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HPV vaccination, knowledge, and attitudes among young cervical cancer survivors in the Deep South

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ABSTRACT

Introduction: Although FDA approved for over 10 years, uptake of the human papillomavirus (HPV) vaccination has been slow, particularly among states in the Deep South with high cervical cancer incidence and mortality. The purpose of this study was to explore variables associated with cervical cancer among survivors who were age-eligible for the HPV vaccine and to assess HPV vaccination history, barriers, perceptions, and other associated behaviors within this cohort.
Methods: A mixed methods strategy was used for the study, first identifying eligible cervical cancer survivors from our institution and abstracting demographic and clinicopathologic medical record data. Twenty-three participants from this cohort then completed semi-structured qualitative telephone interviews regarding HPV vaccination participation, knowledge, and attitudes. Interviews were audio-recorded, transcribed, and analyzed using thematic content analysis.
Results: Of the 464 cervical cancer patients treated at our institution from 2011 to 2016, 137 (30%) were under age 40 at diagnosis. Seventy-seven women with invasive disease were identified (median age = 33 years), and 56% had been seen by a gynecologist within 5 years of diagnosis. Forty-six of these women met eligibility criteria for inclusion in the qualitative interview, of which 23 successfully completed (response rate = 50%). Of those interviewed, the majority (84%) reported current access to regular medical care. While 90.9% did not receive any doses of HPV vaccination, 78.3% stated they likely would have been vaccinated if it had been recommended. Four major themes were identified within the interviews: HPV knowledge, vaccine acceptability, healthcare engagement, and provider communication.
Conclusions: Qualitative interviews revealed significant missed opportunities for prevention since most participants stated they would have been vaccinated if given the option. Substantial gaps in knowledge and mixed understanding HPV's association with cervical cancer were observed, demonstrating potential missed opportunities for education and communication between providers of multiple specialties and their patients.

1. Introduction

Despite efforts to improve screening and vaccination strategies, cervical cancer remains a global health threat to women and affects a disparately young population of women compared to other gynecologic malignancies [1]. While rates have diminished in the US since the widespread adoption of the Pap test, there are still approximately 13,000 invasive cervix cancers diagnosed yearly with 4000 women succumbing to a preventable disease every year [1–3]. Incident cases in the US are not evenly distributed across the country, but rather geographically centered in high-risk regions of the country. The Deep South (Mississippi, Alabama, Georgia, Florida) is host to some of the highest cervix cancer incidences in the country [4] despite advances in knowledge regarding human papillomavirus (HPV) driven carcinogenesis and the subsequent development of prevention strategies. Among the

Abbreviations: AL, Alabama; COC, continuity of care; EMR, electronic medical record; FL, Florida; GA, Georgia; HPV, human papillomavirus; ICD, International Classification of Diseases; IRB, Institutional Review Board; MS, Mississippi; OB/GYN, obstetrician/gynecologist; PCP, primary care physician; Tdap, tetanus-diphtheria-pertussis; US, United States.

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hypotheses underlying this observation, not unlike what is studied in developing nations, is an increased rate of poverty within a rural, geographically sequestered and under-educated population with poor access to care [5]. The Deep South, specifically southern Alabama, is specifically an area of great concern for cervical cancer incidence and is characteristically the paragon of the Centers for Disease Control and Prevention (CDC's) non-metropolitan high risk region [4]. While understanding the regional characteristics underlying the increased incidences of cervix cancer is vital to eradicating it, the current study focuses on better defining this problem at the level of cervical cancer patients themselves.

US Food and Drug Administration (FDA)-approved in 2006, the HPV vaccine represents the greatest opportunity for the primary prevention of cervical cancer [6–8]. The most current, nonavalent iteration offers protection against 97% of infections with HPV-associated cervical cancers [6,9]. Unfortunately, HPV vaccine uptake has been slow across the US, especially among states in the Deep South [4,10]. Alabama is fifth in incidence and first in cervical cancer mortality in the US, coupled with the fact that only 50–59% of its adolescents have received one or more dose of the HPV vaccine [4,10]. This is substantially lower than rates of Alabama adolescents who have received at least one dose of the other recommended adolescent vaccines, Tdap and meningococcal, 91.7% and 72.4%, respectively [11]. Numerous barriers to HPV vaccination have been identified, including limited parental knowledge of the vaccine and/or the disease consequences, lack of healthcare provider recommendation, and limited medical care access [5].

As of 2017, the HPV vaccine has been FDA approved for over ten years [7,8]. Cervical cancer survivors born in or after the year 1980 would have been vaccine eligible well before their diagnosis. These survivors will be of significant importance in understanding motivations for and against HPV vaccination. The purpose of this study was to define characteristics, attitudes, and behaviors of a young cervical cancer survivor cohort treated in Alabama who were age-eligible for HPV vaccination in order to identify both missed vaccination opportunities and future primary prevention strategies.

2. Methods

Given the bimodal incidence of HPV infection cervical cancer with the first peak around age 35 [12], we aimed to identify and describe a cohort of young women from a single institution in a high incidence region reflective of the Deep South. Following IRB approval, utilizing ICD-9 & 10 data, we identified a cohort of women under age 40 years treated at our institution from 2011 to 2016. Demographic and clinicopathological data were abstracted from the electronic medical record (EMR), and semi-structured qualitative interviews of surviving patients was performed.

2.1. Retrospective cohort study

This phase of analysis consisted of a medical record review of young cervical cancer survivors. Variables recorded included: age, race, disease and treatment history (including gynecologic medical history), social history, and healthcare engagement/payor status. Vaccination history was collected when available. Descriptive statistics were calculated using Stata 14.2 software. Utilizing the Alabama vaccination registry, the most updated rates of HPV vaccine completion (2015–2016) within a 7 county referral region were gathered. These rates were then applied to our historical cohort of vaccine eligible cancer survivors to determine the efficiency of current vaccination strategies.

2.2. Qualitative interviews

Qualitative structured interviews were conducted via telephone to collect participant data not available in the EMR. These included: HPV vaccination status, knowledge of HPV and its vaccine, vaccine acceptability (including HPV), healthcare engagement, as well as additional medical/social information. Inclusion criteria for qualitative interview participants were: women treated for invasive cervical cancer between 2011 and 2016 at the authors' institution, born in or after 1980, currently living, English speaking, in good standing with the institution's gynecologic oncology practice, with up-to-date telephone contact information available in the EMR. Participants were randomized using their three-digit ID number prior to contact.

Upon successful contact and agreement to participate, verbal consent was obtained and the interview conducted. Informed consent and interviews were audio recorded using a digital recorder and then transcribed. Interviews lasted 15–25 min, and participants were compensated with a $20 gift card after interview completion. The interview process was complete once a full attempt (three contacts on separate days) was made to contact each eligible participant.

2.3. Qualitative interview analysis

Three of the study authors independently reviewed each interview transcript, noting thematic patterns. Analysis was conducted using thematic content analysis with the analytic phases including familiarization with the data, generating initial codes, coding transcripts, reviewing for and discussing themes and patterns, and naming and defining final domains and themes [13,14]. Four high-frequency motifs were identified and voted upon by study authors to be allocated as primary domains. Themes under each domain were then identified and voted upon in similar fashion. The frequency of comments pertaining to the identified themes was documented individually by each author and then openly discussed to reach a consensus. Comments were only determined to be associated with a given theme if all authors agreed in order to establish intercoder reliability [15]; one author served as moderator during this phase of analysis. Comment frequency was then totaled for final analysis and discussion.

A portion of identified themes was scored by assigning points to specific responses. Themes analyzed using this scoring approach included: perceived vaccine efficacy and importance, continuity of care (COC), and HPV vaccine knowledge. Participants who reported negativity towards vaccine efficacy and/or importance were assigned zero points ("low vaccine efficacy"), while responses that reflected neutrality were assigned a single point ("moderate vaccine efficacy"). Participants who responded positively towards vaccines were assigned two points ("high vaccine efficacy").

For COC, participants who reported currently having an OB/GYN physician were assigned a point. If the participant denied any OB/GYN medical care, they were assigned no points ("no" COC). If the participant confirmed seeing the same OB/GYN physician for one to three years they were assigned another point ("recommended" COC); two additional points were assigned if they confirmed more than four years ("high" COC).

HPV vaccine knowledge was evaluated by assessing responses to: recommended number of HPV vaccine doses, eligible age range for HPV vaccination, eligible population for HPV vaccination, and prevention purposes of HPV vaccine. A point was assigned to each of the above (maximum score = 4) if the participant provided a response with accurate information. A composite score of 1 – 2 was deemed "low vaccine knowledge" while a score of 3–4 was deemed "high vaccine knowledge".

Lastly, cervical cancer risk was scored based on combined participant EMR and qualitative interview data based on established risk factors [1,16]. One point was assigned for each of the following reported characteristics: African American race, sexual initiation at <20 years old, six or more sexual partners in lifetime, and/or having birthed three or more children. Additionally, one point was assigned to those with trade school/"some" college education, and two points were assigned to those reporting GED/high school diploma/"some" high school. One point was assigned to former smokers; current smokers were assigned two points. Points were totaled and each participant was assigned to a risk category based on her summed score (0–4 = "low risk," 5–8 = "medium risk," > 9 = "high risk").

3. Results

3.1. Retrospective quantitative cohort study

Seventy-seven women with invasive cervical disease under age 40 were identified and demographic data is noted in Table 1. The median age of this cohort was 33 years, the majority of cases were squamous cell carcinoma (75%, n = 59), and 25% (n = 20) had stage IB2 disease. The majority were White (n = 48, 65%) and African American (n = 20, 27%). Nearly 50% of women (n = 38) underwent hysterectomy (simple or radical) and 40% (n = 31) received concurrent chemotherapy and radiation. Within our cohort, based on age at diagnosis, 69% (n = 55) were eligible to receive the HPV vaccine based on their age in 2006, when the vaccine first gained FDA approval. In regards to access to cancer care, only 15.5% of patients were unfunded with the vast majority having either private (44%) or state-funded insurance (34%). Notably, 56 (72%) of patients in our cohort had documentation of a medical encounter with a gynecologist within 5 years of diagnosis. At present, 92% (n = 71) of our cohort has survived their diagnosis with a median of 14 months of follow up.

Table 1
Participant demographic characteristic.

Variable	N (%)
Current age (years)*	33.5 (32.5–34.5)+
Age in 2006 (years)	22.6 (21.5–23.6)+
Race	
African American	6 (28.6)
White	15 (71.4)
Insurance type	
Self-pay	3 (13.0)
Medicaid	7 (30.4)
Private	13 (56.5)
State of residence	
Alabama	16 (69.6)
Florida	2 (8.7)
Mississippi	4 (17.4)
North Carolina	1 (4.4)
Age of sexual initiation (years)	16.7 (15.9–17.6)+
Number of sexual partners	6.9 (5.1–8.8)+
Number of children	1.7 (1.0–2.3)+
Education level	
High School/GED	5 (21.7)
Some College/Trade School/Associate's	8 (34.8)
College Degree	6 (26.1)
Master's Degree or Higher	4 (17.4)
Smoking status	
Never	15 (65.2)
Former	4 (17.4)
Current	4 (17.4)
Stage of diagnosis	
Stage I	17 (73.9)
Stage II	4 (17.4)
Stage III	2 (8.7)
Age at diagnosis (years)	29.6 (28.3–30.8)+
Received HPV vaccine	
Received complete course	0 (0.0)
Received at least 1 dose	2 (8.7)
Never received	21 (91.3)

* At time of interview.
+ 95% Confidence interval.

The 2015–2016 Alabama HPV vaccination rates were collected from the state vaccination registry, ImmPRINT. The last complete year of available data was from 2015 where completion rates were significantly improved state-wide over the previous 5 years, approaching 40% in males and females [17]. In an attempt to quantify the impact of poor vaccination strategies in a high incidence region, the 2015 HPV vaccine completion rates from our 7 county referral region were compiled. Strikingly, despite the increases in vaccine uptake state-wide, receipt of > 2 doses of the vaccine in our geographic region was a dismal 7% based on the registry data. As can be extrapolated from this data, current vaccination rates in our at-risk region are so low that a highly effective cancer prevention vaccine fails to prevent one single case of invasive cervical cancer due to underutilization. Interestingly, our findings suggest that these patients are highly likely to have completed Tdap and meningococcal vaccination and have seen an obstetrician-gynecologist within 5 years of their cancer diagnosis. The discrepant behaviors in regards to vaccine uptake and healthcare engagement fail to elucidate why HPV vaccine uptake remains so poor in this area. We therefore turned to the patients themselves in a systematic manner to better understand the obstacles to successful prevention.

3.2. Participant characteristics

Of the 68 women identified through EMR abstraction, 46 met eligibility criteria for qualitative interviewing. Of those, 23 interviews were completed (response rate = 50%) (Fig. 1); however, one participant was excluded from qualitative analysis due to lack of sufficient data provided. Only two participants had received one or more doses of the HPV vaccine; none reported completing the series. The majority of study participants reported low or average risk behaviors [1,16]. Average age of sexual initiation was 16.7 years, the average number of lifetime sexual partners was 7, 65.2% of participants reported never smoking, and 78.3% obtained above a high school education (78.3%). Detailed participant demographics are provided in Table 1.

3.3. Primary domains and themes

The four primary domains identified through qualitative data analysis were: HPV knowledge, vaccine acceptability, healthcare engagement, and provider communication, with several themes within the domains also determined. A total of 149 comments associated with the four domains were identified through coding. Table 2 illustrates the identified domains, themes, and comment frequency for each. A selection of exemplar quotes within the domains/themes is provided in Table 3.

Domain 1: HPV Knowledge

HPV knowledge (or lack of) was noted among all 22 participants (100%). Three notable themes were categorized under this domain: participant association between HPV and cancer, "low" HPV knowledge, and a stated reaction to HPV diagnosis. HPV knowledge was deemed "low" if participants demonstrated misconceptions regarding HPV or indicated a lack of awareness that HPV is a sexually transmitted infection (n = 8, 36.4%). This low knowledge was further reflected among several participants' perceptions of the viral pathogenesis of HPV. One participant specifically said she "did not know it existed" until after her cancer diagnosis. Several

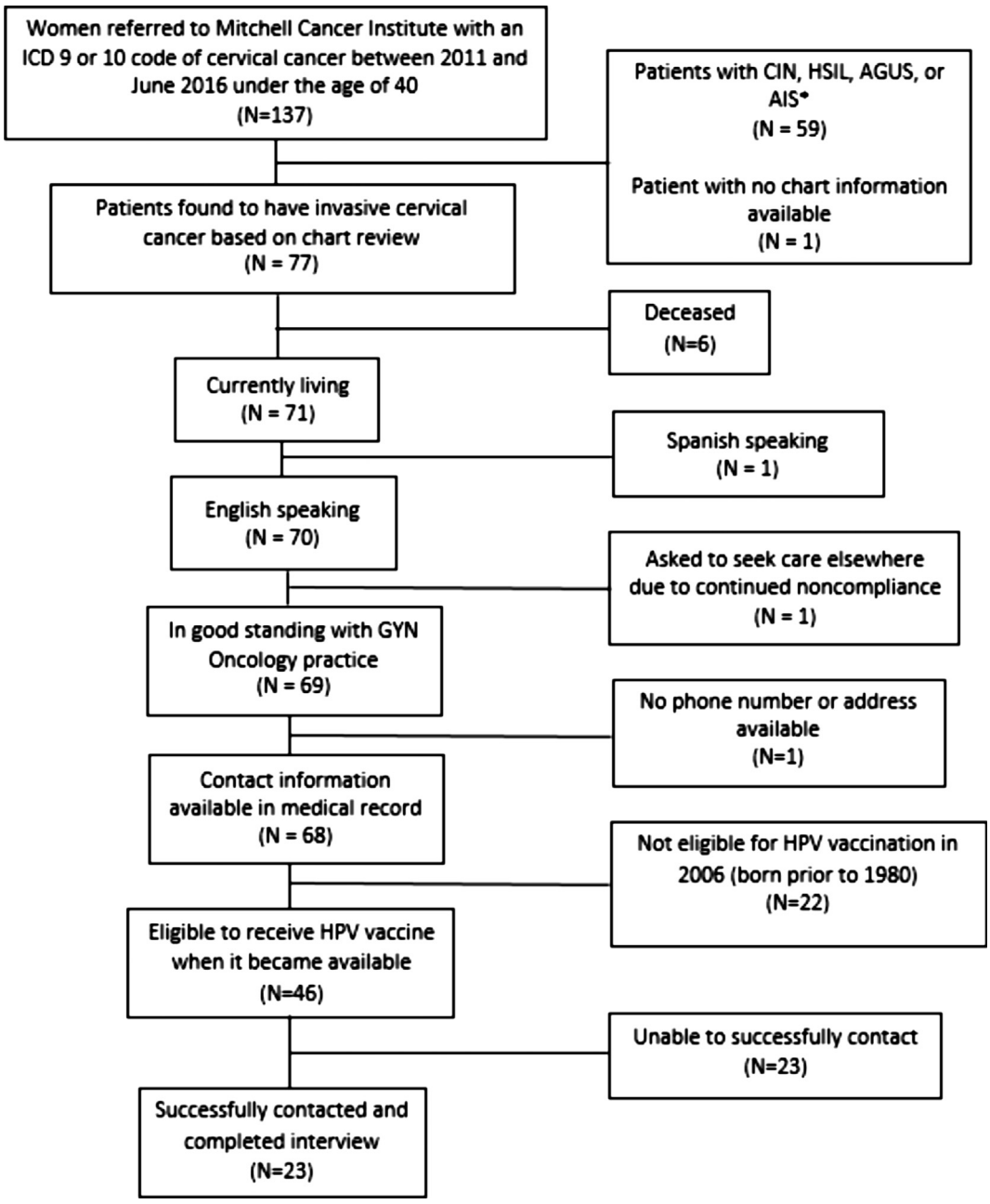

Fig. 1. Inclusion and exclusion flowchart. *CIN = Cervical Intraepithelial Neoplasia; HGIL = High Grade Squamous Intrepithelial Lesion; AGUS = Atypical Glandular Cells of Undermined Significance; AIS = Adenocarcinoma In Situ.

participants provided inaccurate information about the HPV virus. One participant stated that HPV is "a muscle," while another had identified HPV as "a hormone." Another participant stated that "everybody has some form of HPV in them," while another participant believed she contracted HPV "from the birth control I was using." Thirteen participants (86.7%) described experiencing an emotional reaction after being diagnosed with HPV. The emotional reactions that were reported were consistently negative, ranging in intensity, including embarrassment, anger, denial/disbelief, and shame. Other participants, however, lacked any kind of reaction, and some reported indifference and the perception that infection with HPV was an inevitability.

Domain 2: Vaccine Acceptability

Participants varied in their acceptability of vaccines and the HPV vaccine, specifically. This domain was supported by positive or negative statements regarding vaccination made by 20 participants (90.9%). Additionally, each participant was asked if they would have consented to HPV vaccination if offered when they were age eligible; n = 16 (72.7%) stated that they would have been vaccinated if offered. Three notable themes were categorized under this domain: mothers' inclination to have children immunized (particularly for school-required vaccines), negative perceptions of vaccines, and noted sources of information regarding vaccines. Sixteen participants in the study (72.7%) were mothers, and all confirmed that their child(ren) had received at least school-required vaccinations. Seven participants (31.8%) expressed negative perceptions towards vaccinations, citing fears of harmful side effects or doubt regarding vaccine importance and/or efficacy; five of these participants were mothers. Ten participants (45.5%) volunteered sources of information regarding HPV which included television, internet/social media, and physicians.

Table 2
Frequencies of primary domains and themes.

Primary domain/theme	Frequency of comments	Percent of total comments	Frequency in relevant population N of N participants (%)
HPV knowledge			
Makes the connection of HPV and cancer	20	48.8%	20 of 22 (90.9%)
"Low" HPV knowledge	8	19.5%	8 of 22 (36.4%)
Reaction to HPV diagnosis	13	31.7%	13 of 15 (86.7%)
Total comments	**41**	**27.5%**	
Vaccine acceptability			
Most have children vaccinated, especially for those not required in school	16	48.5%	16 of 16 (100%)
Negative perceptions of vaccine	7	21.2%	7 of 22 (31.8%)
Sources of Information	10	30.3%	10 of 22 (45.5%)
Total comments	**33**	**22.1%**	
Healthcare engagement			
Insurance affecting care/barrier	5	17.9%	5 of 22 (22.7%)
Differences before and after cancer	16	57.1%	16 of 22 (72.7%)
Oncologist perceived as OB/GYN or PCP	7	25.0%	7 of 22 (31.8%)
Total comments	**28**	**18.8%**	
Provider communication			
Mothers more knowledgeable of HPV vaccine	14	29.8%	14 of 16 (87.5%)
Participant associates HPV with their cervical cancer	11	23.4%	11 of 22 (50.0%)
High medical knowledge	8	17.0%	8 of 22 (36.4%)
Moderate medical knowledge	3	6.4%	3 of 22 (13.6%)
Low medical knowledge	2	4.3%	2 of 22 (9.1%)
Insufficient evidence of medical knowledge	9	19.1%	9 of 22 (40.9%)
Total comments	**47**	**31.5%**	

Domain 3: Healthcare Engagement

Specific questions investigating healthcare engagement were asked of participants in order to assess healthcare utilization patterns, potential barriers to healthcare, as well as continuity of care (17 participants, 77.3%). Three main themes were categorized under this domain: insurance coverage, differences in healthcare engagement before and after cancer diagnosis, and participant perception of oncologist as their primary care provider (PCP) or OB/GYN physician. Although insurance was not specifically asked about, five women (22.7%) discussed insurance coverage being an influencing factor over their medical care. Cervical cancer patients are encouraged to be evaluated by a healthcare provider more frequently in the years following their diagnosis and treatment [18], medical advice adopted by 16 participants (72.7%) who confirmed differences in number of medical visits and/or screenings post-diagnosis compared to pre-diagnosis. Of those who noted a change in medical visits after their cancer diagnosis, the majority (n = 14, 87.5%) reported more frequent visits. Seven participants (31.8%) reported strictly seeing their oncologist for all of their medical needs and failed to identify a current PCP or OB/GYN.

Domain 4: Provider Communication

Themes related to information that participants received from healthcare providers represented a majority of comments in the study (22 participants, 100%). Three notable themes were categorized under this domain: higher knowledge of the HPV vaccine among mothers, participant association of HPV with her own cervical cancer diagnosis, and level of general medical knowledge. Of the 16 mothers in the study, 14 (87.5%) presented with knowledge of the HPV vaccine. While 20 (90.9%) of the women asserted that HPV causes cancer in general, only 11 (50.0%) associated HPV with their own cancer diagnosis.

Medical knowledge was evaluated based on responses consisting of appropriately used medical terms (i.e. "cervix", "lab", "cells") or correct description of procedures (i.e. "pap smear", "biopsy", "blood work"). Participants who provided no medical terms or information on procedures were scored as having "low knowledge" (n = 2, 9.1%). Participants who provided some medical terms and few/no elaboration on procedures were categorized as "moderate knowledge" (n = 3, 13.6%). Participants with proficient use of medical terms and high elaboration on procedures were categorized as "high knowledge" (n = 8, 36.4%). Some participants failed to provide sufficient evidence of medical knowledge (i.e. answering "yes" to questions gauging knowledge without elaboration on terms/procedures, or not providing a response), prohibiting classification of their medical knowledge (n = 9, 40.9%).

3.4. Qualitative Theme Scores

Regarding vaccine efficacy, the majority of participants expressed "high" beliefs (n = 12, 57.1%). Similarly, most participants indicated a "high" belief in vaccine importance (n = 17, 77.3%). Participants were distributed fairly evenly across measures for COC with n = 7 (31.8%) reporting "high" COC, n = 8 (36.4%) confirming "recommended" COC, and n = 7 (31.8%) denying any OB/GYN care ("low" COC). For knowledge of the HPV vaccine, the majority of participants demonstrated "high" vaccine knowledge (n = 18, 81.8%). Regarding cervical cancer risk, most participants were categorized as having "medium" risk (n = 16, 69.6%) based on their risk factors. As mentioned previously, each candidate was asked if they would have received the HPV vaccine if given the opportunity. These were analyzed using each participant's specific risk score. Three participants (18.8%) in the "low" risk group, 12 (75%) in the "medium" risk group, and 1 (6.3%) in the "high" risk group would have received the vaccine. Of these, more medium risk patients would have been vaccinated. Full qualitative scale results are provided in Table 4.

4. Discussion

This study is the first to specifically analyze cervical cancer patients that were eligible to receive the HPV vaccine. Our study

Table 3
Primary domains/themes and exemplar quotes.

Domain (comment frequency)	Theme (comment frequency)	Exemplar quotes
HPV knowledge (n = 41)	Makes the connection of HPV and cancer (n = 20)	"…certain strands do cause the cervical cancer."
		"It increases your risk of cancers."
		"…it can cause most cervical cancers."
		"…it can lead to types of cancer, specifically cervical cancer."
		"It causes a viral disease that cause abnormal cells …which can lead to cancer if it's not treated"
		"It leads to cancer…if it's left untreated. And it's sexually transmitted."
		"…it is the leading cause of cervical cancer…Most people come into contact with it at some point in their life, but more often than not…most people's immune systems fights it off. And if the immune system doesn't fight it off, then it develops into diseases such as cervical cancer."
	"Low" HPV knowledge (n = 8)	"…I think HPV is called I think a muscle…"
		"…it is uh something that now they found that that grows in the body that can cause cancer…"
		"Somebody was saying they think it was caused due to the birth control I was using…"
		"I just know everybody has some form of HPV in them."
		"…[the HPV vaccine] helps to control whatever the hormone is in the body it controls it or kills it"
		"I did not know it existed until after I was diagnosed"
	Reaction to HPV diagnosis (n = 13)	"It didn't bother me 'cause I knew it was something common…so I figured it would happen."
		"…it was the worst thing I've ever had to go through in my entire life… I was very scared."
		"…it was kind of a shock."
		"I was puzzled…"
		"Horrified!… Ashamed. Sad. Horrible…. Awful."
		"…scared."
		"Emotional."
		"…I would say annoyed mostly, a little grossed out…"
		"Mad."
Vaccine acceptability (n = 33)	Most mothers have children vaccinated, especially for those not required in school (n = 16)	"…I volunteered to have [the HPV vaccine] done for my son because I had HPV myself."
		"…since I'm a cancer survivor, I promote them to getting the HPV vaccine so …he won't go through what I went through…"
		"…my stepdaughter also got the vaccination for [HPV vaccine]…"
	Negative perceptions of vaccine (n = 7)	"I know it's supposed to prevent cervical cancer, but I also know that there has been some people I know recently that's had side effects when they got the shot so I don't know."
		"…I was told that it could be harmful."
		"…it causes harm to younger girls."
		"…I'm not one just to take a vaccine because it's offered…maybe if I researched more."
		"I'm just not too fond of vaccinations for myself."
		"…I don't like vaccines."
		"…I think there is a lot of harm in [vaccines]…"
	Sources of Information (n = 10)	"I've heard of it on commercials."
		"…something I read on Facebook."
		"I learned about it in school."
		"…I [have] seen it on TV."
Healthcare engagement (n = 28)	Insurance affecting care/barrier (n = 5)	"…I missed some years [of testing] because I didn't have insurance."
		"…they wouldn't do anything until I had insurance."
		"…I wish I had, I had been able to go to the doctor more often so they could have caught it earlier."
		"…my medical history was/has been up and down only because I didn't have insurance for a few years."
		"…[treatment] took a while because my insurance has [lapsed]…"
	Differences before and after cancer (n = 16)	"…but now after my diagnosis and my treatment I go once a year."
		"…just one time every year and then it went to two times after I, um, went through all those treatments and everything."
		"[before cancer] Once a year…[after cancer diagnosis] once every three months."
		"Now, every year… [before cancer diagnosis] I wasn't doing it as often. Before I got diagnosed I hadn't been for 5 years."
		"I guess prior to my cervical cancer, I was screened annually, and then now I'm screened a few times a year."
	Oncologist perceived as OB/GYN or PCP (n = 7)	"…right now my…gynecologist is my oncologist."
		"…I have access to a gynecologist, but by me…having cancer, they make me go and see a gynecologist oncologist all the time."
		"[I receive my regular healthcare] just at [the cancer center]."
Provider communication (n = 47)	Mothers more knowledgeable of HPV vaccine (n = 14)	"…I didn't understand what HPV was, uh, because at the time they was just telling me that was the reason why I got cancer…So I didn't really know much about it…until I read about it for my son."
	Participant associates HPV with their cervical cancer (n = 11)	"[I learned about HPV] when I found out about [my cervical] cancer"
		"…that's what caused my cervical cancer."
		"Whenever they told me that I had cancer, they it was …a bad strain of HPV caused it."
		"…I assumed that's what caused my cancer, but I guess the gynecologist never told me…"
		"No, nobody ever tells me."

findings indicate substantial missed opportunities for primary prevention of HPV-driven pathogenesis as well as for patient education and provider communication. We identified a group of patients who, despite having access to medical care including both well-women gynecologic care and adherence to other vaccination schedules, failed to receive the HPV vaccine and went on to develop an invasive cervical cancer. Clearly, the nature of a retrospective chart review is limited in regards to informing us as to the nuances of HPV vaccine acceptance, especially in the early days of its availability. What is striking, however, is that despite a decade of availability, HPV vaccine uptake in the regions at highest risk has not appreciably changed. While this may be a function

Table 4
Qualitative analysis scores and retrospective vaccination decisions.

Variable		N (%)	Would have been vaccinated N (%)	Would not have been vaccinated N (%)
Efficacy of vaccines				
	Low	2 (9.1)	2 (13.3)	0 (0)
	Moderate	7 (33.3)	3 (20.0)	4 (66.7)
	High	12 (57.1)	10 (66.7)	2 (33.3)
	Total	21 (100.0)	15 (100.0)	6 (100.0)
Importance of vaccines				
	Low	1 (4.6)	1 (6.3)	0 (0.0)
	Moderate	4 (18.2)	3 (18.8)	1 (16.7)
	High	17 (77.3)	12 (75.0)	5 (83.3)
	Total	22 (100.0)	16 (100.0)	6 (100.0)
Continuity of care				
	No COC	7 (31.8)	5 (31.3)	0 (0.0)
	Recommended COC	8 (36.4)	5 (31.3)	1 (16.7)
	High COC	7 (31.8)	6 (37.5)	5 (83.3)
	Total	22 (100.0)	16 (100.0)	6 (100.0)
Knowledge of HPV vaccine				
	Low Knowledge	4 (18.2)	13 (81.3)	3 (75.0)
	High Knowledge	18 (81.8)	3 (18.8)	1 (25.0)
	Total	22 (100.0)	16 (100.0)	4 (100.0)
Risk score				
	Low (0–4)	3 (13.0)	3 (18.8)	0 (0.0)
	Medium (5–8)	16 (69.6)	12 (75.0)	4 (66.7)
	High (9+)	4 (17.4)	1 (6.3)	2 (33.3)
	Total	23 (100.0)	16 (100.0)	6 (100.0)

of the accuracy of a state-wide registry, the completion rates in other more urban areas in the state have improved [11]. Therefore we conclude that current strategies to promote the vaccine are still missing patients at high risk of developing disease and these patients appear to be centered in more rural areas of the state. The reasons for this disparity are difficult to define through a retrospective review. We therefore addressed the limitations of our retrospective investigation through a systematic, qualitative approach wherein cervix cancer survivors in whom vaccine eligibility predated their diagnosis were surveyed as to their attitudes and behavior towards the HPV vaccine.

Confirming our retrospective data, the majority of women reported regular access to medical care. However, most participants held misconceptions in regards to the HPV's causative role regarding cancer, with many not making the connection between high risk HPV infection and the direct cause of cervical cancer. Despite this, most of our survivors, at least retrospectively, report that they would have gotten the vaccine if it were offered when the vaccine was first available to them.

Participants' low knowledge of HPV indicates a significant gap in provider-patient communication. Over one-third of participants were unable to describe the basic transmission and consequences of HPV. Of those who demonstrated some knowledge of the virus, over half did not indicate an understanding of the probable connection between HPV and their own cancer. Many participants underwent multiple exams, procedures, and other specialized medical visits with an OB/GYN and/or oncologist prior to and following diagnosis, providing numerous opportunities for patient education. Therefore, this lack of knowledge indicates that these opportunities were missed or presumed to have been covered by other provider(s). The majority of participants indicated a desire to know and understand more regarding the etiology of their cancers and other medical information, implying that this gap is not due to patient disinterest. The majority of participants identified their oncologist as their current primary physician, prioritizing the responsibility specialists equally share with PCPs over the health education of their patients [19]. Unfortunately, few participants cited a healthcare provider as their source of information regarding the HPV vaccine. This finding indicates a significant gap in provider care given that previous studies have shown that provider recommendation is crucial for vaccine uptake [5,20]. HPV vaccine education among medical personnel has been previously shown to be a reliable motivator to increase vaccination uptake among patients [21,22]. Berenson et al. postulated that by increasing educational presentations on disease epidemiology and the HPV vaccine among medical personnel (including physicians, residents, nurses, and students), the quality of HPV counseling for patients can be improved [23]. This is a tactic that could be considered for future communication interventions among providers.

The HPV virus and subsequent cervical cancer can be directly prevented through vaccination, a unique protective factor compared to other cancers affecting women. Informed and educated survivors could be powerful advocates to increase HPV vaccination rates among current adolescents and young adults, utilizing personal experiences and community engagement as potential vaccination promotion strategies. Cancer survivors have historically demonstrated high advocacy potential [24]. However, a portion of this study population does not understand the causation of and preventive actions for their disease (specifically HPV vaccine), a quality similar to previous findings among cervical cancer survivors [25]. While advocacy willingness has been found to be high among similar groups [25], a portion of this population of cancer survivors are unable to serve as effective advocates secondary to a lack of understanding of their own disease process. By closing gaps in provider communication and patient education [26], though, cervical cancer survivors may be provided with important and relevant information and be empowered to share their personal stories. In doing so, survivors can encourage others to take preventative measures through HPV vaccination and ultimately contribute to the reduction of cervical and other HPV-associated cancers.

4.1. Limitations

While the qualitative aspect of this study enabled an in depth study of the participants, the sample size was small. Some participants were close to the maximum eligible age when the HPV

vaccine was first introduced. Therefore, they may not have had the opportunity to become vaccinated because their healthcare provider was not fully aware of it and/or may not have had access to it during their window of eligibility. In addition, some healthcare providers wait for a new vaccine to be available for a given period of time before recommending it to their patients [27]. These interviews were conducted verbally and not in written format. Although the interviewers had a script available during interviews, there were times when the questions were not read verbatim from the script, which could have affected the responses from the participants.

5. Conclusion

Informed and educated cervical cancer survivors have great potential to serve as powerful advocates to increase HPV vaccination rates, utilizing personal experiences and community engagement as potential vaccination promotion strategies [24,25]. This study concluded that the majority of women demonstrated knowledge regarding the HPV virus, HPV vaccination, and the role of HPV in cervical cancer. Despite this, there were still participants who did not fully understand HPV, making it difficult to effectively explain the importance of HPV vaccination in cervical cancer prevention. There were significant deficits present in relating this knowledge to their own cancer process, highlighting a gap in health communication. Some participants expressed concerns over safety and ineffectiveness regarding the HPV vaccine, highlighting other perceptual barriers against vaccine advocacy. This study is among the first to explore vaccine-eligible cervical cancer survivors' knowledge, attitudes, and behaviors; factors that can influence the vaccination decisions among other women who could otherwise be spared from cervical cancer diagnosis. Therefore, continued educational efforts are needed among both providers and survivors in order for these women to fully realize and reach their advocacy potential.

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Conflicts of interest

None of the authors report any conflicts of interest.

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