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The Females Against Cancer Educational Series: A Qualitative Evaluation of Mother/ Daughter Knowledge and Perceptions of Human Papillomavirus and Its Related Cancers

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Abstract

Objective—To evaluate the knowledge, perceptions, and effectiveness of an human papillomavirus (HPV)/cervical cancer education/prevention program.

Methods—Approximately 50 middle and high school girls and their mothers participated in the 7-part educational series. Qualitative pre-evaluations and postevaluations were completed for every session, followed by culminating focus groups with mothers and daughters separately.

Results—Common themes included lack of basic knowledge about HPV and its related cancers. Additionally, mothers and daughters expressed difficulty in communicating with one another about healthy relationships; however, during the focus groups, both mothers and daughters discussed how they had utilized effective communication tools to discuss sensitive topics and make informed decisions together.

Conclusions—Despite recent HPV prevention campaigns, more innovative strategies must be implemented to educate more mothers and daughters of HPV and its dangers. Additionally, in educating communities about HPV and associated cancers, more innovative strategies should be mobilized to trigger discussions regarding protective behaviors against HPV.

Keywords

health disparities; cervical cancer; sexually transmitted diseases; qualitative research; children/ adolescents

INTRODUCTION

Sexual activity and cancer have been linked in numerous studies. Over the past several decades, research has evidenced that viral infections, specifically those transmitted sexually, can lead to cancer.[1] According to the American Cancer Society (ACS), the human papillomavirus (HPV) has been the most important and commonly studied sexually transmitted viral infection identified as a cause of cancer.[2] Many studies have linked persistent high-risk HPV with the most common types of invasive cervical cancer; other strains of the virus cause less serious health challenges or none at all.[1,3–8] Approximately 20 million Americans are currently infected with the more than 40 genital tract types of HPV[9]

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HPV is commonly spread through genital contact, often during vaginal and anal sex. However, HPV is also spread through oral sex, leading to infection in the mouth and throat area as well. Currently, it is projected that at least one half of all sexually active Americans will contract HPV in their lifetime.[9] Most infected people will not realize they have HPV because they will not develop symptoms or experience related health complications from it. In fact, many times, the body's immune system clears HPV within 2 years, through natural processes.[9] However, when HPV does not clear naturally, the risk for cervical cancer may be increased.[10]

In 2011, the ACS estimated that 12710 new cases of invasive cervical cancer will occur and approximately 4290 will die from cervical cancer.[2] In South Carolina, there were an estimated 170 new cases of cervical cancer and 60 deaths due to the disease.[11] South Carolina is ranked 14th in the nation for both incidence and mortality of cervical cancer. Additionally, there is great disparity between those racially classified as white or black, whereas 7.5 per 100000 whites are newly diagnosed with cervical cancer vs 11.5 per 100000 blacks. Furthermore, whites die of cervical cancer at a rate of 1.9 per 100000 compared to 4.9 per 100000 among blacks.[11] Corresponding to high rates of reported Pap testing in South Carolina from 2005 to 2008, with rates greater than 84% among women who participated in the Behavioral Risk Factor Surveillance Survey in 2008 (among the highest in the nation during 2008), the incidence of reported cervical cancer began climbing and rose steadily[9,11] during 2005–2008.

Nationally, recent practices to control and prevent cervical cancer have stressed the need for public health and educational interventions to address low levels of HPV knowledge and to increase uptake of HPV vaccination.[12–18] Therefore, it is necessary to gain understanding concerning the knowledge, skills, and abilities of communities and individuals in order to adequately implement health promotion programs. Specific to South Carolina, a population-based, random-digit telephone survey was conducted in South Carolina to assess knowledge, behaviors, and attitudes related to HPV and the HPV vaccine[19] in May of 2008. Findings from the survey of 1002 of the eligible 3219 households detail that 99.5% of women had heard about Pap testing, 97.8% had ever had a Pap test, and 95.5% had a Pap test within the past 5 years. Regarding vaccination, of the 169 women who had daughters aged 9 to 18 years, 19.5% reported their daughter had been vaccinated. An additional 52.9% of women who had daughters aged 9 to 18 years who had not been vaccinated responded favorably to being willing to have them vaccinated. Using a scoring system with 19 HPV knowledge-based questions, 53.2% of survey participants scored in the low range (0–9 questions correct). Moreover, those categorized as being of white race scored significantly higher on the HPV knowledge-based questions than those racially categorized as black.[19]

Although this study shows an overall lack of education surrounding HPV and cervical cancer testing, it appears that interest has increased among adolescents in learning more about HPV[20] This is important because adolescent knowledge of HPV may be best influenced by physicians, health educators, peer groups, and media.[21] Research has demonstrated that young women familiar with HPV have received their information at school, in a doctor's office, and/or via television.[22,23] One study conducted among African American adolescents and young women aged 14 to 20 years in South Carolina during January–April 2007 examined the association between HPV infection or vaccination and knowledge, beliefs, and attitudes concerning HPV. Of the 73 young women surveyed and 68 interviewed, 61.1% reported having had a Pap test. The mean score of the Pap Test Knowledge Scale was 2.4 out of 5 items, with 1 participant exclaiming, "I couldn't tell you what she is looking for when I have a Pap test!"[24] Similarly, a study conducted among 252 adolescent girls in a hospital setting undergoing educational intervention using a protocol developed with adolescent patients found positive results. Using both quantitative and

qualitative data collection, researchers discovered that a protocol mixed with pictures, diagrams, key phrases, and author scripts significantly increased knowledge scoring from preintervention visit to the postintervention visit. Findings also demonstrated that adolescent girls wanted more pictures to demonstrate the consequences of infection and were surprised that condoms could not completely prevent HPV acquisition or that antibiotics did not cure HPV[25]

Additional studies suggest that parents are key to HPV understanding in order to increase levels of vaccination.[26,27] However, the focus on vaccination may overshadow the educational component of increasing understanding of HPV and cervical cancer. In a randomized intervention study within a cross-sectional survey of parents with 8- to 12-year-olds, half of survey participants received brief information about HPV and the other half was the control group. The half of parents who received brief education scored higher than the control group on the HPV assessment tool. However, there was no significant difference among the 1600 parents surveyed for vaccine acceptability.[28] These studies show that brief, valid, educational workshops and materials can increase knowledge and ultimately may lead to behavior change.

A significant focus of the University of South Carolina/Claflin Center for Excellence in Partnerships, Outreach, Research on Health Disparities and Training was to reduce health disparities in HPV and cervical cancer, particularly among minorities in rural areas of South Carolina. The University of South Carolina/ Claflin Center of Excellence and Orangeburg Consolidated School District (OCSD) 5 partnered to create the Females Against Cancer Education Series (FACES) to enhance knowledge about these diseases.

METHODS

The principal investigators have successfully conducted research through multiple agencies in South Carolina. As a result, cooperative relationships had been established and maintained with key individuals in various agencies, organizations, and communities in the Orangeburg area. The partnership between the Center of Excellence and the OCSD 5 was plausible because of the established presence and relationship in the community. Key school district employees, parents, and young ladies assisted in determining which strategies were most effective for the local area.

The 7-part series consisted of information sessions for the district's middle and high school girls and their mothers. Participants attended 4-hour sessions on selected Saturdays from January to April 2010. The interactive sessions highlighted topics such as HPV and its associated cancers; sexually transmitted infections, including HIV; unhealthy relationships; and decision-making skills. Mothers and daughters who attended all sessions were eligible to receive a gift card at the conclusion of the last session in April 2010. Sessions were held at the James E. Clyburn Community Empowerment Center in Orangeburg. The University of South Carolina institutional review board approved the study.

Participants were recruited through advertising in school organizations and programs, such as parent-teacher-student organization meetings, afterschool club meetings, guidance counselors, and other programs sponsored or endorsed by the district during fall 2009. The eligibility criteria included being a female enrolled in an OCSD 5 middle or high school or being the mother of an OCSD 5 female student. Informed consent and assent were obtained from mothers and daughters; and guidelines for open discussion were reviewed and agreed upon (according to school district and state regulations/ mandates) by participants and session presenters.

Two focus groups were held with mothers and daughters after the last session. Evaluation and focus group questions were based on session objectives previously established by the project team and individual presenters. All questions were reviewed by a panel of experts in qualitative research, sexual risk behaviors, and health education to evaluate ease of understanding and to determine if they were worded in a manner that would elicit the responses of interest.[29]

We wanted to assess mother and daughter knowledge of HPV, HPV screening and prevention, and HPV-related cancers and session-specific information. Approximately 50 open-ended evaluation responses were independently coded by one of the investigators and an external researcher (both who have expertise in qualitative research methodology) for the establishment of a code book and interrater reliability; analysis was conducted using NVivo v.8 (NVivo), while closed-ended descriptive questions were summarized using Excel (Microsoft Corp, Redmond, Washington).[29,30] Interrater reliability was established by a calculating a κ statistic of 0.69; disagreements in coding were resolved in discussion.

RESULTS

Included in these evaluations were 29 daughter responses and 21 mother responses, as 2 mothers brought 2 of their daughters who were eligible to participate. While the majority of the students were high school students (76%), the remaining girls attended 1 of 2 district middle schools in Orangeburg. The girls ranged from 12 to 19 years of age, with an average age of 16 years; the mothers ranged from 39 to 45 years of age, with an average age of 42 years. All of the participants serf-identified as African American.

Written qualitative responses were assigned codes and then linked according to mother/daughter relationship. Initially, we discovered that there was a general lack of in-depth knowledge about HPV. This theme was apparent in mothers and daughters. There were 3 sessions that addressed HPV, prevention, screening, vaccination, and related cancers. These sessions occurred at the beginning and midpoint of the program: Introduction to HPV Signs, Symptoms, and Causes: Our Bodies and Our Cervical Health (session 1); HIV and HPV Prevention (session 4); and Oral Health and Cancers (session 7). Some of the responses that reflect this theme can be found in Box 1.

Additionally, related to the lack of knowledge about HPV, there was also a high level of uncertainty about cancers associated with HPV HPV-mediated cancers were introduced at the beginning of the program during session 1 but were discussed in greater detail during session 6, Cancers caused by HPV Participants were specifically asked: “What cancers can HPV cause?” More than 95% of respondents discussed not knowing many details of what cancers were caused by HPV Some of the responses that reflect this theme can be found in Box 1.

A second theme that arose from participant responses was challenges to open and bidirectional communication. There were 4 sessions that addressed components of communication with family members and significant others that occurred near the beginning, midpoint, and end of the program: Informed Decision Making (session 2); Building Positive Self-esteem (session 3); Legal Aspects and Abuse Issues (session 5); and Developing Effective Communication Skills (session 6). The responses from mothers were generally skewed towards the inability to connect with their daughters about sensitive issues such as sexual intercourse (Box 2).

The daughters disclosed their thoughts on communicating with their mothers about issues they wished they could discuss. Again, the responses were generally skewed towards an

inability to openly talk about sensitive issues that may arise. Some of the adolescent responses that reflect this theme can be found in Box 2.

Upon the conclusion of the final session, 2 final focus groups were conducted separately with mothers and daughters to assess what information was retained and skills that were practiced during the sessions and recommendations for future sessions. The focus groups were conducted according to the strategies recommended by Ulin, Robinson, and Tolley.[31] Both the mothers and daughters were asked about the most memorable sessions and, overwhelmingly, every participant mentioned sessions that specifically discussed HPV and cancers. When asked, "What made those sessions stick out?," respondents indicated that the session information was presented in an interesting way and they did not know a lot about the information shared prior to the program. When participants were asked, "What do you remember specifically about those sessions?," each participant was able to share facts from the sessions mentioned. Most mothers indicated that they were able to continue conversations initiated in the sessions, and their daughters participated openly and freely in dialogue. They specifically discussed how communication had improved with their daughters through seizing unique opportunities to discuss in nonthreatening ways sensitive topics such as intercourse, healthy relationships, and the HPV vaccine; and how they were able to engage their daughters in conversation. Some daughters indicated feeling empowered to not engage in unhealthy relationships and had a desire to abstain from sexual relationships, but if they were to engage they would do so responsibly and not prior to discussing with their mothers.

DISCUSSION

Despite recent HPV prevention campaigns, more innovative strategies must be utilized to educate mothers and daughters of HPV and its dangers. During our study, we discovered many individuals are still unaware of some of the most basic information surrounding HPV and its related cancers. However, it appears that mothers and daughters felt more comfortable discussing healthy behaviors when they were armed with knowledge and information on the disease. This finding is very similar to those discovered in previous studies such as Mays and colleagues, which indicated that the primary reason that parents declined the HPV vaccine was due to a lack of education regarding risk for infection.[32] Health educators, parents, and others must utilize innovative strategies to engage youth and encourage discussions regarding healthy behavior and healthy lifestyle.

It is important to note some limitations of our study. First, the planning and budget process was intricate. Our staff constantly faced challenges securing a start date due to the hierarchy of the school system and the several chains of command in the approval process. Limited funding and budgetary restraints restricted our ability to enhance outreach strategies to more participants and be of assistance to address transportation and childcare needs for those involved. There were many communication barriers during the recruitment process. In compliance with OCSD 5 policies, we relied on district staff for flyer distribution and delivery of other print communication to participants. This process immobilized our ability to produce a more generalized study and reach a more diverse population.

Second, before implementation, all agendas, documents, and presentations had to be prescreened by the OCSD 5 comprehensive health education coordinator, which at times led to the purging of pertinent information, data, and statistics before the participants received it.

Third we had to ensure that our presenters had the capability to communicate effectively with all of the participants because of the generational and sometimes educational differences in the group. As the sessions proceeded, attrition was a challenge (despite

reminder phone calls during the week preceding a session) that affected data collection over time.

Going forward, it will be important for health educators to conduct more outreach activities that equip members of the community with information and skills that lead to healthy lifestyles and behaviors. For youth especially, one of those healthy behaviors is having the ability to have open and honest conversations about their well-being with peers and parents. This study specifically prioritized African American females, due to the disparities in HPV observed in South Carolina, making the results nongeneralizable in other populations. In order to reduce the incidence of HPV and HPV-mediated cancers, it will be imperative to have collaborative partnerships among educators, parents, and health care providers.

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Box 1. General Lack of In-Depth Knowledge About Human Papillomavirus (HPV)

Session Questions Posed to Group Participants

Illustrative responses

- What is human papillomavirus?
  - "I don't know what HPV is."
  - "Don't know"
  - "A disease"
  - "I didn't know about the different types of HPV nor the exact definition of HPV."
- How can HPV affect men?
  - "I didn't know it could affect men."
  - "I didn't know men had HPV."
- What cancers can HPV cause?
  - "I think it causes cervical cancer."
  - "I'm uncertain."
  - "I'm not sure what cancer is caused from HPV."
  - "Maybe mouth cancer?"
  - "People hear a lot about HPV and cervical cancer but not about other kinds of cancer."

Box 2. Challenges to Open and Bidirectional Communication

Session Questions Posed To Group Participants

Illustrative responses

- What do you talk about with your daughter?
  - "I talk to her about boys and sex but she shuts down."
  - "I talk to her all the time but I don't think she gets how serious this [unprotected sex] is or can be."
- What do you wish you could talk to your daughter about, but you feel like it's hard to do?
  - "I wish I could convey to her how bad relationships can affect her health—from abuse to peer pressure to her getting something she'll have to live with for the rest of her life."
  - "I want to know what she's really doing and saying with her friends when I'm not around."
- Why do you think it is difficult?
  - "I feel like I can't get through to her."
  - "She responds well but does not disclose information that she thinks I may fuss about."
- What do you talk about with your mother?
  - "Nothing because she won't listen"
  - "Nothing. She ask too many questions."
- What do you wish you could talk to your mother about, but you feel like it's hard to do?
  - "I want to talk to her about my relationships, but she starts fussing before I can get started or ask questions."
- Why do you think it is difficult?
  - "She talks, I just sit there, because it's like she is just talking at me."
  - "Sometimes she gets offended about things. She thinks I really be doing it but I'm just asking."
  - "She makes me feel weak and I can't do nothing right."