

Understanding Barriers to HPV vaccine uptake in Appalachia

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Abstract

Every year in seven small counties of Ohio seventy-six people lose their lives to a completely preventable Human Papillomavirus-related cancer. These counties are not random, nor are they an anomaly. All seven are considered to be within the Appalachian region of the United States, which, despite holding a little less than one-tenth of the total population, has the highest cancer mortality rates in the country. The term Appalachia describes the counties surrounding the Appalachian mountain range in the eastern United States. Here, rates of Human Papillomavirus (HPV), vaccine uptake are lower than in other areas of the United States. This study seeks to examine, using the 5 A's of Healthcare Access framework (Affordability, Accessibility, Accommodation, Acceptability, and finally Availability) why, despite there being a viable vaccine, rates of uptake remain low using the seven aforementioned counties as a sample. In using a mixed methods approach, the study integrates existing research from major public databases with the direct input of medical professionals gathered via survey. The professionals were asked for their opinion on the impact each of the Five A's of Healthcare Access have on their patients, using data from 2018-19. Through analyzing their answers, as well as related research, the study hopes to provide important information on HPV-vaccine barriers for further programs to use in order to lower the number of preventable deaths.

Keywords HPV Vaccine – Appalachian Region – Health disparities

Introduction

Background

HPV is a sexually transmitted virus so common that nearly all men and women in the United States will contract it in their lifetime (CDC, 2019). Several of the 150 different strains, most notably strains 16 and 18, are cancer-causing (CDC, 2019). Some types of cancer-causing

HPV strains show up as genital warts in the early stages, acting as a kind of warning system, but most types of cancer-causing HPV strains show no symptoms until they cause health problems (CDC, 2019). Those cancer-causing strains are responsible for about 35,000 penile, cervical, anal, vaginal, vulvar, oral, and pharynx cancer cases in the United States each year (CDC, 2019). The HPV vaccine, first approved by the FDA in 2006, has proven extremely effective in preventing these strains from infecting the body and causing these cancers (Franco et al, 2015). The vaccine is widely considered the only way to protect yourself from HPV because it has been proven that other methods of protection (i.e. condoms) are not effective in preventing the spread of the disease (Franco et al, 2015).

All across the United States HPV vaccines have become a more regular occurrence at doctor's offices as knowledge about the virus grows. In the Appalachian region of the United States, this has not necessarily been the case (CDC, 2017). Appalachia is defined by its proximity to the Appalachian Mountain range in the southeast of the United States. The region is expansive, covering 13 states with a population of about 25 million people, which is roughly 13% of the United States population (Appalachian Regional Commission, 2018). Appalachia is largely rural with a culture that values independence, family, and religion (Behringer and Friedell, 2006). In addition to these strong traits, Appalachia struggles with high poverty rates, lower levels of education, and poorer health than the rest of the United States (Reiter et al., 2012).

Because of the consistently poor health outcomes, Appalachia is often studied to understand what factors are influencing these results. In particular, the rates of cancers caused by HPV, most notably cervical cancer, are consistently higher in Appalachia than in any other region (Reiter et al., 2012). This study chose to focus on seven specific counties within

Appalachian Ohio: Vinton, Meigs, Gallia, Highland, Jackson, Pike, and Athens counties. These were chosen for their proximity to the study's location at The Ohio State University. These counties range from "At-Risk" economic status to "Distressed" as classified by the Appalachian Regional Commission (2018). This only means that in these specific counties barriers to healthcare might more often include the cost of the vaccine and travel to offices.

These counties also all have a significant population of people under 18 (an average of 21.6% of total population per county) (Appalachian Regional Commission, 2018). Meaning that a significant portion of the populations of these counties a of their population is within the age group that the CDC recommends should be getting the vaccine (CDC, 2020). To analyze the level of access this population has to the HPV vaccine, the study will use the "Five A's of Healthcare Access" framework; these A's include Accessibility, Accountability; Acceptability, Affordability, and Availability (Wyszewianski, 2002).

The literature on healthcare barriers in Appalachia is expansive because the area has long struggled against the issue of health inequity. There are many different reasons that this area struggles more than others with health inequity. Culturally, Appalachian people tend to be more comfortable doing things themselves, which impacts their access to medical care (Behringer and Friedell, 2006). One study conducted in Tennessee in 2011 sought to better understand the extent that Appalachian cultural values influenced a woman's decision to learn more about, and receive, the HPV vaccine (Hutson, Dorgan, Duvall, & Garrett, 2011). Their study noted that focus group participants were uncomfortable talking about something so personal in public (Hutson, Dorgan, Duvall, & Garrett, 2011). Behringer and Friedell (2006) suggest in their study analyzing the impact of "place" on health that communication is a key factor in building trust between the community and the physicians. With trust, Behringer and Friedell found that community

members, who at one point “reported that they gain most of their information about cancer from family, neighbors, and friends” were more willing to listen and integrate information from their doctors into their lives (2006). These studies have identified cultural values and communication as barriers that are somewhat self-imposed, but with work from physicians and community members, are able to be overcome.

Other studies cite cost as a major barrier for Appalachian families. Much of Appalachia is economically distressed, making paying for vaccines, medicines, and office visits difficult for some families (Appalachian Regional Commission, 2018). A study done in 2013 by Shelley Francis and Mira Katz considered cost a major “prohibitive” factor when it comes to families receiving the HPV vaccine. To try and overcome the barrier of cost, the CDC created the federally funded Vaccines for Children Program (VFC). The VFC program covers the cost of vaccines for people under the age of 18 who are uninsured or cannot afford the vaccine (CDC, 2016). In Appalachian Ohio about 13.9% of the population is uninsured (Appalachian Regional Commission, n.d.). The current study intends to survey medical offices to see if they accept and use the VFC program, to understand its effectiveness in removing the affordability barrier.

Physical accessibility is another barrier to medical care in Appalachia; much of the region is rural, and doctor’s offices are often far from their patients (Syed, Gerber, and Sharp, 2014). Barriers related to transportation mean more people make appointments, but fail to keep them, delayed care, or absence of care (Syed, Gerber, and Sharp, 2014). This lack of consistent care due to unreliable transportation has a detrimental effect on long-term health, and in the context of this study, possibly HPV vaccination rates (Syed, Gerber, and Sharp, 2014).

Methods

Study Description and Design

The study will use an observational design. The study is labeled an ecological study as it seeks to understand the level of access people from the Appalachian population have to the HPV vaccine, and what barriers increase the risk of not receiving the vaccine. The level of access will be determined using the 5 A's of Healthcare Access Framework by analyzing Acceptability, Affordability, Accommodation, Availability, and Accessibility. This design was selected because of its ability to help the study answer the research question: what level of access do Appalachian families have to the HPV vaccine, and to what extent does that impact the likelihood they get the vaccine? The study will analyze secondary data from public databases including health departments, private pediatric doctor's offices, walk-in clinics, and pharmacies, as well as collect primary data through a phone survey administered to medical professionals or staff members within the clinic capable of answering the survey questions. The survey will target those living within seven Appalachian Ohio counties: Meigs, Vinton, Pike, Gallia, Athens, Jackson, and Highland.

The selected counties are located in Appalachian Ohio, which is in the southeastern part of the state. While the study cannot feasibly cover all 32 counties, it will examine the level of healthcare accessibility and specifics of vaccine coverage in the aforementioned southeastern Ohio counties. The surveyor has access to the counties through another research study currently being conducted. The survey will ask for data on HPV uptake, availability, and costs from 2018.

The study will analyze secondary data, as well as collect primary data through a survey administered to members of the medical professional community. The survey will be conducted by phone or email, and every response will be recorded through an online Qualtrics platform. The data will then be analyzed using Excel. Secondary data will be collected via public databases like the Center for Disease Control, the Appalachian Regional Council, and the National

Immunization Surveys. Using the 2018 data, the study will be able to better understand the context of the vaccine uptake numbers before asking members of the Appalachian medical professional community directly.

The information gathered by the survey can help to inform further programs on an Appalachian family's level of access to the HPV vaccine, as well as to what extent each "A" impacts their access to the vaccine.

Data Collection Strategy

Every family doctor, pediatrician, public health department, and pharmacy within the study area will be surveyed, and they will complete the survey either by phone or online. The study intends to have at least 50 offices per county, for a total of 350 offices surveyed. The study will offer no incentives for participation.

Tests, Instruments and Measures

Variables

The independent variable of the study is the level of access an Appalachian family has to the HPV vaccine. The study will use several dependent variables to determine is the level of access, using the 5 A's of Healthcare Access Framework. The first "A", Accessibility, will be measured by mapping the surveyed offices to determine how far members of the community must travel to reach them. The second "A": Affordability, will be measured by asking the offices about their administrative fees, and whether they accept the Vaccines for Kids program. The third "A", Accommodation, will be measured by asking if the office recommends the vaccine. The fourth "A", Availability, will be measured by asking whether they have the vaccine or not, and how many they administered in 2018. The fifth and final "A", Acceptability, will be

measured by asking the professionals their opinion on the impact that stigma has on family's willingness to receive the vaccine.

Data and Instruments

A survey will be given to each doctor's office, with 7 closed-ended questions, and 3 likert-scaled questions about their office's administrative costs, whether they provide and recommend the vaccine, the stigma attached to HPV and what they think are the most influential barriers to care. This survey can be found in Appendix 1. Before completing the survey every office will be read an informed consent script (Appendix 2). Once they have consented, they will be administered the survey. In addition to these surveys, locations of the offices will be mapped to better understand where offices are located, and what impact their locations may have on access to care. That way the survey can get clear answers to questions regarding the uptake of the vaccine, and there will be a place for them to share their experiences. The survey will take 10-15 minutes. If the surveyor is clear with their language, and quick to clarify if they feel something is misunderstood, mistakes will be kept at a minimum.

Data Analysis

This study will use descriptive analysis to describe what is happening to keep people from care in Appalachia. In addition, the study will use comparative analysis to identify the degree to which each barrier affects the uptake rates, then compare them to one another to see which plays the greatest role. The results will be categorized using the 5 A's of Healthcare Access Framework (Wyszewianski, McLaughlin 2002).

Results

As the survey interviewed medical professionals, they were given the opportunity to elaborate on any of their answers regarding the impact of travel, stigma, and cost on their patients’ decisions to vaccinate their children.

Twenty doctors’ offices, pharmacies, and public health departments agreed to participate in the survey of the sixty contacted for a response rate of 30%. These offices are located in seven counties of Appalachian Ohio: Vinton (5% of responses), Meigs (11%), Highland (11%), Athens (32%), Pike (5%), Gallia (11%), and Jackson (26%). These medical professionals were surveyed in order to assess how much, and in what ways, Appalachian people experience barriers to receiving the HPV vaccination.

The study used the 5 A’s of Healthcare Access: Accessibility, Accommodation, Acceptability, Affordability, and Availability framework as cited by Wyszewianski and McLaughlin in 2002 to categorize the findings.

Affordability

On average, the administrative cost of an office visit was \$40, but the results ranged from zero dollars to two-hundred and forty, with the most common cost being zero because of insurance. Those who are uninsured, however, are most frequently paying a

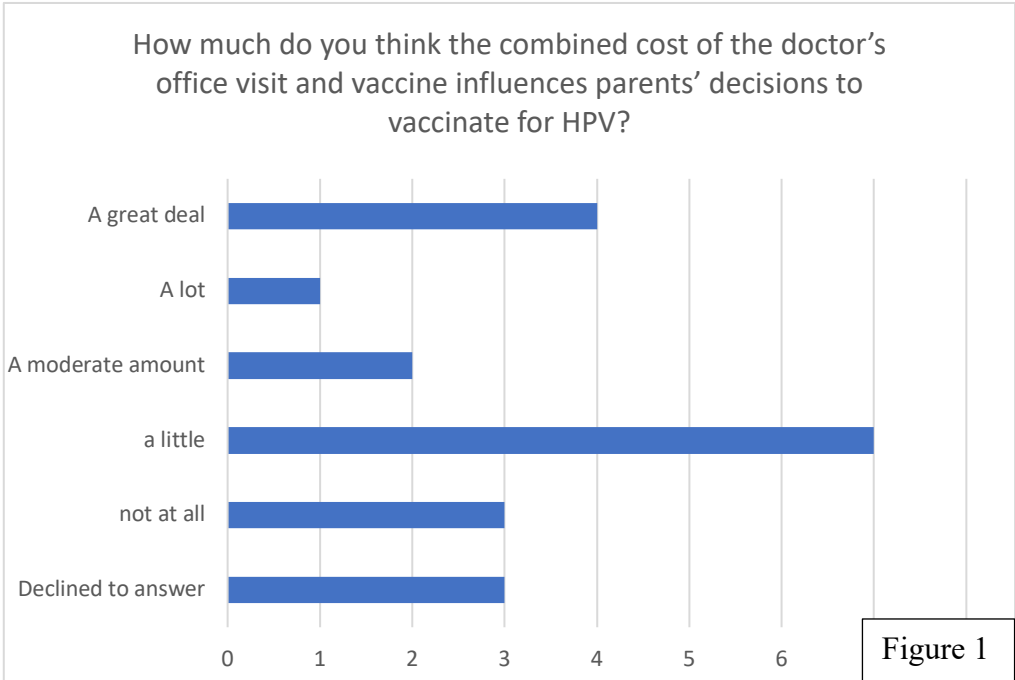


Figure 1

\$20 co-pay, which when asked about the impact of cost, one office said makes the visit a “no-go”. One medical professional disagreed, arguing that “It's not the cost in my opinion that deters the vaccine approval, it's lack of knowledge”.

Most of the offices mentioned the impact of insurance coverage on vaccine uptake, saying that “If there is even a chance that the insurance won't pay, they [parents] will not give permission”, and “parents won't pay for vaccines if they haven't hit deductible”. Insurance, outside the actual cost of the vaccine, was reported by professionals as limiting how often and where patients can receive medical care. One professional said that most people in their community “go to the doctor once a year, based on coverage”. Some insurances “will not cover [vaccines] from a pharmacy, only doctor's offices”, which limits a person's ability to get vaccines where it is most convenient.

The Vaccines for Children program, which 80% of the offices surveyed said they accepted, covers the cost of the vaccine; however, this program is only available to people under 18 who qualify, and only enrolled doctor's offices can provide the free vaccine. Despite these respondents' concerns on the impact of insurance coverage on vaccinations, most medical professionals said that the cost has only “a little” impact (Figure 1).

Accessibility

In terms of accessibility, studies in the past have cited long travel times to reach doctor’s offices as a barrier to receiving proper medical care in the Appalachian region (Syed, Gerber, Sharp 2013). The ability to reach these offices is critical to receiving proper, and timely, medical care. The

question
 “How much
 do you think
 the travel
 cost/distance
 to the
 doctor’s
 office

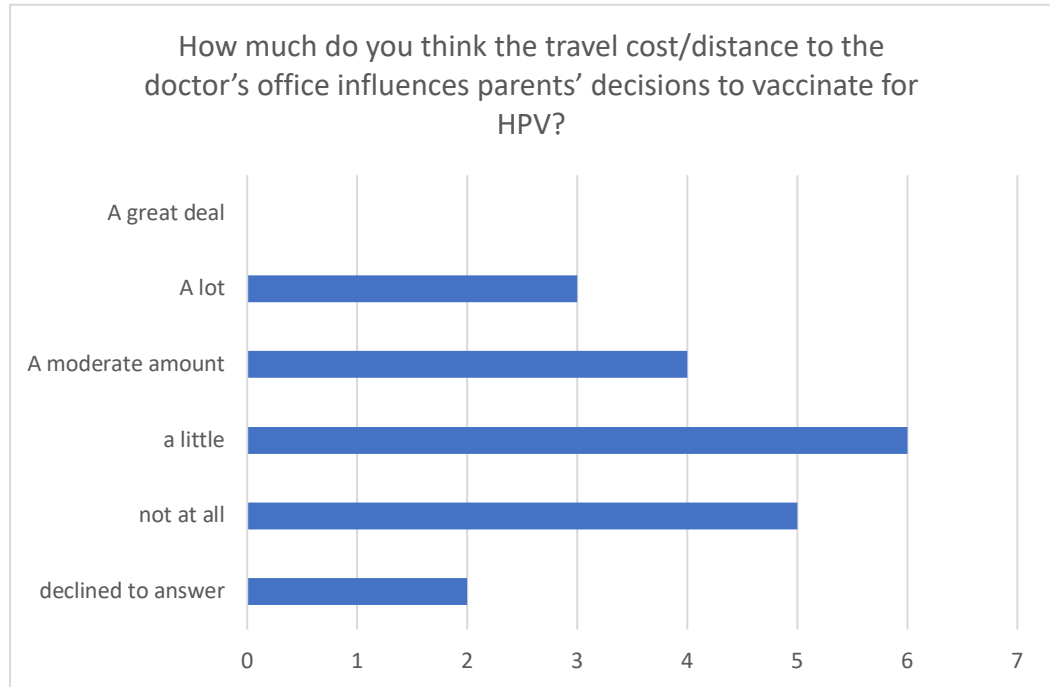


Figure 2

influences parents’ decisions to vaccinate for HPV?” was posed to medical professionals in the community to see how often they have patients struggling with this barrier, and according to the respondents, travel time and cost played only a small role in a parent’s decision to vaccinate (Figure 2). Their comments reflected the literature, saying that “There are several parents who have transportation barriers” that keep them from receiving vaccines on a regular schedule. Other offices indicated that the cost of travel was more important to families than distance, because “people do not like spending money on gas”. Several offices have attempted to circumvent this barrier by making the office more convenient. One, originally based at Ohio University, went mobile to address the transportation barrier. They traveled all over Appalachia to provide medical care; however, at the time of the interview for this study, the clinic had closed.

Accommodation

Accommodation refers to the lengths some offices go to make their services known and available to the public. One office took up residence in a school where they said “pulling the children out of class is more effective” than asking parents to come after work or school. Other offices noted that they “educate as much as possible”, and “do a lot of teaching to help parents to understand”. In this way they improve communication between the offices and parents, as well as reduce stigma through education.

Acceptability

When asked about the stigma surrounding HPV, and its’ impact on vaccinations, many offices agreed that it has “a lot” of impact (Figure 3). Some offices chose to elaborate reporting

that “many parents think it's an approval to have sex because the child won't get a disease” which is what Francis & Katz found to be the case in 2012. Other offices disagreed with that

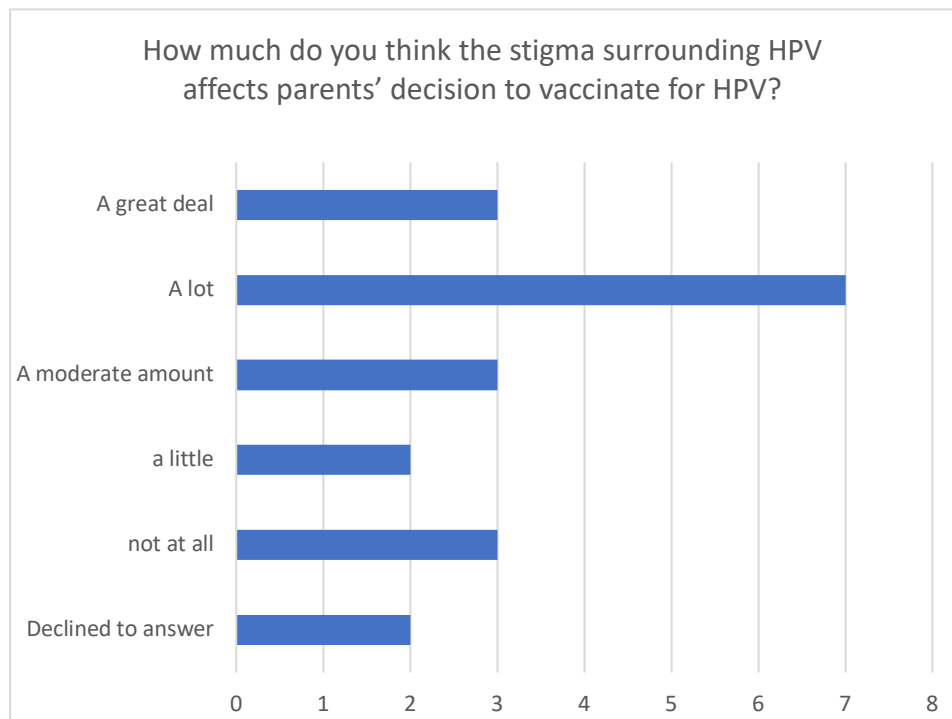


Figure 3

observation, saying that “[Stigma is] lessening over time.” More than anything else, though, offices described a lack of awareness as the greatest issue, going as far as to say “[There is] too little knowledge for there to be a stigma”.

Availability

The study found that 85% of the office’s surveyed had all rounds of the HPV vaccine on hand at the time of the call, and 10% did not. The 10% that did not report having it did say that they could order it from another office or pharmacy. The remaining 5% chose not to answer. These offices gave out on average 411 HPV vaccines in the year 2018, with the average number of patients seen being 16,175. Larger corporate doctor’s offices gave out significantly more than the pharmacies and smaller local offices. Only 80% of offices reported that they regularly recommend the vaccine to parents, while 10% reported that they do not, and the other 10% chose not to respond.

Map of Office Locations

The map in Figure 4 shows the locations of all offices surveyed. Those marked with a red dot are offices who refused to participate, while those marked with green completed the survey.

Most of the medical offices are clustered in larger cities within the surveyed counties.

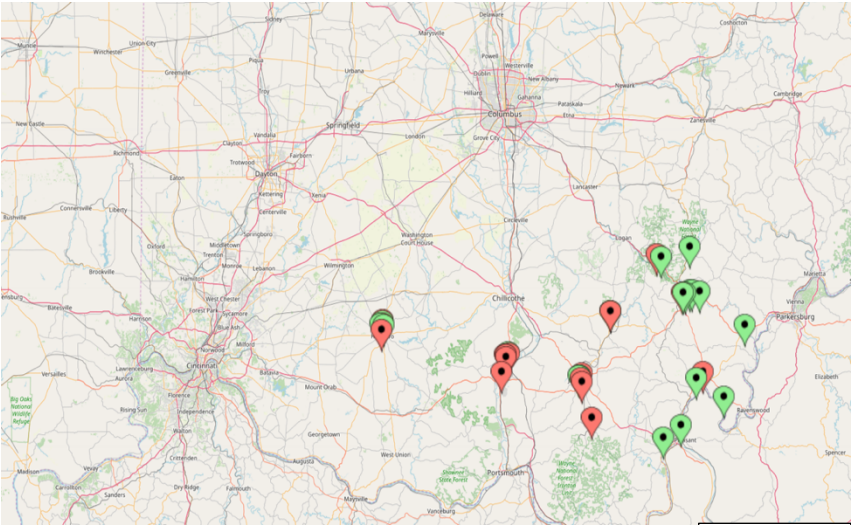


Figure 4

Discussion

While there are a number of reasons why parents choose not to vaccinate their children, this study has identified several interesting themes in the responses. Firstly, the location of each

office was mapped, and it showed that the offices were located mostly in city centers of each county, even though most of the Appalachian population is rurally located. Despite this, not as many offices as expected cited transportation as a barrier to healthcare in the Appalachian community.

Cost, however, seemed to polarize the results. The Appalachian Regional commission categorizes all of the seven counties included in the study as “At-Risk” or “Distressed” economically, but the [study’s](#) results [show](#) the majority of medical professionals see cost as a small barrier. [However](#), a comparable amount of offices sees it as the greatest barrier (ARC, 2018). In this case, it seems that location plays a large factor. Some counties are less economically distressed than others, making cost more important in some counties than others. Continuing to do smaller-scale studies into why this is would allow programs combatting cost to be tailored to counties as needed.

Education emerged as a prevalent theme [throughout](#) the qualitative responses. Many professionals opined that their patients do not know enough about the HPV vaccine, or even HPV, to feel strongly about it one way or the other. This barrier was mentioned on every question from travel to stigma. Several offices made a point to mention their education programs, but the majority did not explain any measures they have taken to educate the public. There are a number of reasons why there would be a lack of education on HPV. A lack of knowledge on healthcare can fall into every “A” of [healthcare](#) access. Lack of consistent transportation was shown to disrupt healthcare continuity, which could account for the lack of understanding, as could affordability. In addition, insurance coverage was mentioned several times as a limiting factor to how often a person sees a physician and how much they pay, which in turn acts as a barrier. Because insurance can limit the amount of time a person gets to spend with their doctor,

it can also influence what kind of information is given in that meeting. So, while it is interesting that so many medical professionals saw a lack of education as an issue, it might be an issue that is outside of their control. Similarly, if there is a general lack of acceptability, teaching parents about the vaccine would prove difficult. The literature suggests that outside of education, the larger issue is a lack of communication between professionals and patients (Behringer and Friedell, 2006). This could be yet another reason, supported by literature, why so many health professionals believe that a lack of education acts as a barrier to HPV vaccination. The implementation of a community-based health-education course would be an interesting intervention for further study.

Limitations

This study experienced several limitations that may have impacted the results. Firstly, the study projected that it would survey three hundred and fifty total offices (fifty per county). This was an extreme overestimation. In reality, some counties had only four total offices the study could survey. In total, the study contacted about sixty offices, and received twenty responses. Although this is a third of the total number of surveyed offices, these numbers do not allow the study to provide an informed conclusion regarding HPV vaccine barriers within Appalachian communities. Future studies may consider narrowing the focus to one county and going in-person to get responses rather than conducting surveys via phone and email.

Secondly, while phone and email interviews were considered the best option for this study, given time restraints, face-to-face interaction would have likely yielded better results. In face-to-face interviews the surveyor can read body language, ask for more information, and

make sure that each question is answered. In the online format medical professionals were allowed to skip questions, which could have altered the findings.

Thirdly, the study experienced a time constraint that made it difficult to conduct the study to its fullest possible extent. The study had about three weeks to set up the survey, ten weeks to do data collection, and another two weeks to complete data analysis. This constraint impacted the number of times offices were contacted for responses, how many amendments were made to the IRB to better the study, and the amount of data analysis done. More time spent building trusting relationships with offices and trying out different question wording would have produced a better outcome with clearer conclusions.

Lastly, after going through the results, the study found a slight discrepancy in results of surveys filled out online where the researcher was unable to further explain the context of the questions, and those filled out over the phone with the researcher. These discrepancies are attributed to some wording of questions being confusing or unintentionally misleading. In the future, it is recommended that surveys should be practiced by several different parties of varying levels of experience with the subject, then perhaps given to a control group to test validity.

Recommendations

Because the study only received twenty responses, it is difficult to make definitive conclusions. Overall, it was found that the HPV vaccine is available, accessible, and affordable in these seven Appalachian counties. It was also found that, for the most part, offices are accommodating to the needs of their patients, with some offices going further than others.

However, because so many medical professionals saw acceptability a barrier, the study recommends that future studies focus on stigma and ways to combat it in their communities. One

possibility, based on the answers regarding a lack of education as fueling stigma, would be a course be created for community leaders on how to educate and communicate about HPV. There are numerous reasons why medical professionals are unable to give this information including time constraints, limited resources, and lack of consistent care. Creating a community-led program will ensure that the information is coming from a trusted source, and hopefully combat the education gap so members of the Appalachian community can make informed decisions about their own health.

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b. 2

c. 3

d. 4

e. 5 – a great deal

i. **giving them the option of explaining their reasoning for their answer

9. In 2018, how much do you think the stigma surrounding HPV affected parents' decision to vaccinate for HPV? On a scale of 1-5, 1 being not at all, 5 being a great deal

a. 1 – not at all

b. 2

c. 3

d. 4

e. 5 – a great deal

**giving them the option of explaining their reasoning for their answer

Appendix 2: Informed Consent Script

“Hello, my name is Michaela Murphy. I am an undergraduate student at The Ohio State University in the College of Social Work and I am in the United States undertaking research that will be used in my thesis.

I am doing research on HPV Vaccine uptake; I want to understand why vaccine uptake rates are low, and what can be done to raise them. As a member of the medical professional community of Appalachia you are the best person to talk to about barriers to HPV uptake in your county. I would like to ask you some questions regarding this and your practice's HPV vaccine costs.

The information you share with me will be invaluable in completing my research. Your expertise will help me understand, from a clinical perspective, barriers to vaccine uptake.

This survey will take approximately 15 minutes of your time.

There is a minimal risk of a breach of confidentiality. I will not link your name or the name of your practice to anything you say, either in the transcript of this interview or in the text of my thesis or any other publications.

Your de-identified information may be used or shared with other researchers without your additional informed consent.

There is also a risk that hearing these questions will make you feel uncomfortable.

Participation is voluntary. If you decide not to participate, there will be no penalty or loss of benefits to which you are otherwise entitled. You can, of course, decline to elaborate on any issue or answer any questions, as well as to stop participating at any time, without any penalty or loss of benefits to which you are otherwise entitled.

If you have any additional questions concerning this research or your participation in it, please feel free to contact me at (615) 587-2673, my thesis supervisor at freisthler.19@osu.edu, or our university research office at any time.

Do you agree to participate? Do you have a few minutes now to complete the survey or would it be better to schedule another time?

The survey is available by email as well, if that is more convenient.

Do you have any questions about this research?

Do you consent to being part of this study?"