

## Faculty of Medical Sciences

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### A Qualitative Study

**Title:** Exploring the reasons why Barbadian mothers consent, or do not consent for their preteen daughters to receive the HPV vaccine.



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## Abstract

**Aim:** The aim of this qualitative study was to explore the reasons why Barbadian mothers consent or did not consent for their pre-teen daughters to receive the human papilloma virus (HPV) vaccine.

**Design/Method:** Four focus groups, totaling 25 Barbadian mothers whose pre-teen daughters were eligible for the HPV vaccine during the 2013-2014 school year were conducted. The groups were homogenous with two groups consisting of mothers who consented, and two groups of mothers who did not consent. Each session was audio-recorded, and data was analyzed to examine emerging themes.

**Results:** A lack of information from the Ministry of Health and an inadequate time frame to make an informed decision were the most common reasons for parental non-consent to the HPV vaccine. Other reasons included: a fear of side-effects of the vaccine, a low perceived risk of persons within the 10 to 12 age group of contracting the HPV virus, negative advice (particularly from medical practitioners), and a lack of trust and confidence in the information provided by the Ministry of Health.

The most common reasons for giving consent were: positive advice, (especially from health care professionals), having had a past experience with the Human Papilloma Virus, a family history of cancer, or knowing someone diagnosed with a HPV infection or cervical cancer.

**Conclusion:** There is a need for more public information in relation to the Human Papilloma Virus and the HPV vaccine. This will allow for informed decision making, which may contribute to an increased uptake of the HPV vaccine.

## Introduction

The human papilloma viruses are a group of viruses that can affect the skin and mucous membranes with over 200 types identified. However about 50 types can infect the genital area.(1) There are low risk types which cause genital warts, and high risk types which accounts for almost 100% of cervical cancers.(1)

Cervical cancer is the second most common cancer in women world-wide, and the 6<sup>th</sup> leading cause of death in women in the 45-49 age group worldwide.(1,2) Globally, there is a yearly incidence of approximately 530,000 cases with 275,000 deaths, with over 85% of the cases occurs in developing countries. (1) (2) Women are affected in their most productive years, which impacts on the family, the community, the work place, and the country.

Local statistics from the Queen Elizabeth Hospital (Barbados' main hospital) revealed an average annual incidence of 38 cases of cervical cancer in Barbados, resulting in 21 deaths annually. Current trends indicate an increasing incidence of cervical cancer. It has been projected that by the year 2025, the incidence of cervical cancer will be approximately 52 cases, resulting in 31 deaths. (3)

A quadrivalent vaccine (Gardasil) was approved and licensed in 2006 in the United States by the Food and Drug Administration (FDA), and is recommended by the World Health Organization for preadolescent girls for the prevention of 70% of cervical cancers caused by HPV genotypes 16 and 18, and 90% of genital warts caused by HPV 6 and 11. (1) (2) (4) during clinical trials, this vaccine has been proven to be efficacious. (5) A second bivalent vaccine (Cervix) was later licensed in 2007; this vaccine can also be used for the prevention of HPV 16 and 18.

In January 2014 the HPV vaccine (Gardasil) was added to Barbados' immunization schedule to be administered to girls ages 10 to 12 years old. Parental consent must be obtained prior to the administration of this vaccine

Despite mass media awareness campaigns, unpublished reports thus far indicate that the uptake of the vaccine is low only 20% of eligible girls received the vaccine. (6) The HPV vaccine was introduced in Barbados four months prior to the commencement of this study. The response was poor with an uptake rate of 20% for the first two doses of the vaccine. Therefore it is crucial to know the reasons for this poor response. A qualitative method of research using the grounded theory is the most effective means of determining the reasons for a low vaccine acceptance rate. This study explored the reasons why

Barbadian mothers consented or did not consent for their pre-teen daughters to receive the HPV vaccine. This information is critical for a successful HPV immunization program.

## Methods

### **Study design**

Focus groups were utilized for the purpose of data collection as in depth information can be gathered using this forum, providing rich data. Semi-structured interview guides were utilized. Prior to commencement of the study, two pilot focus groups were conducted. The interview guide was tested and was found to be appropriate. Following the pilot four focus groups consisting of 6-7 participants per group were conducted; two groups consisted of mothers who gave consent for the HPV vaccine and the other two groups consisted of mothers who did not give consent. Written informed consent was obtained from all participants before conducting the sessions. Each session was audio-recorded and transcribed verbatim. The study was conducted at a public polyclinic.

The participants in the study were Barbadian mothers whose pre-teen daughters were eligible for the HPV vaccine during the 2013-2014 school year. There were no restrictions on the age of the mothers. The rationale for selecting mothers only to participate in the study is that: 1) Mothers are usually the primary parent who discusses with their daughters matters pertaining to the female reproductive system, 2) This topic may be a bit sensitive so having a homogenous group will help to alleviate some sensitivity in this area, 3) Within the Barbadian cultural setting, many families are single parent families with mothers as the head of those families.

The sample was chosen from the list of mothers with eligible daughters, in First Forms attending Barbadian secondary schools, which was obtained from the Ministry of Health. The sample was purposely selected from the target population to include the first 60 mothers on the list who gave consent, and the first 60 mothers who did not give consent. Mailed invitations were sent to these mothers, explaining the purpose of the study, and invited them to participate. The first 16 mothers [8 consenting to vaccine and 8 not consenting to vaccine] who agree to participate were invited to attend the pilot groups, the next 32 [16 consenting to vaccine and 16 not consenting to vaccine] mothers who agree to participate were selected for the study.

## **Analysis**

Analysis was conducted using the grounded theory, which is exploratory in nature. A list of codes developed, patterns and themes identified were the basis of providing answers to the research question. The qualitative software ATLAS.ti assisted in data management.

## Results

Five themes emerged from the data. 1) Mothers' knowledge of the human papilloma virus and the HPV vaccine, 2) The need for more information, 3) Mothers' perception of the HPV vaccine, 4) Reasons for not giving consent, and 5) Reasons for giving consent. These themes gave valuable insight into the reasons why mothers gave or did not give consent. Mothers who participated ages ranged between 29 to 53 years of years. They were from varying socio-economic backgrounds.

### **Mothers' knowledge of the human papilloma virus and the HPV vaccine**

Mothers from all groups mentioned the association of the HPV vaccine in the prevention of cervical cancer. However, they were all uncertain if the vaccine will actually prevent cervical cancer, and most mothers knew very little or stated that they knew nothing about the virus. The few participants who were knowledgeable about the HPV sourced information from various reputable internet sites, example PAHO and WHO sites, obtained clarity from various health professionals or, attended a the Town Hall meetings conducted by personnel from the Ministry of Health. Three of the mothers stated that they had personal experience with the virus, and were quite knowledgeable in terms of the HPV, but knew very little about the vaccine.

### **Need for more information**

Most mothers indicated that the information on the human papilloma virus and the HPV vaccine given by the Ministry of Health was inadequate, the quality was poor, and the time frame given to make a decision was too short. *'To me there was not enough information given about the vaccine.'* *My thing is, it just appeared as soon as I heard about it in less than a month or two, they want you to make a decision about it. To me it was so rush rush.*" (38 year-old non-consenting mother). Other mothers indicated that mothers not knowing where to source reputable information became victims of misconceptions. Only two consenting mothers in this study stated that the information given by the Ministry of Health was adequate. However, these mothers indicated that they attended the Town Hall meetings, and viewed a discussion on

national television in which health officials gave information on the HPV virus and the HPV vaccine. Both mothers concluded that the forums were very informative. According to one mother; the Town Hall meeting which she attended was not well attended and she believed that others would have benefited from the information if they had attended. Not all mothers shared the previous opinions, with some mothers who attended the Town Hall meetings, stating that they were not convinced to give consent. They stated that the response to questions were not convincing. One non-consenting mother stated that the presenters themselves appeared not to be convinced about the effectiveness of the vaccine.

### **Mothers' perception of the HPV vaccine**

Although generally all mothers had a positive view of routine vaccines, they had mixed reactions on the HPV vaccine. Some mothers questioned the efficacy of the vaccine, were fearful of the side effects, and doubtful of the information provided by the Ministry of Health, based on the fact that the vaccine is new, and there is a lack of research in regards to the effects of the vaccine: *"I saw a fairly heated television program and the people voiced their concerns saying they don't understand why the government is forcing young children to have this vaccine. I think the critical thing is, there was a lot of misinformation at the beginning. People had no trust in the system, they think that there was some sinister reason that this vaccine was being given."* (36 year-old consenting mother)

On the other hand some mothers stated that they had no reasons to doubt what the medical fraternity stated about the vaccine, and they believed that it was a progressive step introducing the vaccine in Barbados for the prevention of cervical cancer.

### **Reasons for not giving consent**

There was a low perceived risk of persons within the ten to twelve age group of contracting the HPV. Some of the mothers suggested that the age was too young, they lacked the knowledge that the vaccine was prophylaxis and should be given before the onset of sexual activity. This 42 year old non-consenting mother was very vocal: *' I went on line and read up about the vaccine, and the side-effects were horrific to me, so it's like seeing medication advertise on T.V and the fine print, all the different side-effects seem that it can take you faster than the actual cancer.'* (42 year old non-consenting mother)

Another common factor for not giving consent which needs to be highlighted was negative advice, from medical practitioners. *'A practitioner when I called and spoke with her, she said she think the vaccine is not bad, but personally she would wait giving it to her daughter, her daughter is a week older than mine, and she is a medical practitioner.'* *"I spoke to my obstetrician, her pediatrician and the pharmacist and they all recommended against it."* (two non-consenting mothers)

Other factors noted for not giving consent included, negative information from the internet. Some of the parents who sourced information from the internet, visited the sites randomly and had no knowledge how to identify reputable sites, and some mothers stated that they did not understand the information obtained via the internet, some mothers sought clarity, and others did not and became victims of myths and misconceptions. The vaccine being new was another concern expressed by mothers. Some non-consenting mothers stated that they prefer to wait and see what happens they preferred to be cautious as there was no point of reference. One mother stated that she did not refused giving consent, she just did not return the consent form to the school, as she still awaits information in order to make an informed decision.

### **Reason for giving consent**

The mothers who gave consent shared similar characteristics. In contrast to the experience of some non-consenting mothers, many of the consenting mothers received positive advice from health care professionals “...when I had my first conversation with him [pediatrician] on the phone, He immediately put my fears to rest.” (36 year old consenting mother)

The most common reason stated were past experiences with the human papilloma virus, a family history of cancer or having a close friend or significant other with any of the above mentioned conditions. “I have cancer in my family and I said, I really have to protect my daughter.” (34 year old consenting mother)

In general those mothers who were convinced that the benefits of the vaccine out-weighted the risk, and wanted to prevent their daughters from contracted cervical cancer willingly gave consent.

## Discussion

This study is the first of this nature within the Caribbean region, however when compared with other studies globally produced overwhelmingly similar findings. This could indicate that some of the challenges encountered with the introduction of the HPV vaccine could have been anticipated. This study gives valuable insight into understanding the reasons for acceptance or non-acceptance of the HPV vaccine especially in other Caribbean regions where this vaccine is likely to be introduced in the near future which may allow for a better response to the HPV vaccine. It is important to note that minority groups' such as Rastafarians who usually refuses routine vaccine did not participate in this study.

Countries intending to introduce the HPV vaccine can benefit from this and others studies to avoid similar short-comings, and can therefore develop appropriate strategies for a successful HPV implementation program. Countries like Barbados, who have already introduced the vaccine with a low acceptance rate, can revisit their strategies and develop a plan of action based on their specific needs to increase the uptake of the vaccine.

One important finding from this study which is integral to the success of program implementation is having a consistent message from the health sector. The fact that some mothers received negative messages from practitioners regarding consenting to their daughters having the HPV vaccine while other mothers received positive message, speaks to inconsistent information being given. Therefore training and information for health professionals will be important to a successful program. Also, if the current avenue for disseminating information such as town hall meetings is not being utilized by the public, other avenues to reach the target population must be considered. Additionally, further research is necessary, especially in the Caribbean region, to determine the attitudes of health care professions towards the HPV Vaccine.

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