

## Research Report

## Barriers and facilitators affecting presentation in women with early versus advanced stage cervical cancer

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## ABSTRACT

**Background:** This study was performed to evaluate the barriers and facilitators associated with patient presentation for early stage (ES) versus advanced stage (AS) cervical cancer (CC).

**Methods:** A mixed-method approach was used to collect quantitative (i.e., demographics and medical/screening histories) and qualitative data (individual interviews assessing patients' perceptions regarding their general health, HPV and CC screening, and barriers and facilitators to CC care). Two separate investigators coded the interviews for major themes that occurred with an agreement that 50% or more of the themes would be included.

**Results:** Twenty-five women agreed to participate in the study with 80% completing the interview. Patients with ES disease were classified as Stage IA1–Stage IB3; patients with Stage IIA–IVB disease were classified with AS disease. Frequent barriers in the ES group were lack of knowledge, competing priorities, feeling healthy, lack of time or health insurance, and being embarrassed/uncomfortable. Frequent barriers in the AS group were lack of knowledge, competing priorities, avoidance/procrastination, fear of the healthcare system or finding something wrong, and lack of perceived risk to CC. Facilitators for ES included understanding the importance of the Pap test, having an abnormal Pap test, and knowing someone with CC. Having abnormal symptoms was the only facilitator for AS patients.

**Conclusions:** Structural and intrapersonal barriers to CC care persist but differ between ES and AS patients. Multi-level interventions are needed to address the wide array of issues that women highlighted in this study including potential innovative methods to increase access to care and engagement with the healthcare system.

## 1. Introduction

Cervical cancer is a largely preventable disease due to the effectiveness of screening and introduction of the HPV vaccination. The incidence of cervical cancer decreased by more than half from the 1970s to 2000s in the United States (U.S.) (Institute, 2020). Instead of continuing to decrease, more recently there has been a plateau in cervical cancer incidence from 2013 to 2018 (Institute NC, 1975–2017). In Alabama, cervical cancer screening coverage is at the national average, but the mortality rate has increased over the time frame of 1997–2017 (Division of Cancer Prevention and Control CfDCaP, 2021). Moreover, in 2021, there will be an estimated 14,480 new cases of cervical cancer in the U.S. compared with 12,831 new cases in 2017 (Society, 2021). The

greatest morbidity and mortality are associated with patients who are diagnosed with advanced stage (AS) disease (Coker et al., 2009; Zhan and Lin, 2014). However, when diagnosed at an early stage (ES) cervical cancer is largely curable (Waggoner, 2003). ES cervical cancer has a 5-year survival rate of 92%, but AS disease 5-year survival rate ranges from 17 to 58% depending on metastatic disease (American Cancer Society, 2021). Therefore, in order to decrease morbidity and mortality, it is imperative to diagnose women with ES disease.

Cervical cancer continues to have concerning disparities regarding incidence and mortality rates in racial/ethnic minorities, patients with lower socioeconomic status, and in those from rural communities (Zhan and Lin, 2014; American Cancer Society, 2019–2021; Yu et al., 2019; Benard et al., 2008; Olusola et al., 2019). The highest rates occur in

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racial and ethnic minorities including Latinx women at 8.9/100,000 and Black women at 8.3/100,000 compared with White women at 7.3/100,000 (Control. CfD, 2021). Despite Black women having equal or higher reported rates of cervical cancer screening, they continue to have a higher rate of incidence, AS disease, and mortality associated with cervical cancer (Ford et al., 2021). Similarly, Latinx women are 40% more likely to be diagnosed with cervical cancer when compared with White women and 20% more likely to die from it (Division of Cancer Prevention and Control CfDCaP, 2021).

Barriers to cervical cancer screening and treatment exist at the patient, provider, and healthcare system levels. Previous research has demonstrated that patient barriers include lack of awareness, low health literacy, fear of discovering cancer, embarrassment, and competing interests (del Carmen et al., 2007; Coronado et al., 2004; Lindau et al., 2002; Tipirneni et al., 2018; Kiefe et al., 1998). Provider and systems barriers have included lack of insurance, cost, lack of physician recommendation, low quality healthcare services, or limited or no access to care (Coronado et al., 2004; Chen et al., 2012; Pierce Campbell et al., 2012). These barriers either delay or prevent a woman from seeking evaluation, and ultimately the absence of care can lead to the development of cervical cancer in a patient with risk factors. Given the multitude of barriers, it has been difficult to develop tailored interventions that optimize having access to cervical cancer care (Tejeda et al., 2013).

While there have been previous retrospective studies evaluating factors associated with AS presentation primarily, to our knowledge, no studies have examined barriers and facilitators among patients with ES versus AS cervical cancer that can inform targeted efforts. It has been highlighted at the Congressional level and from the National Institutes of Health that cervical cancer survival rates are stagnant, and a call-to-action has been made (Health OoRoWs, 2021; Gaffney et al., 2018). Given the continued disparities associated with cervical cancer and the plateau in incidence, the purpose of this study was to evaluate what the barriers and facilitators are in women who present with ES versus AS cervical cancer. It has been shown that less than 50% (44%) of women present with ES disease (which is largely curable). Thus, through the delineation of the barriers and motivators that women with ES and AS cervical cancer face, attempts at targeted interventions may be employed to eliminate some morbidity associated with cervical cancer.

## 2. Methods

Data collection, analysis, and interpretation of barriers and facilitators in stages of cervical cancer presentation was focused on three domains (patient, provider, and healthcare system level) because barriers and motivators with cervical cancer diagnosis are multifactorial. They were then classified into two sections examining intrapersonal and structural barriers and facilitators. Barriers were defined as a factor that potentially makes a patient less likely to engage with screening and facilitators are factors that make a patient more likely to undergo screening. Intrapersonal factors include knowledge, attitudes, and beliefs that may contribute to or deter engagement in seeking follow-up care for abnormal cervical cancer screening results. Structural or community factors include variables at the provider and system levels such as resources, accessibility, and referrals that affect an individual's interaction with the health system.

### 2.1. Participant quantitative survey

Participants were recruited from our tertiary care center's gynecologic oncology clinic. Inclusion criteria were pathology proven cervical cancer, age  $\geq 21$  years old, and no prior diagnosis of cervical cancer. Exclusion criteria were women who had previously been treated for cervical cancer or those with a mental impairment preventing conversation. ES disease was classified as Stage IA1 to Stage 1B3 (confined to the cervix). Patients with Stage 2A to IVB disease were classified as AS

disease. The quantitative assessment comprised of 26 questions that were yes/no, multiple choice, and open-ended for response. These questions focused on demographic factors, social determinants of health, medical history, preventive screening history, and if the COVID-19 pandemic interfered with their healthcare. They were based off validated questionnaires from the Behavioral Risk Factor Surveillance System (BRFSS) and previous work from Scarinci et. al. (Control. CfD. BRFSS Questionnaires Online January 14, 2021; Gibson et al., 2019). The primary purpose of the quantitative assessment was to describe the patients involved in the study with their demographics, socioeconomic factors, past medical history, and overall engagement with the healthcare system.

### 2.2. Participant qualitative interview

Patients were recruited on their initial visit to our gynecologic oncology clinic and written informed consent was obtained. The patient was given the option of performing the interview the same day or over the phone within the next 1–2 weeks. Interviews were conducted between October 2020 and May 2021.

A standardized interview topic guide was developed with open-ended questions and contained three main sections including general health, HPV and cervical cancer screening, and the patient's presentation to care. The final section was aimed at understanding the barriers and facilitators in a patient's presentation to care. It examined areas such as presenting symptoms, motivation for presenting to care, delays that prevented presentation, fears and worries associated with seeking care, and if the COVID-19 pandemic played a role in affecting their care.

The interviews were performed by one investigator (TB) to maintain consistency across all participants. Interviews were recorded using two recording devices to eliminate possible technical errors. They were then transcribed by a HIPAA-compliant company. Saturation was reached once themes were continually repeated with no new information presented. Two investigators independently evaluated and coded the interviews. These codes were reviewed and agreed upon by both coders. The codes were categorized and placed into themed sections. Major themes were those that occurred in at least 50% of interviews in one category.

Patients were reimbursed \$20 for their participation in the study. Qualitative data was organized and analyzed using nVivo software (QSR International, Australia). Descriptive statistics were used to examine the quantitative data given the goal was to characterize the sample. These factors were analyzed relative to cancer stage at presentation. Statistical analysis was performed using SPSS Statistics v. 25. Institutional Review Board approval was obtained.

## 3. Results

A total of 25 individuals were approached with 100% of patients agreeing to participate in the study. 20 of the 25 patients completed surveys (80% completion rate) with 5 participants being lost to follow-up (LTFU) when they were attempted to be reached by telephone. Up to 5 call attempts were made for each patient with voicemails left over the period of several weeks. In the 5 patients who were LTFU, 3 were AS and 2 were ES. The goal was to recruit and interview enough patients to reach saturation which was achieved at 11 for AS and 9 for ES cervical cancer patients.

### 3.1. Participant survey

Demographic information is included in Table 1. The average age was 45 years in the ES group and 51 years in the AS participants. There were more Whites in the AS patients (81.8%) but it was nearly equally distributed in the ES group with 55.6% being Black. Of the women with ES and AS cancer, 55.6% and 81.8% used tobacco products, respectively. Over half of the women in each group stated they had a primary

**Table 1**  
Patient demographics.

	Early Stage, n = 9	Advanced Stage, n = 11
Age (mean years+/- standard deviation)	44.8 +/- 11.2	51.2 +/- 10.0
Race		
Black	5 (55.6%)	2 (18.2%)
White	4 (44.4%)	9 (81.8%)
Stage of disease		
I	9 (100%)	
II		4 (36.3%)
III		5 (45.5%)
IV		2 (19.2%)
Work status		
Full time job	8 (88.9%)	3 (27.3%)
Disabled	-	6 (54.5%)
Retired	-	2 (19.2%)
None	1 (11.1%)	-
Average monthly income (\$)	3489 +/- 2014	2507 +/- 1595
Tobacco Use		
Yes	5 (55.6%)	9 (81.8%)
No	4 (44.4%)	2 (18.2%)
Average pack years (smoking)	18	22
Alcohol use		
Yes	5 (55.6%)	6 (54.5%)
No	4 (44.4%)	5 (45.5%)
How often do you go for a checkup?		
Once a year	6 (66.7%)	6 (54.5%)
Every 5 years or more	2 (22.2%)	2 (18.2%)
Never	1 (16.6%)	3 (27.3%)
Primary Care Physician		
Yes	5 (55.6%)	8 (72.7%)
No	4 (44.4%)	3 (27.3%)
Type of current insurance		
Private	4 (44.4%)	6 (54.5%)
Medicaid	3 (33.3%)	-
Medicare	-	3 (27.3%)
None	2 (22.2%)	2 (18.2%)
Lack of insurance at some point prevented access to care		
Yes	6 (66.7%)	5 (45.5%)
No	3 (33.3%)	6 (54.5%)
Preventive Care (up-to-date*)		
Pap test		
Yes	6 (66.7%)	3 (27.3%)
No	3 (33.3%)	8 (72.7%)
Mammogram		
Yes	4 (44.4%)	2 (18.2%)
No	1 (16.6%)	8 (72.7%)
Not applicable due to age	4 (44.4%)	1 (9.2%)
Colonoscopy		
Yes	2 (22.2%)	2 (18.2%)
No	-	5 (45.5%)
Not applicable due to age	7 (77.8%)	4 (36.3%)
Delay due to COVID**		
Yes	5 (55.6%)	3 (27.3%)
No	4 (44.4%)	8 (72.7%)

\* Per U.S. Preventive Services task force guidelines

\*\* Delayed appointments through the hospital system, or difficulty getting access to care

care physician and that received care from them for chronic medical problems. Less than one-third of women in the AS group reported adherence to any sort of preventive screening (Pap test, mammogram, or colonoscopy). ES participants were more likely to report being up to date with Pap tests than AS women (66.7% vs. 27.3%). Half of the women in each group reported that a lack of insurance at some point in their life prevented access to care.

### 3.2. Qualitative interview major themes

During the interview, participants were asked about barriers that prevented them to follow-up for care as well as any facilitators that motivated them to seek out care. Topics that were mentioned at least

50% of the time were considered a major theme (Table 2). For instance, when the interviews discussed possible ways to increase access to screening, both groups expressed interest in HPV self-sampling.

Fig. 1 exhibits similarities and differences of major themes between ES and AS patients. Minor themes were additional themes that were mentioned more than once but did not meet criteria for a major theme. They primarily included only going to get a Pap test when pregnant (ES), healthcare systems issues (ES and AS), and recommendations from family to get preventive care (AS).

#### 3.2.1. Barriers

Participant barriers that were cited by at least 50% of those in the ES disease group included lack of knowledge, competing priorities, feeling healthy, lack of time, no insurance/financial difficulties, being embarrassed/uncomfortable, and COVID-19 pandemic delay. In the AS disease group, the most common barriers endorsed were lack of knowledge, competing priorities, avoidance/procrastination, fear of the physician/lack of trust, feeling healthy, lack of perceived risk, and fear of finding something wrong. Examples from both groups are included in Table 3.

#### 3.2.2. Facilitators

In the ES group, there were three main facilitators that were cited by at least 50% and included understanding the importance of the Pap test, having an abnormal Pap test, and having a family member or friend with a history of cervical cancer (Table 3). Other minor themes that did not reach significance included having a physician explain the importance (33.3%), self-care/ being healthy for family (44.4%), and getting insurance (33.3%). The only facilitator in the AS group that was present in 50% of the participants was having abnormal symptoms that led the patient to get evaluated (Table 3). One minor theme was having a friend or family member tell them they needed to go to the physician for preventive care or evaluation (36.6%).

## 4. Discussion

This study demonstrates that there remain significant barriers at the patient, physician, and systems level that prevent and/or deter women from being screened for cervical cancer or present for evaluation by a

**Table 2**  
Major themes.

	Early Stagen = 9	Advanced Stagen = 11
<b>INTRAPERSONAL FACTORS</b>		
Positive		
Understood importance of Pap test	(55.6%)	
Negative		
Lack of knowledge	(66.7%)	(81.8%)
Competing priorities	(55.6%)	
Feel healthy	(88.9%)	(54.5%)
Fear of going to a physician/healthcare system		(72.7%)
Avoidance/procrastination		(63.6%)
Lack of perceived risk to cervical cancer		(63.6%)
Fear of finding cancer/something wrong	(55.6%)	(54.5%)
Lack of time	(55.6%)	
Uncomfortable/embarrassing		
<b>STRUCTURAL FACTORS</b>		
Positive		
Abnormal Pap tests	(88.9%)	
Symptoms (vaginal bleeding, pain, etc.)		(63.6%)
Family/friend history of cervical cancer	(55.6%)	
Negative		
No insurance	(55.6%)	
Delay appointment due to the pandemic	(55.6%)	
<b>WILLINGNESS TO DO SELF-SAMPLING FOR HPV TESTING</b>		
Self-sampling for HPV testing	(55.6%)	(63.6%)

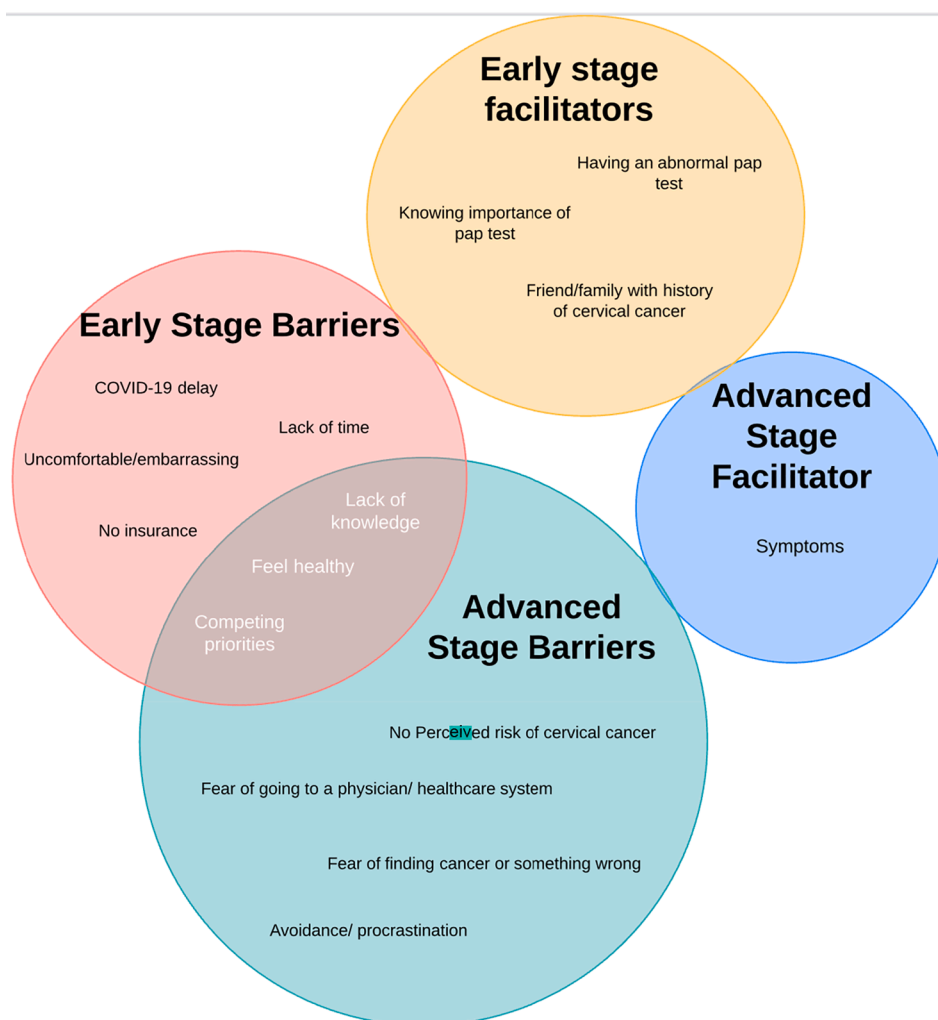


Fig. 1. Barriers and facilitators for early stage versus advanced stage disease.

healthcare professional following abnormal results. Previous studies have shown patient barriers including fear of discovering cancer, embarrassment, and lack of knowledge about risk factors (del Carmen et al., 2007; Coronado et al., 2004; Lindau et al., 2002; Tipirneni et al., 2018; Kiefe et al., 1998). Provider- and system-level barriers have included lack of insurance, cost, competing priorities, lack of physician recommendation, or poor access to care (Coronado et al., 2004; Chen et al., 2012; Pierce Campbell et al., 2012). This study confirmed these findings, highlighted new ones, and was additionally able to expand on the distinct differences of women who present with ES versus AS disease. Identifying women with ES disease is paramount in order to decrease the morbidity associated with AS disease.

Women with ES disease were more likely to note barriers related to: insurance issues, feeling uncomfortable or embarrassed, lack of knowledge, competing priorities, feeling healthy, or a lack of time. Half of the ES patients also reported a delay in care due to the COVID-19 pandemic. ES patients were more likely to have had a routine Pap test (66.7%) but did not follow-up for colposcopy or further treatment. It has been demonstrated that there is an alarmingly low rate of follow-up in women after abnormal cervical cancer screening which ranges from 20 to 70% (Katz et al., 2014; Fish et al., 2013). In general, women did not follow-up due to lack of knowledge/understanding the abnormal result and also having competing priorities. Motivators for women with ES disease to obtain care included having a friend or family member with cervical cancer, understanding the importance of screening with Pap tests, and having an abnormal Pap test. Many ES women were compliant with

initial cervical cancer screening but would then delay follow-up for their abnormal result. Therefore, even though they had a visit with a healthcare provider, they did not understand the importance of follow-up. Given this information, it is critical to develop interventions and educate women about the importance of follow-up after an abnormal Pap test in order to prevent progression to cervical cancer. Methods may include the use of health technologies in order to provide personalized, on-demand information and explanations (Kumar et al., 2013) or mobile health clinics (i.e. a mobile colposcopy van/clinic) to provide flexible curbside care in these vulnerable populations (Yu et al., 2017).

The majority of women with AS disease cancer did not receive routine preventive care and had not had a Pap test in five or more years (72.7%) and frequently reported having fear associated with the healthcare system or of having a pathologic diagnosis. The women with AS disease in this study had a general lack of knowledge about cervical cancer but did not understand their own risk for the disease. Previous studies have not specifically delineated these findings being associated with AS disease, but they have been found in general with cervical cancer patients (Pierce Campbell et al., 2012; Nonzee et al., 2015). The majority of women with AS had current health insurance coverage, but nearly half cited that previous lack of insurance had prevented them from obtaining care at some point. This raises the question if a lack of preventive care for a period of a patient's life sets the tone for patients not seeking it out once they have access to insurance? Studies have also shown that even if individuals have health insurance but poor health literacy, they are less likely to seek out preventive care (Tipirneni et al.,

**Table 3**  
(Appendix) Select phrases from participants.

	Early Stage	Advanced Stage
Barriers	<ul style="list-style-type: none"> <li>- Lack of knowledge (66.7%): “I knew what a Pap smear was, but I didn’t know why I needed it.”</li> <li>- “Well, to be honest, I don’t know anything about it (cervical cancer).”</li> <li>- Lack of time (55.6%): “Like I literally did not have time. I worked 12 h a day as an ER nurse and my days off I had my daughter.</li> <li>- Competing priorities (55.6%): “I had the boys and everything and it was just - you know, it was like hard, you know, for years to - like for any of us, like to go to a doctor.”</li> <li>- “I was working, ma’am, I was always working. I had no time. If I had known, I would’ve gotten checked.”</li> <li>- Lack of insurance (55.6%): “When I applied for Medicaid I got denied. So, it was like, okay, well, I can’t go to the doctor because I don’t have any insurance. Then my job, I’m a waitress so we don’t have any insurance there.”</li> <li>- Embarrassed/uncomfortable (55.6%): “It’s very uncomfortable the whole Pap smear thing. It’s extremely uncomfortable.”</li> <li>- “You know it’s also kind of unnerving knowing you have to go in and go through the whole process.COVID-19 Pandemic Delay (55.6%): “I had an iffy Pap smear, and then three months later I had another iffy Pap smear and I had to wait one year before I could get a colpo because of COVID.”</li> </ul>	<ul style="list-style-type: none"> <li>- Lack of knowledge (81.5%): “I just never knew the importance of it (the Pap test), and I’ve started addressing it to my girls now. But yeah, I just never knew.”</li> <li>- “I don’t know anything about it. You know I know to go on the internet and look up stuff. But I’m so afraid now because I have this. “</li> <li>- Avoidance/procrastination (63.6%): “Well if I avoided the doctor, then that meant there was nothing wrong. Pretty much I just didn’t want to know.”</li> <li>- Fear of going to a physician/the healthcare system (63.6%): “Yeah, right. I think it’s the fear of somebody looking between your legs, to be honest, with me, and I think that’s what it was... you’re just afraid.”</li> <li>- Felt healthy (72.7%): “But you know, like I said, I always felt healthy. I mean, you know, I didn’t get sick a lot, I didn’t really have colds and flus a whole lot, you know?”</li> <li>- Lack of perceived risk (63.6%): “I’m very healthy. I exercise a lot. And I try to eat fairly reasonable and things like that. So it was a shock to me in a sense that I even had [cervical cancer].</li> <li>- “No. No, I never thought I would have cancer.”</li> <li>- Fear of findings something wrong (54.5%): “But it’s tough getting there...having this Pap smear done. That’s the fear of getting there, going on and having the Pap smear done and see what’s wrong and get it fixed. That’s the fear.”</li> <li>- Abnormal symptoms (63.6%): “I started bleeding, which I knew I went through menopause so, I knew that that weren’t normal. It just kept getting worse and worse. The pain just kept getting a lot worse and it just got to where I couldn’t stand the pain anymore and I couldn’t do what I want to. Back then, I was trying to work and it got where that I couldn’t do it no more. They done an ultrasound on me and they done a CAT scan and she come in there and told me that I was sick.”</li> <li>- “So, I had my first child and I never cramped like that again until about four months ago. And so, that’s when I got off my butt and said, I’ve got to see what’s going on down there.”</li> </ul>
Facilitators	<ul style="list-style-type: none"> <li>- Importance of Pap test (55.6%): “I know that you have to get a Pap smear and see those abnormal cells and then have somebody determine what it is. So, you know, it can get worse and cause cancer. Pap smears are important.”</li> <li>- Abnormal Pap test (88.9%): “I didn’t have insurance, so I went to the health department. They gave me one, and then that’s when they came back with saying that they found precancerous cells.”</li> <li>- Family/friends with history of cervical cancer (55.6%): “My mother and my aunt, my mother is a survivalist. My aunt is going through it, my best friend just had a radical hysterectomy and I’m white and she’s black if that makes a difference in all of this. Same age, same lifestyle, same everything, got the same cancer.”</li> </ul>	

2018). The facilitator for women with AS disease was physical symptoms (vaginal bleeding, pain, and abnormal discharge). Overall, there is still a large gap in health literacy and understanding of the role of preventive care understanding in this population of women. Many of these women indicated that they would prefer a method such as an HPV self-swab in order to be screened for cervical cancer (Table 2).

The majority of patients that were affected by the COVID-19 pandemic delay were in the ES cervical cancer group. Most of these individuals reported COVID-19 associated delays due to the healthcare system stating they could not get the appropriate follow-up appointment scheduled for an abnormal Pap smear (i.e. colposcopy). It has been reported that up to 40% of patients delayed or avoided routine medical care because of COVID-19 (Czeisler et al., 2020), and delayed medical care can increase morbidity and mortality (Prentice and Pizer, 2007). Initially, many thought that it was largely patients that were avoiding the medical system during the pandemic (Lange et al., 2020), but our study demonstrates that it was also due to the healthcare system being shut down that patients did not receive adequate care. The implementation of the widespread use of telemedicine did mitigate some of the burden and improved access to medical providers (Temesgen et al., 2020). This leads to the important idea of utilizing telemedicine even beyond the pandemic to evaluate patients and find particularly high-risk individuals that may need in-office evaluation (Lee and Hitt, 2020; Woodall et al., 2021).

In general, there is lack of understanding and knowledge about cervical cancer and screening at the patient level that was expressed by the majority of individuals in this study (Musa et al., 2017). At the provider level, it is imperative for all primary care providers and OBGYNs to ensure they are educating their patients on the care they are receiving. Women noted this could be a handout in the office or a verbal discussion with the provider. One woman commented, “I’m telling the doctors, I never knew how important it was to get a Pap smear. That’s something that I never learned.” It should also be emphasized that nursing staff should feel empowered to have these discussions with patients to educate or reinforce the message and mitigate barriers (Fowler et al., 2020). Furthermore, Medicaid expansion has been shown to increase cervical cancer screening in low-income women (Sabik et al., 2018). Therefore, it is important to continue to increase access to care for women who live in states where it has not been expanded, such as Alabama. The majority of women (both ES and AS) noted how they would prefer a home self-sampling for HPV testing method if this becomes broadly available. In previous studies, this has been found to be a highly- accepted method among women for cervical cancer screening (Nishimura et al., 2021).

A limitation of this study includes that it occurred during the COVID-19 pandemic which could have affected how women sought preventive care. We accounted for this by asking women if they felt like their care was delayed by the COVID-19 pandemic. Another limitation is that this study is only comprised of Black and White women, and the one Latinx patient was lost to follow-up. Given the small sample size, we were unable to look at statistical significance between the two groups. However, given some of the differences, more in-depth examinations are warranted to better understand how these demographic and social factors may play a role in the presentation of care following abnormal cervical cancer screening results. Furthermore, definitive conclusions cannot be drawn from this data as it is a hypothesis generating paper. A major strength of this study includes the fact that it occurred at a tertiary care center where patients obtain care from all over the state.

## 5. Conclusions

While cervical cancer prevention is the ultimate goal, improving ways to diagnose women with ES disease is crucial to improve long-term outcomes. Ranging from no health insurance coverage to lack of knowledge to embarrassment and fear, women continue to face barriers that prevent them from obtaining preventive care which increases their

risk for developing cervical cancer. A multi-level evaluation and intervention is needed to further evaluate and address the wide array of issues highlighted in this study. Efforts such as self-sampling for HPV testing and Medicaid expansion will eliminate the screening barrier for some women, but there still remains a large gap in care for follow-up after abnormal testing. Evaluations and interventions specifically targeting this group could have a significant impact on preventing or diagnosing ES disease before it progresses. Innovative methods such as a mobile colposcopy clinic or the use of telemedicine visits with local rural providers may be needed in order to increase adherence to care. Finally, continuing to educate women to increase health literacy is a fundamental practice that all providers should embrace.

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#### CRediT authorship contribution statement

**Teresa K.L. Boitano:** Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Writing – original draft. **Mary A. Powell:** Formal analysis, Validation. **Charles A. Leath:** Conceptualization, Writing – review & editing. **J. Michael Straughn:** Conceptualization, Methodology, Resources, Supervision, Writing – review & editing. **Isabel C. Scarinci:** Conceptualization, Methodology, Supervision, Validation, Writing – review & editing.

#### Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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