

Using focus groups to plan culturally acceptable primary cervical cancer screening in Grenada, West Indies

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ABSTRACT

Objective. To document Grenadian women's knowledge about cervical cancer and human papillomavirus (HPV) infection, as well as their attitudes towards primary cervical cancer screening methods.

Methods. In this qualitative study, we used focus groups in Grenada to gather information concerning women's knowledge about, attitudes towards and perceptions of screening for cervical cancer and general knowledge about HPV. Ten focus groups comprising 73 participants representing 5 of the 6 parishes in Grenada were conducted with women aged 19–59. Participants were asked about pelvic exams, Pap smears, HPV, reasons for seeking or avoiding cervical cancer screening and how different modalities of testing might affect their decision-making. Responses were then coded and organized into common themes.

Results. While many respondents had heard of HPV, far fewer knew about its causative role in cervical cancer, how to prevent HPV infection or testing for the high-risk HPV types that cause almost all cases of cervical cancer. Many participants were aware that cervical cancer screening was beneficial, but numerous barriers to obtaining that screening were noted, including concerns about privacy and stigma, potential discomfort, and the cost and inconvenience involved.

Conclusions. Our findings have implications for future cervical cancer screening efforts in Grenada. Central to these efforts should be a focus on educating Grenadians about the role of HPV infection in cervical cancer and the importance of early detection through screening. In addition, addressing issues of stigma and privacy are key to eliminating cervical cancer in Grenada.

Keywords

Uterine cervical neoplasms; papillomavirus infections; health knowledge, attitudes, practice; Grenada; women.

Cervical cancer is one of the leading causes of morbidity and mortality in Latin America and the Caribbean, being the third most common type of cancer in the area and responsible for a yearly toll of 56 000 diagnoses and more than 28 000 deaths (1). The impact is particularly notable in the small island state of Grenada, as research has documented an even higher prevalence of cervical cancer and associated mortality than

seen in the rest of Latin America and the Caribbean, with an observed prevalence of 52.4 cases of cervical cancer per 100 000 women (2).

Grenada comprises three islands: Petit Martinique, Carriacou and Grenada, the latter being the largest of the three and home to most of its inhabitants. The island of Grenada is 300 km², and it is divided into six parishes; St. George's is its largest city and

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capital. Of its 111 000 total population, more than 36 000 Grenadians are women between the ages of 15 and 65 years (3). Public health care services, many offered for free or at a nominal cost, are provided by the Ministry of Health, which oversees 5 hospitals, 6 health centers and 30 smaller medical stations spread throughout the country (4).

Human papillomavirus (HPV) is the most common of all sexually transmitted infections, and the high-risk types of HPV cause nearly all cases of cervical cancer (5). Most of these infections are spontaneously cleared by the immune system, and those that persist typically, although not always, take years to cause the cervical lesions that if left untreated can progress to cancer (5). This makes cervical cancer highly preventable, and screening has long been the foundation of disease-control efforts in high-resource settings. Implementation of cytological screening in the United States resulted in the incidence of invasive cervical cancer declining by nearly 50% from 1975 to the present and total deaths from cervical and uterine cancer decreasing by more than 80% from 1930 to 2012 (6). Unfortunately, these gains have not been matched where the implementation of large-scale screening is more difficult: 85% of cervical cancer cases now occur in the developing world (6).

Increasing screening and HPV vaccination are key to reducing the substantial burden of cervical cancer in Grenada. This is particularly true in the context of the generalized shift towards direct testing for high-risk HPV types, which requires less-frequent tests than Pap tests alone (6). Currently, women in Grenada can obtain cervical cancer screening at public or private facilities. The number of tests conducted nationwide is not readily available, but there is evidence that screening services are not actively pursued by most Grenadian women (7). Indeed, it is the very prevalence of cervical cancer morbidity and mortality in Grenada that is the best indication that the current process of screening and follow up is insufficient.

Successful screening programs require broad participation, but many women in Grenada have an incomplete understanding of HPV infection and its relationship to cervical cancer (8, 9). Therefore, we held a series of focus group discussions with Grenadian

women to gauge their knowledge about HPV infection and cervical cancer and attitudes towards screening for cervical cancer, including testing for high-risk HPV types. We explicitly solicited discussion of HPV infection in this study in anticipation of shifts in screening modalities, as well as to ascertain how efforts to increase screening might interface with future efforts to promote HPV vaccination. We anticipate this knowledge will inform further development of culturally acceptable approaches to and methods of primary screening for cervical cancer that work towards the goal of eliminating cervical cancer in Grenada.

METHODS

In this qualitative study, we analyzed data collected by women's health care professionals from 10 separate focus groups held between 2018 and 2019 at several locations in the capital, St. George's. The study population was defined as women who were possibly at risk for cervical cancer, and participants were selected from a purposive sample and recruited by the investigators through organizations that provide health care and social services to Grenadian women. Bus fare, snacks and educational materials were provided as incentives, and participants donated their time. The research plan was approved by the Institutional Review Board at St. George's University.

There were 73 participants in total, and focus groups ranged from 3 to 18 participants, with a median group size of 7. Sessions lasted approximately 90 minutes. Before the focus group session, each woman signed a consent form approved by the Institutional Review Board at St. George's University and answered a few demographic questions, including providing her age and home parish. Participants were aged 19 to 59 years, and 5 of Grenada's 6 parishes were represented. Groups contained women from a variety of socioeconomic and educational backgrounds.

Each session began with an orientation briefing and used a standardized set of discussion prompts (Box 1). Participants were asked about their knowledge of pelvic exams, Pap smears, HPV, reasons for seeking or avoiding cervical cancer screening and how different modalities of testing (including

Box 1. Prompts for facilitators of focus groups seeking to understand what women in Grenada know about screening for cervical cancer and human papillomavirus, 2018–2019

- Do you get pelvic exams? How do you feel about these examinations? Is there anything that prevents you from having them done?
- Are you familiar with the Pap test? What about others in your community?
- Have you ever had a Pap test? Is there anything that would make you hesitate to get a Pap test or follow up?
- What do you know about HPV?
- Have you ever had an HPV test?
- Cervical cancer rates and related mortality are much higher in Grenada than the World Health Organization estimates for the region. Did you know this already? What do you think about this?
- One proposed HPV screening method might make it possible to get results in 1–5 days, which could quickly tell whether follow up is needed. Would this make a difference to you?
- Would you prefer to be taught to collect the sample for HPV screening yourself [in a process described by the facilitator] or have a health care provider collect the sample for screening [as is done for a Pap test]?
- Would you be willing to go to a mobile clinic to get cervical cancer screening?
- What could we do to make cervical cancer screening most comfortable – that is, accessible, available – to you?

HPV: human papillomavirus.

Source: Box prepared by the authors based on the results of their study.

sample self-collection, testing for high-risk HPV types, the use of mobile clinics) and reporting of results might affect their decision-making. A single facilitator conducted each focus group, and multiple members of the research team were present at each session to provide support and ensure consistent delivery. Each session ended with a short verbal educational session contextualizing the discussions and providing basic information about HPV infection and cervical cancer. The audio from participants' responses during the discussion was recorded and then later manually transcribed by university students who had also attended the session.

Individual transcribed responses were de-identified during the process of transcription; researchers were subsequently unaware of which participant provided which response. The resulting data were analyzed through a process of identifying themes and codes (10). Initially, two researchers (ES and AB) reviewed the transcribed responses and developed a controlled vocabulary of codes. They then independently applied one or more codes to each response, reviewing their choices with one another until a consensus was reached for each response. Working with CHP and JM, they then defined broader themes under which each code could be organized.

RESULTS

Four broad themes emerged (Table 1), and responses representative of each theme are included below.

Theme 1: knowledge about screening rationale and methods

When questioned about the reasons for getting a pelvic exam or Pap smear, many respondents knew that it had something to do with cancer.

"The primary aim of the test is to collect samples from the cervix, and that will detect if there [are] any precancerous growth cells. I am not sure of the correlation with STDs [sexually transmitted diseases]."

"To detect if you have cancer."

"Yes, it is when they test for cancer and to see if the uterus is clean or if there is any infection."

"To check to see if you have an infection."

It was unclear, however, if participants understood the differences between a pelvic exam, a Pap smear and an HPV test.

Theme 2: knowledge about HPV and cervical cancer

Many participants responded that they had heard of HPV prior to the discussion, and a good number said that they had some knowledge of the disease and its etiology. The extent of the respondents' knowledge, however, varied a great deal: indeed some responses were factually incorrect (denoted as [*]).

"I know that it's an STD and you get it through sexual contact. There is no cure, but the symptoms are treatable."

TABLE 1. Coded responses and number of appearances in the data set from 73 female focus group participants asked about screening for cervical cancer and about human papillomavirus infection, Grenada, 2018–2019

Response codes	No. of appearances in data set	Corresponding theme or themes ^a
Need for more education about cervical cancer and HPV infection	43	2, 4
Discomfort or pain associated with testing	33	1, 3
Concerns about confidentiality	14	3
Fear of the testing process itself	13	1, 3
Fear of a positive result	12	2, 3
Expense associated with testing	11	2, 3
Stigma associated with seeking testing	11	3
Inconvenience associated with testing	10	1, 3
Embarrassment associated with getting tested by familiar or male providers	7	3

HPV: human papillomavirus.

^a Theme 1: knowledge about screening rationale and methods; Theme 2: knowledge about HPV and cervical cancer; Theme 3: reasons for avoiding cervical cancer screening; Theme 4: need for further information.

Source: Table prepared by the authors from the results of their study.

"When we eat certain things HPV develops." [*]

"The HPV virus can allow the woman to become more susceptible to other things. If you have it, you are at a higher risk of developing cervical cancer. There is a new vaccine for it and they are targeting younger girls, even though they are not sexually active. This is in order to prevent them from getting the virus later on in their lives."

"You can die if you contract HPV. If you get it at a young age, especially in your teens, your life span will be shortened." [* not all HPV infections progress to cancer]

"It can be spread by body fluids: if a child who has HPV sits on a chair and another child goes and sits in the same area, they can contract HPV." [*]

Theme 3: reasons for avoiding cervical cancer screening

Some respondents were aware of the availability of cervical cancer screening services, yet still actively avoided obtaining them. They volunteered several reasons for doing so, including the following.

Pain. Many respondents identified physical discomfort or pain, from either their own experience or as reported by others, as a reason for avoiding cervical cancer screening.

"Some of the nurses are rough and I think if someone is in that field, they need to be interested in the job they are doing. They also need to have patience."

"I wanted to do one, but I heard people say that it was painful and it is done by men, so that would be uncomfortable."

"I heard that it is very invasive. Also, the instrument used is very cold and the procedure is very uncomfortable and that turns me off."

Confidentiality. Many participants expressed concern that their information might be disclosed by health workers or that people they knew would see them while they were accessing screening services.

“I didn’t want to do it in my area because the people there like to talk [about other] people’s business.”

“I was thinking about confidentiality. If you are in an area where you know the nurses and you know that some of them have a bad habit of talking about people’s business, you won’t go there because you would not want the entire community to know your business.”

“Not only nurses but other people [are] seeing you go there as well. They don’t keep things to themselves. They like to talk.”

Fear. Many respondents noted that they were reluctant to be screened because they were afraid of the results they might receive.

“A lot of young people, even though they know that they have to do it, they may not [have screening] because of their pride. They may think that they have one thing or the other because of the way they lived their life. They may not want to go because they will be concerned about the results.”

“Fear of the unknown....Sometimes I feel that if I am not having any symptoms, it is best not to check because there is a possibility that you find that you have something.”

“It is still fear for me. I am really afraid of finding out that I have something, because my mom had cancer. It is better to know and do something, but I am scared.”

Accessibility. The cost and inconvenience involved in obtaining screening or treatment was a common concern.

“Finance – it is a big issue. You cannot get treatment for that if you cannot pay for it.”

“It does not make me uncomfortable to go and do a Pap smear, it is the time I do not have to go and sit at the doctor’s office and wait....”

“[I] will not do an HPV test, because the issue is not the length of time it takes, it is the cost of doing the test. It costs too much to take just a simple swab. I have to pay for the doctor’s visit and the test; the total cost is too high.”

Theme 4: need for further information

A critical theme that emerged from participants’ responses was the need for more information about HPV and cervical cancer.

“[A] lack of education – once they are educated about what the risk is all about, then they will put themselves out to get it done.”

“I do think that if people had more knowledge they would get screened.”

“There are a lot of women that don’t know, because it is not something that is out there. There are talks about a lot of other cancers, but not cervical cancer. It is not something that I will sit and have a conversation about. I will talk about breast cancer or any other. Many years ago, people did not like talking about sex.”

“We have a little session here and we are just hearing about it. What about all the women who do not know about it. They need to get the information out to them.”

DISCUSSION AND CONCLUSIONS

This study documents Grenadian women in their own words and what they understand about HPV and cervical cancer screening. Critical insights for health professionals planning future interventions to reduce cancer emerged from these women’s voices. While many women had some awareness of HPV, their knowledge of its relationship to cervical cancer was inconsistent. Many were also unaware of the importance of screening itself: that precancerous lesions and cervical cancer are more easily treated when they are detected earlier. Providing education about this point is crucial because it would reinforce the utility of screening and follow up. Conveying that cervical cancer is preventable should help lessen commonly expressed resistance to screening and the fatalism associated with the idea of a positive test.

Providing education about the ubiquity of HPV infection could also reduce the pervasive stigma surrounding screening for HPV and cervical cancer (9). It was notable how often considerations of privacy and potential stigma were voiced by respondents as being barriers to seeking screening services. One challenge to privacy is the context of Grenada itself: it is difficult to anonymously seek medical services when surrounded by people one knows, particularly in a smaller village. This also indicates a need for further education of health care workers about the importance of protecting patients’ privacy and publicizing existing protections more widely to patients.

One limitation of this study was the difficulty in finding a suitably broad geographical cross-section of participants to interview. While the original intent was to conduct focus groups in several different parishes, this led to scheduling difficulties, as many potential participants from smaller villages have very long commutes during the workweek. The investigators compensated for this by hosting sessions in St. George’s during the workday, attempting to recruit participants living in many parts of the island.

Another challenge was the fact that many participants were hesitant to talk about HPV or other reproductive health issues. This was particularly true when focus groups were primarily composed of acquaintances, such as from a single workplace. However, the investigators found that the method of the focus group itself was helpful in eliciting responses: the longer the discussion went on, the more candid people became. Indeed, in some cases the most reticent-seeming respondents had shared the most by the end of the session.

This was an exploratory study rather than an interventional one; however, two potential indications of the utility of more education were apparent. First, the women seemed to have an

active interest in learning more about these issues. In most sessions, participants requested information to take back to their peers or that additional educational sessions be held in their communities. Second, by the end of the session, many participants who had not previously done so expressed an interest in obtaining an HPV test.

Increasing the intensity and effectiveness of screening is crucial to controlling cervical cancer in Grenada. The resources available for public health promotional efforts are finite, so it is vital to understand women's knowledge of, and attitudes towards, screening for HPV and cervical cancer. The findings of this study can inform the development of culturally appropriate interventions that will eliminate cervical cancer in Grenada.

Authors' contributions. CHP, JSG, JM and AB designed the study. CHP and JSG recruited participants for the focus groups, and CHP was also primarily responsible for organizing and conducting those groups; JSG, JM and AB were also present for selected groups. CHP, ES, JM and AB analyzed the data and collaborated on drafting the manuscript. All authors reviewed and approved the final version.

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Conflicts of interest. None declared.

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Uso de grupos focales para planificar exámenes primarios de detección del cáncer cervicouterino culturalmente aceptables en Granada, Caribe

RESUMEN

Objetivo. Documentar los conocimientos de las mujeres granadinas sobre el cáncer cervicouterino y la infección por el virus de los papilomas humanos (VPH), así como sus actitudes hacia los métodos primarios de detección del cáncer cervicouterino.

Métodos. En este estudio cualitativo, se han empleado grupos focales en Granada para recopilar información sobre los conocimientos, las actitudes y las percepciones de las mujeres sobre la detección del cáncer cervicouterino y nociones generales sobre el VPH. Participaron 73 mujeres de 19 a 59 años de edad, representantes de 5 de las 6 parroquias de Granada. Se formaron diez grupos focales, a los que se les preguntó sobre los exámenes pélvicos, las pruebas de Papanicolaou, el VPH, las razones para buscar o evitar la detección del cáncer cervicouterino y cómo las diferentes modalidades de examen podrían afectar sus decisiones. Luego se codificaron las respuestas y se organizaron en temas comunes.

Resultados. Si bien muchas participantes habían oído hablar del VPH, un número considerablemente menor conocía su relación causal con el cáncer cervicouterino, cómo prevenir la infección por VPH o los exámenes de detección de los tipos del VPH de alto riesgo que causan casi todos los casos de cáncer cervicouterino. Muchas participantes sabían que los exámenes de detección del cáncer de cuello uterino eran convenientes, pero mencionaron numerosos obstáculos para obtenerlos, como las preocupaciones sobre la privacidad y la estigmatización, posibles molestias, así como el costo y los inconvenientes relacionados.

Conclusiones. Nuestros hallazgos tienen implicaciones para la futura labor de detección del cáncer cervicouterino en Granada. En esta labor debería ser esencial adoptar un enfoque dirigido a educar a las granadinas sobre la relación de la infección por VPH con el cáncer cervicouterino y la importancia de la detección temprana mediante exámenes. Además, combatir los problemas de estigmatización y privacidad es clave para eliminar el cáncer cervicouterino en Granada.

Palabras clave

Neoplasias del cuello uterino; infecciones por papillomavirus; conocimientos, actitudes y práctica en salud; Granada; mujeres.

Uso de grupos focais para planejar estratégias culturalmente aceitáveis para rastreamento de câncer do colo do útero primário em Granada, Índias Ocidentais

RESUMO

Objetivo. Documentar o conhecimento das mulheres de Granada sobre o câncer do colo do útero e a infecção por papilomavírus humano (HPV), bem como suas atitudes em relação aos métodos de rastreamento de câncer do colo do útero primário.

Métodos. Neste estudo qualitativo, usamos grupos focais em Granada para coletar informações sobre conhecimentos, atitudes e percepções das mulheres sobre o rastreamento de câncer do colo do útero e conhecimentos gerais sobre HPV. Foram conduzidos dez grupos focais, incluindo 73 participantes e representando 5 das 6 paróquias de Granada, com mulheres de 19 a 59 anos de idade. As participantes responderam perguntas sobre exames ginecológicos, Papanicolau, HPV, razões para procurar ou evitar o rastreamento de câncer do colo do útero e como diferentes modalidades de testes podem afetar sua tomada de decisão. As respostas foram codificadas e organizadas por temas comuns.

Resultados. Muitas participantes já tinham ouvido falar do HPV, mas um número muito menor conhecia sua relação causal com o câncer do colo do útero, formas de prevenir a infecção por HPV ou os testes para os tipos de HPV de alto risco, que causam quase todos os casos de câncer do colo do útero. Muitas participantes sabiam que o rastreamento de câncer do colo do útero era benéfico, mas várias barreiras para o rastreamento foram indicadas, incluindo preocupações relacionadas à privacidade e ao estigma, o potencial desconforto e o custo e inconveniência envolvidos.

Conclusões. Nossos achados têm implicações para as futuras iniciativas de rastreamento de câncer do colo do útero em Granada. Essas iniciativas devem se focar em educar a população de Granada sobre o papel da infecção por HPV no câncer do colo do útero e a importância da detecção precoce por meio do rastreamento. Além disso, é fundamental abordar questões de estigma e privacidade para eliminar o câncer do colo do útero em Granada.

Palavras-chave

Neoplasias do colo do útero; infecções por papillomavirus; conhecimentos, atitudes e prática em saúde; Granada; mulheres.
