American Congress of Obstetricians and Gynecologists</td>
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<td>HPV</td>
<td>Human papillomavirus</td>
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<td>hrHPV</td>
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<td>FTM</td>
<td>Female-to-male</td>
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<td>TM</td>
<td>Transmasculine</td>
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Efficacy and Acceptability of Self-Collected Versus Provider-Collected HPV Samples Among the Transmasculine Population

BACKGROUND

In the United States, human papillomavirus (HPV) is the most common sexually transmitted infection, and it is estimated that 1 in 4 people carry the virus. High-risk strains of HPV (hrHPV), namely 16 and 18, cause roughly 99% of all cervical cancer cases, which leads to substantial morbidity and mortality worldwide. Appropriate screening can detect hrHPV and cervical dysplasia, and ultimately prevent the development of cervical cancer through prompt treatment. The incidence of cervical cancer, and resultant death rate, declined by approximately 70% over the last 65 years, which is commonly attributed to regular screening through the Papanicolaou (Pap) test. In fact, most cases of cervical cancer occur in patients whom never had a Pap or have not had one in the last five years. This underutilization often happens in minority populations, including the gender diverse community. Studies suggest that TM patients are significantly less likely to be up to date on cervical cancer screening compared to cisgender women.

Transmasculine (TM) patients were assigned female at birth, but identify along the masculine gender spectrum (man, trans man, non-binary, genderqueer, other). These patients still require cervical cancer screening unless the cervix has been surgically removed, which is usually not included in the procedure. TM patients face numerous physical, emotional, and logistical barriers to cervical cancer screening. The speculum exam required to obtain a cytology sample is
invasive and often heightens feelings of gender dysphoria as patients are forced to face the discordance between self-perception and genital anatomy.\textsuperscript{7−9} Many patients report previous trauma surrounding pelvic examinations and for those taking testosterone, vaginal atrophy can make the exam painful and more triggering.\textsuperscript{4,5} TM patients also have a nearly 10-fold risk of having a Pap specimen return as “inadequate”, making the experience more frustrating and increasing the likelihood of loss to follow up.\textsuperscript{10}

Current guidelines for cervical cancer screening include a Pap test with cytology alone every 3 years for patients aged 21-29 years.\textsuperscript{1} For those aged 30-65 years, the recommendation is for Pap testing plus hrHPV testing (also known as co-testing) every 5 years.\textsuperscript{1} An alternative for this age group is to continue doing the Pap test alone every 3 years. These screening guidelines apply to all women with a cervix, regardless of prior HPV vaccination. However, official American Congress of Obstetricians and Gynecologists (ACOG) and U.S. Preventative Services Task Force (USPSTF) guidelines make no specific mention of the care of TM patients.\textsuperscript{8} This taking place despite lower Pap test frequency in this group and confusion regarding cervical cancer risk among patients and providers alike.\textsuperscript{7−9} Compounding the matters above, TM patients frequently experience difficulty with insurance coverage if their gender marker changes from female to male.\textsuperscript{4,5}

A less invasive and triggering screening method may be more acceptable to TM patients, which would likely increase screening rates in this hard-to-reach population. Self-collected samples appear efficacious, although not as good as Pap testing, in cisgender women,\textsuperscript{11} but the research is lacking when it comes to
the unique circumstances that TM patients face. This review seeks to explore patient perception of self-collection methods and the efficacy of self-collected HPV samples among TM patients, especially those taking testosterone.

**METHODS**

A comprehensive literature search using MEDLINE-PubMed, CINAHL, and Web of Science was conducted. The following terms were used in the search: *transmasculine, screening, self*, and *HPV*. For articles that appeared relevant, their references were searched for possible additional articles. Included were studies conducted on self-identified transmasculine patients, evaluating self-collected vaginal HPV swabs in comparison to provider-collected cervical samples or patient perception of such collection methods. Additionally, studies were required to be published in English. Posters, abstracts, presentations, or other similar reports that did not list specific study details were excluded, as were studies that did not specify the gender identity of subjects. The quality of included articles was evaluated using the Grading of Recommendations Assessment, Development and Evaluation (GRADE) Working Group guidelines.\(^\text{12}\)

**RESULTS**

The literature search generated 36 articles for review, 17 of which were duplicates. The remaining articles were screened using eligibility criteria, yielding a total of 3 articles. These articles were 2 observational studies,\(^\text{13-14}\) and 1 mixed methods study\(^\text{15}\) with a randomized controlled trial portion and an observational portion. (See Table 1.)

**Seay et al**

This was an observational study\(^\text{14}\) seeking to understand transmasculine
individual’s preferences for cervical cancer screening in association with certain sociodemographic features and previous healthcare experiences. The study was conducted via a community-based participatory research model, in which informed community parties collaborate in all aspects of the research. To be eligible for the survey, participants needed to self-identify as transgender men and they needed to be age 21-65. Subjects were excluded if they reported a previous hysterectomy.14

The authors created a survey that addressed previous experiences with preventative healthcare, cervical cancer screening history, sociodemographic characteristics, and cervical cancer screening preferences following a description of self-sampling procedures. Questions regarding previous healthcare experiences were largely based on items from the National Transgender Discrimination Survey.16 The survey was completely anonymous and was distributed via in-person recruitment at relevant community events in Florida. This method proved to be too slow, so the authors switched to email and social media recruitment, followed by online delivery of the survey. Ninety-one subjects, age 21-63, completed the survey and were included in the analysis.14

Upon analysis, 90.1% of participants believed transgender men need cervical cancer screening, but only 49.5% of participants were adequately screened in the past 3 years. In looking at screening preferences, 57.1% preferred self-sampling, while only 20.9% preferred Pap testing. The remaining subjects expressed no preference (14.3%) or said they would refuse both methods (6.6%). The authors conducted a univariate logistic regression to examine the association between self-sampling preference and certain sociodemographic factors or
previous experiences with healthcare. They found that subjects who said they previously avoided preventative care because of cost (OR = 3.51, p = .006) or discrimination (OR = 3.29, p = .007) were more likely to prefer self-sampling. They found no significant association with age, education, race, or employment status.\textsuperscript{14}

The authors concluded that traditional cervical cancer screening approaches are less desirable among transgender men and the plausibility of alternative methods should be investigated. They did note that their pool of participants was not representative of the overall population, and that their study did not randomly select participants. They also noted that they only selected subjects who identified as transgender men specifically, excluding those that identify somewhere else along the transmasculine spectrum.\textsuperscript{14}

\textbf{McDowell et al}

This was an observational study\textsuperscript{13} in which the authors sought to explore cervical cancer screening perceptions and preferences among transmasculine individuals. Participants were recruited through social media posts, flyers, and outreach at community events in Massachusetts and were eligible if they identified as transmasculine, were age 21-64, and had a cervix. Subjects completed either an in-person interview (n = 31) or an online survey (n = 32). The interview was semi-structured using an interview guide created by experts in the fields of cervical cancer, transgender health, and thematic research. The questions assessed previous experiences with the healthcare system, perceptions of HPV and cervical cancer risk, and attitudes regarding various screening methods.
The authors utilized thematic analysis to transform qualitative data from open-ended interview and survey questions into quantitative, descriptive data. A full description of their coding process is described in the original article. The authors found that 90.3% of in-person interview participants and 68.8% of survey participants preferred the self-collected vaginal HPV swab over a traditional Pap test. Most subjects (93.5% interview, 90.6% survey) also expressed a general preference for a self or provider-collected vaginal HPV swab over a traditional Pap test. Participants collectively reported Pap testing to be invasive and emotionally uncomfortable, whereas self-sampling promoted greater agency and incited less gender dysphoria.

Reisner et al

This was a mixed methods study, with an observational component assessing acceptability to patients and a randomized controlled trial portion assessing test performance of self-collected HPV samples. The authors recruited participants through flyers, referrals, local outreach, and social media, leading to 150 TM participants. To be eligible, participants had to be age 21-64, identify along the masculine spectrum after being assigned female at birth, have a cervix, and have been sexually active within the last 3 years. Subjects received $100 as compensation. The authors utilized a Community and Provider Task Force, comprised of individuals considered experts in transgender healthcare, to ensure all aspects of the study were culturally informed.

Participants completed an electronic survey addressing topics such as demographics, Pap history, healthcare utilization, and sexual behavior. Participants then completed the clinical portion, in which they completed both a
self-collected vaginal HPV sample and a provider-collected cervical HPV sample. All subjects completed both exams but were randomized as to which sampling method they would complete first. This randomization was unblinded. Participants were given detailed written instructions and verbal direction for the self-collected swab, which they completed in a private room or bathroom stall. The provider-collected sample was completed by a physician or nurse practitioner. All participants completed an exit questionnaire measuring their experience with and perception of the sampling methods. The final 53 participants completed one additional swab, as the authors identified a gap in the research they wished to fill. This was a provider-collected vaginal HPV swab. All types of specimens underwent testing for thirteen hrHPV strains using a DNA hybridization assay.15

The primary outcome variables of the study were concordance (Cohen’s kappa statistic) and performance (sensitivity and specificity) of the self-collected sample versus the current gold standard (provider-collected cervical sample). Concordance (kappa) was categorized as follows: poor (<0), slight (0-.20), fair (.21-.40), moderate (.41-.60), substantial (.61-.80), and almost perfect (.81-1.00). The authors conducted a sensitivity analysis to assess whether the order of collection (randomization component of the study) impacted concordance. They also completed a post hoc subgroup analysis to determine whether or not testosterone use among participants impacted concordance. Analysis was completed on the data from only 131 participants because ten subjects did not complete both collections (self and provider) and nine subjects had provider-collected samples that could not be assayed.15
The authors found that compared to the gold standard, self-collected vaginal HPV samples had a sensitivity of 71.4% (95% CI: 0.52-0.91) and a specificity of 98.2% (95% CI: 0.96-1.00). In assessing concordance, they found it to be substantial (kappa = 0.75; 95% CI: 0.59-0.92; p<.0001). They found no statistically significant difference in any of the primary outcome variables when adjusting for randomization order. The post hoc analysis revealed no statistically significant difference in any of the primary outcomes variables for participants currently on testosterone therapy (p = .20) or participants with any prior short or long-term testosterone use (p = .60). In comparing the provider-collected vaginal specimens to provider-collected cervical specimens (n = 53), sensitivity was 85.7% (95% CI: .42-1.00) and specificity was 100% (95% CI: .92-1.00). Concordance between the provider-collected vaginal specimens and the self-collected vaginal specimens reached the threshold of ‘almost perfect’ (kappa = .84; 95% CI: .61-1.00; p<.0001). The exit interviews showed that 90% of participants preferred self-collection over provider-collection.15

DISCUSSION

TM adults are under screened, face numerous barriers to care, and participate in higher rates of cigarette smoking and risky sexual behavior. All of these characteristics increase the risk of persistent hrHPV infection and dysplasia.7 This, combined with the fact that TM patients are considerably less likely to be up to date on screening,4–6 puts them at increased risk of serious morbidity and mortality secondary to cervical cancer. Finding an appealing and efficacious alternative is an important step in keeping these patients healthy and developing new ways of reaching underserved communities.
The 3 included articles\textsuperscript{13–15} all demonstrate that self-collected vaginal HPV swabs are highly acceptable to TM patients. Although much of the data was qualitative, making it more difficult to interpret, the interview answers give important insight into the care of TM patients. Numerous participants described the emotional pain associated with such an invasive exam that often incites intense feelings of dysphoria.\textsuperscript{13} In the Reisner et al study,\textsuperscript{15} many participants noted in their exit interview that self-collection as an alternative would “increase healthcare empowerment”, especially in those who may otherwise never participate in screening. Importantly, many participants cited the speculum specifically as the reason for avoiding Pap testing.\textsuperscript{13} The self-collection method would circumvent this and provide a less triggering form of screening while also letting patients remain in control of their bodies.

The Reisner et al study\textsuperscript{15} assessing test performance showed that the self-collected swabs have a reasonable sensitivity and specificity. This study also demonstrated that when compared to the gold standard, self-collected vaginal HPV swabs have substantial concordance. It is important to note that this study included participants who had never completed this test before. They received only brief verbal and written instruction, from a provider with whom they did not have any rapport. In primary care, with an established patient-provider relationship, it is reasonable to believe that the sensitivity, specificity, and concordance may be even greater than the study showed.\textsuperscript{15} Patients could learn better technique and have the opportunity to ask meaningful questions to improve specimen collection and further build rapport.

Despite the promising findings, there are numerous limitations in the
reviewed studies. Unfortunately, much of the data comes from small, observational studies using unvalidated measures to assess attitudes and perceptions. Qualitative data, as meaningful as it is, is more difficult to code and report in a concise manner without losing the true responses of participants. Another major limitation is the fact that each of the participant pools were not representative of the general population, as each study employed purposive sampling only. Included participants were predominantly white, educated, employed, and insured.\textsuperscript{13–15} It would provide more meaningful insight if the studies included those who are most underserved and would likely benefit most from self-collection.

The randomized controlled trial portion of the Reisner et al study\textsuperscript{15} lacked blinding and a true control group. The investigators also added an additional area of study (provider-collected vaginal swabs) when two-thirds of the study was already complete. Additionally, it is problematic that all data on specificity, sensitivity, and concordance came from only one small study. These are areas for improvement as research moves forward on this topic.

**CONCLUSION**

If HPV self-swabs are effective, accurate, and acceptable as shown in the studies, it appears reasonable to offer it as a primary screening method. Pap testing should still be encouraged, and patients should receive education on the efficacy of each method, but TM patients should not be pressured into standard screening. Pap testing remains superior, but at-home self-collection provides a patient-centered and empowerment-based approach to improving the care of TM patients.
Further study is greatly needed, especially long-term data to assess whether self-collected swabs will detect cervical dysplasia and reduce cervical cancer. Research among a larger population of TM patients on testosterone is also needed to assess the efficacy of self-collected swabs in patients with a very high risk of inadequate specimens. Furthermore, research should be conducted to determine if this patient-centered option will encourage greater use of the healthcare system by TM patients. This approach could serve as a model for other necessary screenings in the TM population and beyond.
References


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<sup>a</sup> Use of non-validated outcome measures; different outcomes used across studies

<sup>b</sup> Lack of blinding in the Reisner et al study

<sup>c</sup> Only one small study providing evidence