Contents lists available at ScienceDirect

Gynecologic Oncology Reports

Research Report

Increased disparities associated with black women and abnormal cervical cancer screening follow-up

Teresa K.L. Boitano [a,*], Peter Ketch [b], Julia G. Maier [c], Christine T. Nguyen [b], Warner K. Huh [a], J. Michael Straughn [a], Isabel C. Scarinci [a]

[a] Division of Gynecologic Oncology, Department of Obstetrics & Gynecology, O'Neal Comprehensive Cancer Center, University of Alabama at Birmingham, Birmingham, AL, United States
[b] Department of Obstetrics and Gynecology, University of Alabama at Birmingham, AL, United States
[c] University of Alabama at Birmingham School of Medicine, Birmingham, AL, United States

ARTICLE INFO

ABSTRACT

Background: To determine whether race and ethnicity impacts patient adherence to follow-up for colposcopy after abnormal cervical cancer screening.

Methods: This retrospective chart review included women that were randomly selected from patients presenting to our colposcopy clinic from 1/2019 to 12/2019. Inclusion criteria were females age ≥21 years-old and appropriate referral for colposcopy. Patients were grouped into three categories: (1) ADHERENT to follow-up if they came to their first scheduled appointment; (2) DELAYED if they presented more than three months from their original referral (usually missing 1–3 appointments); and (3) NOT ADHERENT if they did not show for their appointment after referral. Analysis was performed using SPSS v.26.

Results: 284 women met inclusion criteria for the study. The majority of women were Black (65.2 %) followed by non-Hispanic Whites (20.0 %) and Latinx (14.8 %). Overall, 39.1 % were ADHERENT, 18.6 % were DELAYED, and 42.3 % were NOT ADHERENT. When compared with non-Hispanic White women, there was a significant difference between race/ethnicity and timing of follow-up (p = 0.03). Blacks were more likely to be NOT ADHERENT (45.9 %; p = 0.03), and Latinx and Blacks were the most likely to be DELAYED (35.7 % and 21.1 %; p = 0.03). Private insurance patients were more likely to be ADHERENT for care compared with un-/underinsured patients (78.9 vs 27.8 %, p = 0.0001).

Conclusion: There is inadequate follow-up after abnormal cervical cancer screening across all races/ethnicities; however, lack of adherence is higher in Black patients. Moreover, 25% of Hispanic and Black women present in a delayed fashion. Culturally relevant assessments and interventions are needed to understand and address these gaps.

1. Introduction

Cervical cancer is a preventable disease, yet the incidence and mortality has remained stable for the last two decades instead of decreasing (Insitute, 2021). Given the overall effectiveness of screening and implementation of the HPV vaccination, the incidence of cervical cancer decreased by more than half from the 1970 s to 2000. However, instead of it continuing to decrease, there was a plateau in the incidence of cervical cancer from 2013 to 2018 (Insitute, 2021). In 2022, there will be an estimated 14,100 new cases of cervical cancer and over 4,280 deaths in the U.S. (Society, 2021). Because of these issues, Congress and

the National Institutes of Health (NIH) have announced a call-to-action to address this issue in order to decrease the incidence of cervical cancer (Health OoRoWs, 2021).

The U.S. has seen a continued increase in cervical cancer screening (CCS) with 80 % of eligible women currently adherent to cervical cancer guidelines (Institute, 2020; Promotion OoDPaH, 2021). However, the reported rate of follow-up (i.e., adherence) for women after abnormal CCS is alarmingly low and ranges from 20 to 70 % (Katz et al., 2014; Fish et al., 2013; Miller et al., 2017). It has been demonstrated that over half of patients screened for cervical cancer have at least one barrier causing them to be lost to follow-up and/or have delayed care (Katz et al., 2014).

* Corresponding author.
E-mail address: tlboitano@uabmc.edu (T.K.L. Boitano).

The lowest adherence rates occur in racial/ethnic minority women and women with a lower income and educational attainment (Miller et al., 2017).

Likewise, there remain diffuse outcome disparities in CCS follow-up and cervical cancer seen within racial/ethnic minorities, lower income, and those living in rural communities (American Cancer Society, 2019–2021; Yu et al., 2019; Benard et al., 2008). While 85 % of Black women report being screened compared with 83 % of White women, Black women have a higher incidence of cervical cancer, are more likely to present with advanced stage disease, and have a higher rate of mortality (American Cancer Society, 2019–2021). One study recently showed that Black women when compared with White women reported lower HPV awareness, fewer reported getting their Pap test results, and were less likely to report having a follow-up treatment scheduled (Ford et al., 2021). Regardless, there continues to be an unacceptably high rate of non-compliance with colposcopy follow-up for abnormal CCS overall, and there is a paucity of recent data evaluating abnormal CCS follow-up and subsequent interventions and outcomes (Miller et al., 2017; Yabroff et al., 2000; Eggleston et al., 2007; Engelstad et al., 2001). Thus, the objective of this study was to evaluate current factors associated with delayed or lack of follow-up after abnormal CCS.

2. Methods

This retrospective study included 284 women that were randomly selected from patients who were referred to the colposcopy clinic at our institution from 1/2019–12/2019. Inclusion criteria included females age $\geq$ 21 years-old with an appropriate referral for colposcopy per the American Society for Colposcopy and Cervical Pathology guidelines. Patients who had a prior history of cervical cancer or inadequate information in the medical record were excluded from the study. Patients were grouped into three categories: (1) ADHERENT to follow-up if they came to their first scheduled appointment; (2) DELAYED if they presented more than three months from their original referral (usually missing 1–3 appointments); and (3) NOT ADHERENT if they did not show for their appointment after referral. Random selection occurred by evaluating the first 30 patients scheduled for an appointment at our colposcopy clinic during the first week of every month in 2019. 48 women were excluded from analysis due to inadequate data.

Our institution has a statewide referral colposcopy and loop electrosurgical excision procedure (LEEP) clinic that is run in an accessible outpatient clinic near our hospital. Patients park in an adjacent no-pay, open parking lot. This clinic has a wide representation of patients coming from both rural and urban locations. Patients with abnormal Pap tests requiring further evaluation or treatment are referred to this clinic through our institution, county-based health departments, or other community healthcare providers. Patients are evaluated per protocol with colposcopy or treated with an excisional procedure. The patient is followed in the clinic as needed or referred back to undergo routine care with her primary provider.

Demographics including age, race/ethnicity, pap test result, HPV positivity, referral source, and location were all obtained from the electronic medical records. Given that some patients never presented for care at our institution, this information was obtained from scanned-in records from the referring provider. The primary outcome of this study was adherence to follow-up.

Patient demographics, clinical characteristics, and adherence were summarized using descriptive statistics. Statistical analysis was performed using independent *t*-test, chi-squared and the Kruskal-Wallis test to evaluate if any variables were associated with increased or decreased adherence rates. Characteristics and variables between ADHERENT, DELAYED, and NOT ADHERENT patients were compared using independent t-tests and the chi-squared test. Statistical analysis was performed using SPSS Statistics version 26 (IBM, Armonk, NY). Institutional Review Board approval was obtained.

3. Results

284 women (unique individuals with no duplicate encounters) met inclusion criteria for the study and baseline patient demographics are included in Table 1. The majority of women were Black (65.2 %) followed by non-Hispanic White (20.0 %) and Latinx (14.8 %). 39.1 % of patients were ADHERENT to timely follow-up, 42.3 % were NOT ADHERENT, and 18.6 % were DELAYED (rescheduled or did not present for their appointment for over 3 months). The most frequent abnormal Pap tests were ASCUS and LSIL at 36.3 % and 37.8 %, respectively. 72.6 % of women were referred from a health department within the state, and the majority of women had Medicaid (48.6 %) or were self-pay (37.8 %). From the women who presented for colposcopy, there were 14 women referred for an excisional procedure following their colposcopy results and 80.0 % of them returned to our institution for this as scheduled.

There were no significant differences between type of Pap test result or referral source and the category of follow-up adherence (p = 0.1 and p = 0.6, respectively). However, there was a significant difference between race/ethnicity and timing of follow-up (p = 0.03) and type of insurance and timing of follow-up (p = 0.0001) (Table 2). Approximately 46 % of Black patients were NOT ADHERENT, compared with 39 % of White and 29 % of Latinx patients (p = 0.03). Latinx and Black patients were more commonly DELAYED (35.7 % and 21.1 %) compared with White patients (14.0 %, p = 0.03). When a multivariate regression analysis was performed, race was still found to be significant (OR 1.6, 95 % CI 1.1–2.4). There was no difference between racial/ethnic groups who were ADHERENT to their originally scheduled appointment (p = 0.1).

Table 1
Patient Demographics.

Patient Demographics	N = 284
Average age (years)	35.0 ± 8.2
Race/Ethnicity	185
Black	(65.2 %)57
Non-Hispanic White	(20.0 %)42
Latinx	(14.8 %)
Follow-up	111
Adherent	(39.1 %)120
Not adherent	(42.3 %)53
Delayed	(18.6 %)
Pap Test*	35
NILM	(12.4 %)103
ASCUS	(36.3 %)107
LSIL	(37.8 %)27
ASC-H	(9.5 %)6
AGC	(2.0 %)6
HSIL	(2.0 %)
HPV	218
Positive	(76.6 %)25
Negative	(9.0 %)41
Unknown	(14.4 %)
Referral Source	206
Health department	(72.6 %)28
Private physician	(10.0 %)35
Study institution	(13.4 %)
Other	11
	(4.0 %)
Insurance	138
Medicaid	(48.6 %)38
Private/other	(13.4 %)108
None/self-pay	(37.8 %)

In *Abbreviations: Negative for intraepithelial lesion (NILM), Atypical cells of unknown significance (ASCUS), Low-grade squamous intraepithelial lesion (LSIL), Atypical squamous cells, cannot rule out high-grade (ASC-H), High-grade squamous intraepithelial lesion (HSIL), Atypical glandular cells (AGC).

Table 2
Factors associated with abnormal cervical cancer screening follow-up.

	Adherent	Not Adherent	Delayed	p-value
Race/Ethnicity	61		39	
Black	(33.0 %)27	85 (45.9 %)22	(21.1 %)8	
White	(47.4 %)15	(38.6 %)12	(14.0 %)15	**0.03**
Latinx	(35.7 %)	(28.6 %)	(35.7 %)	
Pap Test	13	18	4	
Normal	(37.1 %)88	(51.4 %)79	(11.5 %)43	
Low-grade*	(41.9 %)13	(37.6 %)16	(20.5 %)10	0.1
High-grade**	(33.3 %)	(41.0 %)	(25.6 %)	
Insurance	56	45	37	
Medicaid	(40.6 %)30	(32.6 %)5	(26.8 %)3	**0.001**
Private/other	(78.9 %)30	(13.2 %)61	(7.9 %)17	
None/self-pay	(27.8 %)	(56.5 %)	(15.7 %)	
Referral Source	82	76	47	
Health department	(39.8 %)13	(36.9 %)11	(22.8 %)4	
Private physician	(46.4 %)17	(39.3 %)14	(14.3 %)4	0.6
Study institution	(48.6 %)3	(40.0 %)7	(11.4 %)1	
Other	(27.3 %)	(63.6 %)	(9.1 %)	

Percentages are reported based on sub-groups.
*Low-grade: Atypical cells of unknown significance (ASCUS), low-grade squamous intraepithelial lesion (LSIL).
**High-grade: Atypical squamous cells, cannot rule out high-grade (ASC-H), high-grade squamous intraepithelial lesion (HSIL), atypical glandular cells (AGC).

4. Discussion

With early detection and timely follow-up, treatment for early stage cervical cancer is highly effective, and it is concerning that there is low rate of follow-up adherence for women after abnormal CCS (Katz et al., 2014; Fish et al., 2013). Our study showed that patients were not adherent with follow-up over 40 % of the time with an additional 20 % presenting for delayed care. Approximately half of patients undergoing CCS have at least one barrier causing them to be lost to follow-up or have delayed care (Katz et al., 2014). While there is limited data published on delayed colposcopy affecting outcomes specifically, there is data showing that lack of screening is increased with morbidity and mortality (Campos et al., 2019). Furthermore, delayed care in cervical cancer diagnosis and treatment of more than 3–4 months has been shown to increase mortality in patients (Shen et al., 2016), and diagnostic delays have also been shown to be a contributing factor in the increased cancer burden in ethnic minority populations (Ashing-Giwa et al., 2010). Therefore, it is important to evaluate the factors behind both delayed and lack of adherence to follow-up for abnormal CCS.

Previous research has shown that racial/ethnic minorities have a lower adherence to follow-up after an abnormal screen in breast cancer and other preventive screening methods (Jones et al., 2005; Adams et al., 2009). Our study demonstrated that over one-third of Latinx women and one-fifth of Black women presented for follow-up of abnormal CCS in a delayed fashion. Research has highlighted that poor health literacy, low education levels, language barriers, and distrust and fear may contribute to lack of follow-up after abnormal screening in breast and cervical cancer in this patient group (Yabroff et al., 2004; Lindau et al., 2006; Percac-Lima et al., 2010; Yang et al., 2011; Ashing-Giwa et al., 2004). It is vital to understand women's cultural perspectives along with potential systems barriers to create appropriate patient-centered interventions.

Black women in the United States currently have a higher reported CCS rate than their non-Hispanic White counterparts (75.1 % vs 65.0 %) (Institute, 2020). Our study demonstrated that even with a higher rate of CCS and referrals, Black women did not present for follow-up 45.9 % of the time compared with 38.6 % of White women. However, our study did show that once a Black woman entered the system, she had an 80.0 % rate of follow-up for further evaluation and treatment. This might suggest that once an individual is adequately educated and engaged within a system, she is more likely to follow-up for abnormal results.

Not surprisingly, two-thirds of patients with private insurance presented for their appointment as scheduled. However, over 50 % of uninsured patients never presented for their care (Tsui et al., 2019), and Medicaid patients were more likely to present for their care delayed when compared with private and uninsured patients (p = 0.001; 26.5 % vs 7.4 % vs 15.8 %, respectively). It is important to be aware of patients who are underinsured/uninsured in states where there has been a lack of Medicaid expansion as Medicaid expansion has been associated with improved CCS rates (Sabik et al., 2018). Special outreach and preventative interventions are needed to ensure these underserved individuals have access to the care they need (Tangka et al., 2010).

Are healthcare and public health systems providing adequate and accessible screening options, is the public educated about them, do patients receive their results, are they verbally contacted with their next scheduled appointment? Several studies have consistently demonstrated that Black women report being notified about abnormal results less frequently than their White counterparts (Ford et al., 2021; Smedley et al., 2003). It is also noted that many women have competing interests such as transportation and childcare issues (Roman et al., 2014).

Weaknesses of this study include those that are inherent to a retrospective review and the fact that only a random sampling was taken from the total amount of patients presenting to clinic. Given the large number of patients referred to the clinic, a random sampling was performed to be a representative sample. In order to limit selection bias, patients were randomly selected from all clinics during the timeframe based on percentages of rates of "show" and "no show" for that clinic. Given the nature of the clinic (strictly a colposcopy visit), there is limited documentation regarding other potential factors that might influence the ability for the patient to be adherent with follow-up. For example, a targeted history is obtained, but comprehensive social, demographic, and medical information may not be fully obtained. Furthermore, the majority of patients referred to this clinic have Medicaid or are uninsured. However, historically this has been the group that tends to be lost to follow-up (Tsui et al., 2019; Sabik et al., 2018), so this may be beneficial when trying to evaluate trends in this patient population. Strengths of this study include that it is performed at a large, tertiary care center where women are referred to from all over the state.

5. Conclusion

There have been significant advances in CCS since the implementation of the Pap test with an initial decrease in incidence and mortality; however, over the last several years there has been a plateau in incidence and mortality associated with cervical cancer. As demonstrated by this study, one of the areas that could be largely contributing to this is the low rate of follow-up after abnormal CCS. There is a significant gap in this population as a whole with nearly-two-thirds of women being delayed or not adherent to follow-up. Moreover, while Black women have an overall higher rate of reported Pap tests, they have a lower rate of follow-up for abnormal Pap tests. Furthermore, a quarter of Hispanic and Black women presented in a delayed fashion. Despite the increase in coverage of preventive care services (i.e. Pap test screening rate of 80 % and HPV vaccination), unique, patient-centered assessments and interventions are needed to understand and address these gaps.

Declaration of Competing Interest

References

Adams, S.A., Smith, E.R., Hardin, J., Prabhu-Das, I., Fulton, J., Hebert, J.R., 2009. Racial differences in follow-up of abnormal mammography findings among economically disadvantaged women. Cancer 115 (24), 5788–5797.

American Cancer Society, 2019-2021. Cancer facts & figures for African Americans. American Cancer Society, Atlanta, Ga. v. p.

Ashing-Giwa, K.T., Padilla, G., Tejero, J., Kraemer, J., Wright, K., Coscarelli, A., Clayton, S., Williams, I., Hills, D., 2004. Understanding the breast cancer experience of women: a qualitative study of African American, Asian American, Latina and Caucasian cancer survivors. Psychooncology 13 (6), 408–428.

Ashing-Giwa, K.T., Gonzalez, P., Lim, J.-W., Chung, C., Paz, B., Somlo, G., Wakabayashi, M.T., 2010. Diagnostic and therapeutic delays among a multiethnic sample of breast and cervical cancer survivors. Cancer 116 (13), 3195–3204.

Benard, V.B., Johnson, C.J., Thompson, T.D., Roland, K.B., Lai, S.M., Cokkinides, V., Tangka, F., Hawkins, N.A., Lawson, H., Weir, H.K., 2008. Examining the association between socioeconomic status and potential human papillomavirus-associated cancers. Cancer 113 (S10), 2910–2918.

Campos, N.G., Tsu, V., Jeronimo, J., Regan, C., Resch, S., Clark, A., Sy, S., Kim, J.J., 2019. Health impact of delayed implementation of cervical cancer screening programs in India: A modeling analysis. Int. J. Cancer 144 (4), 687–696.

Eggleston, K.S., Coker, A.L., Das, I.P., Cordray, S.T., Luchok, K.J., 2007. Understanding barriers for adherence to follow-up care for abnormal pap tests. J. Womens Health (Larchmt) 16 (3), 311–330.

Engelstad, L.P., Stewart, S.L., Nguyen, B.H., Bedeian, K.L., Rubin, M.M., Pasick, R.J., et al., 2001. Abnormal Pap smear follow-up in a high-risk population. CancerEpidemiol Biomarkers Prev. 10 (10), 1015–1020.

Fish, L.J., Moorman, P.G., Wordlaw-Stintson, L., Vidal, A., Smith, J.S., Hoyo, C., 2013. Factors Associated With Adherence to Follow-up Colposcopy. Am. J. Health Educ. 44 (6), 293–298.

Ford, S., Tarraf, W., Williams, K.P., Roman, L.A., Leach, R., 2021. Differences in cervical cancer screening and follow-up for black and white women in the United States. Gynecol. Oncol. 160 (2), 369–374.

Health OoRoWs, 2021. NIH Request for Information (RFI): Advancing NIH Research on the Health of Women: A 2021 Conference (ARHW2021) Online: National Institute of Health; 2021 [Available from: NIH Request for Information (RFI): Advancing NIH Research on the Health of Women: A 2021 Conference (ARHW2021).

Insitute NC, 2021. Trends in SEER Incidence and U.S. Mortality Using Joinpoint Regression Program, 1975-2017 Online 2021 Available from: https://seer.cancer.gov/csr/1975_2017/browse_csr.php?sectionSEL=5&pageSEL=sect_05_table.01#d.

Institute NC, 2020. Cervical Cancer Screening progressreport.cancer.gov: National Institute of Health; 2020 [updated 3/2020. Available from: https://progressreport.cancer.gov/detection/cervical_cancer.

Jones, B.A., Dailey, A., Calvocoressi, L., Reams, K., Kasl, S.V., Lee, C., Hsu, H., 2005. Inadequate follow-up of abnormal screening mammograms: findings from the race differences in screening mammography process study (United States). Cancer Causes Control. 16 (7), 809–821.

Katz, M.L., Young, G.S., Reiter, P.L., Battaglia, T.A., Wells, K.J., Sanders, M., Simon, M., Dudley, D.J., Patierno, S.R., Paskett, E.D., 2014. Barriers reported among patients with breast and cervical abnormalities in the patient navigation research program: impact on timely care. Womens Health Issues. 24 (1), e155–e162.

Lindau, S.T., Basu, A., Leitsch, S.A., 2006. Health literacy as a predictor of follow-up after an abnormal Pap smear: a prospective study. J Gen Intern Med. 21 (8), 829–834.

Miller, S.M., Tagai, E.K., Wen, K.-Y., Lee, M., Hui, S.-K., Kurtz, D., Scarpato, J., Hernandez, E., 2017. Predictors of adherence to follow-up recommendations after an abnormal Pap smear among underserved inner-city women. Patient Educ. Couns. 100 (7), 1353–1359.

Percac-Lima, S., Aldrich, L.S., Gamba, G.B., Bearse, A.M., Atlas, S.J., 2010. Barriers to follow-up of an abnormal Pap smear in Latina women referred for colposcopy. J. Gen. Intern. Med. 25 (11), 1198–1204.

Promotion OoDPaH, 2021. Healthy People 2030 Online: U.S. Department of Health and Human Services; 2021 [Available from: https://health.gov/healthypeople/objectives-and-data/browse-objectives/cancer/increase-proportion-females-who-get-screened-cervical-cancer-c-09.

Roman, LeeAnne, Meghea, C., Ford, S., Penner, L., Hamade, H., Estes, T., Williams, K.P., 2014. Individual, provider, and system risk factors for breast and cervical cancer screening among underserved Black, Latina, and Arab women. J. Womens Health (Larchmt). 23 (1), 57–64.

Sabik, L.M., Tarazi, W.W., Hochhalter, S., Dahman, B., Bradley, C.J., 2018. Medicaid Expansions and Cervical Cancer Screening for Low-Income Women. Health Serv. Res. 53, 2870–2891.

Shen, S.C., Hung, Y.C., Kung, P.T., Yang, W.H., Wang, Y.H., Tsai, W.C., 2016. Factors involved in the delay of treatment initiation for cervical cancer patients: A nationwide population-based study. Medicine (Baltimore). 95 (33), e4568.

Smedley, B.D., Stith, A.Y., Nelson, A.R. (Eds.), 2003. Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care. Washington (DC).

Society, AC, 2021. Key Statistics for Cervical Cancer Online2021 [updated Jan. 12, 2021. Available from: https://www.cancer.org/cancer/cervical-cancer/about/key-statistics.html.

Tangka, F.K.L., O'Hara, B., Gardner, J.G., Turner, J., Royalty, J., Shaw, K., Sabatino, S., Hall, I.J., Coates, R.J., 2010. Meeting the cervical cancer screening needs of underserved women: the National Breast and Cervical Cancer Early Detection Program, 2004–2006. Cancer Causes Control. 21 (7), 1081–1090.

Tsui, J., Llanos, A.A.M., Doose, M., Rotter, D., Stroup, A., 2019. Determinants of Abnormal Cervical Cancer Screening Follow-Up And Invasive Cervical Cancer Among Uninsured and Underinsured Women in New Jersey. J. Health Care Poor Underserved. 30 (2), 680–701.

Yabroff, K.R., Breen, N., Vernon, S.W., Meissner, H.I., Freedman, A.N., Ballard-Barbash, R., 2004. What factors are associated with diagnostic follow-up after abnormal mammograms? Findings from a U.S. National Survey. Cancer Epidemiol. Biomarkers Prev. 13 (5), 723–732.

Yabroff, K.R., Kerner, J.F., Mandelblatt, J.S., 2000. Effectiveness of interventions to improve follow-up after abnormal cervical cancer screening. Prev. Med. 31 (4), 429–439.

Yang, T.-C., Matthews, S.A., Hillemeier, M.M., 2011. Effect of health care system distrust on breast and cervical cancer screening in Philadelphia, Pennsylvania. Am. J. Public Health 101 (7), 1297–1305.

Yu, L., Sabatino, S.A., White, M.C., 2019. Rural-Urban and Racial/Ethnic Disparities in Invasive Cervical Cancer Incidence in the United States, 2010–2014. Prev. Chronic Dis. 16, E70.