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Attitudes toward HPV vaccination among parents of adolescent girls in Mysore, India

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ABSTRACT

This study investigates attitudes toward human papillomavirus (HPV) vaccination among parents of adolescent girls in Mysore, India. Seven focus group discussions were held among parents of adolescent girls stratified by sex, religion and region to explore attitudes about cervical cancer and HPV vaccination. The study found that while parents have limited knowledge about HPV or cervical cancer, most are still highly accepting an HPV vaccine. In addition, high acceptability levels appear to reflect positive attitudes toward the government universal immunization program in general, rather than to the HPV vaccine in particular. The results highlight the need for additional education and health promotion regarding HPV and cervical cancer prevention in India.

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1. Introduction

About 493,000 new cases of cervical cancer occur worldwide each year, and 274,000 women die from cervical cancer annually [1]. Four out of five of those deaths occur in developing countries where cervical cancer screening programs are either unavailable or ineffective [2]. India, with approximately one sixth of the world's population, bears one fifth of the world's burden of cervical cancer [3]. With more than 130,000 new cases each year, India's cervical cancer age-standardized incidence rate of 30.7 per 100,000 is more than 300% higher than rates in the United States and other countries including United Kingdom and Canada [4]. Cervical cancer mortality at 18.6 per 100,000 is more than 8 times higher than the United States and almost 11 times higher than Australia [5,6].

Vaccines preventing human papillomavirus (HPV) infection, the primary cause of cervical cancer [7], offer dramatic new opportunities for reducing cervical cancer related deaths. Because HPV vaccines are recommended prior to the initiation of sexual activity, girls aged 9–15 years are primary targets. As a consequence, understanding the parental acceptability of HPV vaccination is critical as governments consider how such vaccine programs should be

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implemented. In many settings, parents have been found to have low levels of knowledge about HPV and cervical cancer [8–11]. They expressed concerns that vaccines against sexually transmitted infections like HPV could encourage early sexual debut [12] and promote increased sexual risk behavior [13]. Despite those concerns, research to date has shown broad support among parents for vaccinating children and young adults against HPV infection [14–20].

In a review of studies of HPV vaccine acceptability in the U.S. and other parts of the world, higher intention-to-vaccinate was associated with a perceived elevated risk for HPV infection and cervical cancer [17,21,22]; belief that HPV infection could be severe [23,24], belief that the HPV vaccine was efficacious [16,23,25,26] and recommendation of a pediatrician [17]. Obstacles to HPV vaccine acceptance reported by parents include concerns about cost [21,25,26], fears about safety [23,27], concerns that the HPV vaccine may cause discomfort or have side effects [16,23] and fears that vaccination may promote increased sexual activity [16,17,24,25,27].

With the recent Government of India approval of Merck's quadrivalent HPV vaccine for girls and women aged 9–26 years, there is a pressing need for further research on the acceptability of vaccination among parents from a variety of different settings. Because the vaccine will initially be introduced as an optional vaccine with a price tag of a \$ 120 (Rs. 5800) per dose, there are serious questions about whether Indian parents will immunize their daughters [28]. Although there has been considerable research on the parental acceptability in developed countries, few studies have been carried

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P. Madhivanan et al. / Vaccine xxx (2009) xxx-xxx

out in countries like India [29]. This study examined attitudes of parents of adolescent girls about HPV vaccination in Mysore, India.

2. Materials and methods

2.1. Site

Mysore is a large city in southern India with a population of just under 1 million people. We selected Mysore, India, for the study because it is highly diverse: more than 76% of the population are Hindu, 19% Muslim, and the remaining 4% Christian, Jain, Buddhist, and other religions [30] with an average per capita income of 15,632 INR (\$ 312 USD). In addition, while Mysore, at 800,000 people, is the second largest city in Karnataka state; the metropolitan area is surrounded by more than 100 rural villages-making it an ideal location for sampling rural as well as urban populations. The focus group participants were stratified by sex, religion, urban vs. rural residence. All participants gave written informed consent to participate in the study. The Independent Ethics Committee at the C.S.I. Holdsworth Memorial Hospital, and PATH USA Ethics Committee, approved the study.

2.2. Participants

Recruitment took place between April and July 2008 following 12 outreach and community education programs focused on reproductive health and prevention of cervical cancer. After each presentation, interested community members were invited to take part in a focus group discussion. To be eligible, potential participants had to have at least one daughter between 9 and 15 years of age; be able to speak Kannada or English; be willing to be audiotaped and give informed consent. Additional focus group members were recruited by asking participants to refer others who met study criteria, and by referrals from community organizations. The study employed both male and female recruiters to ensure adequate participation of both mothers and fathers.

2.3. Study procedures

We conducted focus group discussions at the Public Health Research Institute office in Mysore, India. Each discussion lasted between 60 and 90 min. At the end, participants were reimbursed for their time in the amount of INR 100 (approx \$ 2 USD). A trained female social worker (YMN) facilitated all the discussions. Two additional study staff members observed and took notes. Study staff explained the purpose of the study and collected informed consent from each potential participant. Study staff also collected basic demographic information from each participant.

An experienced qualitative research scientist trained the study staff in qualitative research methods and adapted a FGD guide based on a prior published study [31]. The facilitator's guide was translated into Kannada and pilot-tested with a group of six mothers from the community. A pilot FGD was conducted to ensure that terms and phrases used in the FGD guide were understandable to participants, that discussions on vaccination were relevant to the Indian setting including types of vaccines available, costs, and general availability. Attention was also given to making sure that all sections of the FGD

Each focus group consisted of two main parts: the first explored knowledge about HPV infection and cervical cancer and the second, after participants received additional information about HPV and cervical cancer, about their beliefs and intentions regarding HPV vaccination e.g., who should be included in vaccination programs, concerns about vaccine side effects, costs and willingness to vaccinate children against sexually transmitted diseases.

2.4. Analysis

FGD were audiotaped, transcribed verbatim and translated into English by a study investigator (YMN) and one additional staff person from PHRI. The primary investigator (PM) listened to three recordings selected at random to confirm the accuracy of the transcripts. Data were analyzed using framework analysis [32] by three investigators (YMN, KK and PM). In brief, a matrix-based approach was used to identify emergent themes and develop a framework. We identified recurring and important themes based on a combination of a priori issues, emergent issues and recurring attitudes or experiences. Once themes were identified, we applied the framework to additional transcripts and further refined the analysis to capture the diversity of participant opinions. Any differences were resolved by reviewing transcripts together (YMN, KK). If a consensus was not reached, we used another author (PM) to reach consensus. Simple descriptive statistics were used to describe the demographics of the study participants.

3. Results

Table 1 shows the demographic characteristics of study participants. In all, 23 mothers (aged 25-42 years), and 21 fathers (aged 27-54 years) of girls aged 9-15 participated in the focus group discussions. Seven discussions with 6-7 members per group were held among urban Muslim mothers and fathers; urban non-Muslim (Hindu, Christian) mothers and fathers; rural non-Muslim mothers and fathers; and urban English-speaking Hindu mothers. No focus groups were conducted among rural Muslim parents because the Muslim population in Mysore is heavily concentrated in urban areas. All but one of the discussions (urban English-speaking mothers) was conducted in the local language of Kannada.

3.1. Knowledge about HPV infection and cervical cancer

At the beginning of each FGD, the facilitator asks each participant what they could tell the group about cervical cancer and its prevention. Participants in only one group, the English-speaking urban Hindu mothers, had heard of cervical cancer specifically, or HPV infection. Several of those women had read about the new HPV vaccine and were aware that cervical cancer was highly prevalent in India. In most other groups however, while participants had heard of cancer, and several said they had lost family members from cancer of the uterus, none were able to talk about the subject with any specificity. While participants felt that many diseases were preventable, most considered cancer to be a random and unexplainable event. One woman whose mother had recently died from what may have been a cervical cancer explained:

"My mother was not sick. Then one day she had white discharge. They gave her treatment in Mandya [a nearby town] and she got weaker and died. We don't know what makes cancer. There is no cure. What is the guarantee that cancer will come in later life? Some get it and some don't. It may come and it may not." Rural Hindu Mother

After hearing more about the relationship between HPV infection and cervical cancer, some participants expressed skepticism that a cancer could be associated with sexual activity or be caused by an infectious agent. One mother expressed her disbelief in this way:

"...people with cancer don't have sex diseases and people with sex disease don't have cancer. If both are together, there will be a problem, so those who get cancer should get one vaccine and those with sex disease should receive other vaccines. If we go to

guide could be completed in the proscribed time.

P. Madhivanan et al. / Vaccine xxx (2009) xxx-xxx

Table 1

Sociodemographic characteristics of the focus group participants in Mysore, India (N=44).

Characteristic	Men (<i>n</i> =21)		Women (<i>n</i> = 23)	
	n	(%)	n	(%)
Age categories				
≤35 years	7	33.3	14	60.8
>35 years	14	66.6	9	39.2
Years of education				
No formal schooling	8	38.1	5	21.7
8th grade or less	8	38.1	9	39.1
9th grade or higher	5	23.8	9	39.2
Religion				
Hindu	14	66.7	12	52.2
Muslim	7	33.3	7	30.4
Christian	-	-	4	17.4
Occupation				
Housewife	-	_	4	17.4
Unskilled	6	28.6	5	21.7
Skilled	15	71.4	14	60.9
Number of people living in the household				
<u>≤4</u>	14	66.7	8	34.8
>4	7	33.3	15	65.2
Median total monthly household income (INR) (range) [1 USD=48 INR]	3000	(1000-8000)	3000	(1500–15,000)

the shop they give different tablets for different things, so causes for diseases should be different." Urban Hindu Mother

In general participants were unfamiliar with the concept of disease prevention as opposed to treatment. A Muslim father explained the difficulties of spending for prevention when there was limited income and competing priorities:

"We don't know if there will be cancer. If it comes we will have to pay because there is nothing else to do. But we don't know if that will come so we have to deal with the problems that we have now." Urban Muslim Father

3.2. Knowledge and attitudes toward vaccination in general

Most participants said that they were aware of vaccines through contact with the government of India universal immunization program. In general, mothers were more familiar with childhood vaccines than either fathers or extended family members because they usually accompanied their children for vaccination. Many were highly supportive of vaccines in spite of the fact that some had children who had experienced minor side effects after being vaccinated. One woman explained it this way:

"Sometimes a baby can get fever after DPT [Diptheria Pertussis Tetanus vaccine] but still they are not in the situation of dying. Now we can have healthy children. That is why people feel it is okay to have one or two children because not so many die now." Rural Hindu Mother

Most mothers believed that having their children vaccinated was one way they could provide them with a happier and healthier life. Many expressed the notion that prevention was preferable to treatment and saw vaccines as an investment in their child's future. One mother put it this way:

"We have to take necessary measures to prevent diseases. Once our body gets weakened, we cannot do anything. As we are poor, we cannot spend money if something happens to our children. We can go to government hospitals to get vaccinations." Muslim Mother

Interestingly, both rural mothers and fathers were more knowledgeable about vaccines than their urban counterparts. While rural parents reported that health workers came to their villages to talk about vaccines, Hindu urban fathers appeared to have few sources for information about vaccines. Most reported that they had learned what they knew from family and friends. As a consequence many were less informed than their rural counterparts and some were openly fearful and suspicious of government vaccine programs. One father reported what he had heard about the polio vaccine at his workplace:

"A man told me his wife took their boy for polio drops. He was normal. After taking drops in his mouth he is now disabled. Why should they put polio drops in? What is the use?" Urban Hindu Man

3.3. Factors related to HPV vaccine acceptability among parents with adolescent girls

Despite poor knowledge about HPV infection and its relationship to cervical cancer, after reading the information provided many parents reported that they were willing to vaccinate their daughters if the government had approved the vaccine. Most expressed very positive feelings toward government immunization programs and seemed to have great confidence in both the efficacy and safety of government recommended vaccines.

"The nurse comes and tells us that we should vaccinate our children. We know it is our duty to take our children to the hospital to get vaccination. Sometimes we will not know what type of vaccination will be given but we must have faith because we are not educated so we must listen when they tell us." Urban Muslim Father

"If we get the vaccine from the government we are not afraid. If it is from outside [from private sector sources] then we are scared." Urban Hindu Mother

In addition to endorsement of the vaccine by government, fear of cancer also appeared to be a facilitator of vaccine acceptance among parents regardless of their sex, religion or locality. Most focus group participants knew of people who had died of cancer, sometimes after extended and unsuccessful treatment. A mother expressed her enthusiasm for any vaccine that would prevent cancer in this way:

P. Madhivanan et al. / Vaccine xxx (2009) xxx-xxx

"There is no cure for cancer. If there is an injection, we will take it. We know that once we have cancer it is too late. Better to spend the money now or we will end up spending a lot more later." Rural Hindu Mother

Cost was a significant obstacle to vaccine acceptance among participants. While all groups expressed concerns about the expense of an optional HPV vaccine, rural parents expressed more willingness to accept a higher cost than urban parents. Urban Hindu mothers suggested they might pay from 100 to 200 rupees per dose (\$ 2.00 to \$ 4.00 USD), urban Muslim fathers up to 500 rupees (\$ 10 USD) and rural parents were willing to pay up to 5000 rupees (\$ 100 USD). The median family income in India is approximately Rs.4500 (\$ 90 USD) a month [33].

"We are willing to pay rupees 100 for this vaccine, otherwise where can we get the money? If the government gives free of cost, we will take it and get others to take. Even people who are BPL [below poverty line] will take it." Urban Hindu Mother

"I can spend around 500 to 1000 rupees maximum. If it is available for fewer prices, everyone can buy it. If is about paying 2000, 10,000 or 20,000 rupees we can never even think about it." Urban Muslim Father

"For our children's future we will pay 5000 and get the vaccine. We can take a loan and get the vaccine. We can't do more than that." Rural Hindu Mother

The second biggest obstacle to the HPV vaccine among participants was fear of side effects. Several parents expressed worries that the HPV vaccine might cause infertility. Others feared that the vaccine might cause cancer. In general, however, most parents simply wanted more information about the vaccine and wanted to know about common side effects such as fever, pain or discomfort:

"If there is a problem for the child if we give the vaccine once, we will never touch it again. We will say 'namaskara' [Thank you] and leave. If it is good, we will go back and we will tell others it is good and send them as well." Rural Hindu Mother

3.4. Other issues with HPV vaccination of adolescent girls

3.4.1. Age at vaccination

While many parents found HPV vaccination to be acceptable, most did not support vaccinating young girls between the ages of 9 and 15 years. An overwhelming majority of participants felt that girls should not be vaccinated until they had attained puberty:

"Younger children are scared of injections. If they are fifteen years then we can tell them why. With young girls, their fathers say 'if they don't want injections, we will not give them'. If they are 15 years old they will understand and accept." Rural Hindu Mother

"At 15 they are mature so that is why we should give it at that age. That is the time they know a little about the world so we have to give it at that age." Urban Muslim Mother

An overwhelming majority of participants also felt it was unlikely that girls younger than 15 would be sexually active. Not surprisingly, many parents felt their own daughters were unlikely to have sex prior to marriage but some reported that teenage girls sometimes engaged in premarital sex without their parent's knowledge. As a consequence, an overwhelming majority of participants felt there was a need to vaccinate girls between 15 and 18 years of age. Several parents expressed their feelings this way:

"Girls do not need until they are older. I will educate them and they will do what is right. No one in my family has illegal sexual relationship with anyone. Not my father or my mother. My children know about this and they will do what is right." English speaking Upper Income Hindu Mother

"Sometimes children get in trouble. We know this but it is hard to find out. Better to vaccinate in case something happens. Then we will not regret later." Rural Hindu Father

3.4.2. Locus of decision making in HPV vaccine uptake

A majority of participants suggested that decisions about whether to vaccinate adolescent girls would be made jointly by mothers and fathers. Some urban Hindu mothers suggested that it was necessary to discuss the vaccine within the family and the ultimate decision maker would be the father. Urban Muslim fathers also perceived themselves to be the ultimate decision makers for vaccination, particularly if vaccines were optional and costly for the family.

3.4.3. Access to vaccines

Both urban and rural parents voiced fears that only high-income families would be able to afford vaccines unless they were part of the universal immunization program.

"We will not see these vaccines if they are not brought by the government. Rich people go to private hospitals and they have money to buy treatments. We are poor and do not have the money so we will go to a government hospital. Without a government program we will not have the vaccine for our families." Rural Hindu Mother

Surprisingly, urban parents seemed especially concerned that they would not have access to vaccination for their daughters. A low-income urban Muslim father expressed it this way:

"Vaccine programs are not coming and politicians are also not coming. We are coolies and poor so they do not care about us. Even if a vaccine is free we will not get it unless we give money. When we give money they do it fast. When we don't give money they tell us to show somewhere else or tell us to come next month or come on a certain date." Urban Muslim Father

4. Discussion

In this study we explored knowledge, attitudes, beliefs and intentions to vaccinate adolescent girls among Hindu and Muslim parents from different socioeconomic backgrounds in Mysore, India. Similar to other studies from around the world, we found low levels of knowledge among participants regarding HPV and cervical cancer [8–11]. Most participants were unaware of HPV and its relationship to cervical cancer. In spite of this, acceptance of an HPV vaccine appeared high with many parents being interested in immunizations that would prevent cancer. Our data are consistent with other studies which showed that while parents had little or no knowledge about HPV or cervical cancer, most were still highly accepting of an HPV vaccine [24,25,34]. In India, these high acceptability levels appear to reflect positive attitudes toward the government universal immunization program and vaccination in general, rather than to the HPV vaccine in particular.

We observed several important differences among the various groups who participated in the study. First, participants from rural areas appeared to be more knowledgeable about general issues related to vaccination than their urban counterparts. This is not surprising given the extensive efforts of the National Rural Health Mission to increase immunization coverage at village level. In spite of this, rural and urban parents, except for English-speaking urban Hindu mothers, all had relatively poor knowledge about cervical cancer and HPV infection. Secondly, rural parents appeared to have

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4

P. Madhivanan et al. / Vaccine xxx (2009) xxx-xxx

greater willingness to pay a higher price for an HPV vaccine—an interesting observation that may be related to rural parents being exposed to more morbidity and mortality related to cervical cancer. Thirdly, we found no differences around issues related to the HPV vaccine by religion. Finally, both women and men agreed that the locus of decision making concerning the HPV vaccine uptake resided primarily with father who had most to say about how family resources would be used. In some families however, both men and women agreed that mothers also played an important role in deciding whether an adolescent girl would receive the HPV vaccine.

The main facilitators of acceptability of HPV vaccination were endorsement of the vaccine by the government and fear of cancer. Major obstacles to acceptability included high cost and the fear of side effects. Most parents in our sample felt strongly that young girls below 15 years of age should not be vaccinated against HPV. While many parents felt that their daughters were unlikely to become sexually active before marriage, several admitted that young people did engage in premarital sexual relations sometimes. While there was no universal consensus about the most appropriate age for vaccination, most participants felt that adolescent girls should be vaccinated between the ages of 15 and 18 years.

This study has several limitations which may affect the interpretation of results. We sampled a small group of parents, so the data are not generalizable to other populations. Although we included fathers and mothers, we were unable to gender match facilitators with the participants raising the possibility of a reflexivity bias. We also cannot rule out the possibility that additional important themes might have emerged if additional focus group discussions had been held. Furthermore, while using focus groups as opposed to one-to-one interviews helps facilitate discussion due to the group dynamics, individual beliefs cannot be assessed independently because the presence of a group may preclude individuals from sharing unpopular beliefs. Finally, while people articulated high acceptability of HPV vaccination, it is impossible to assess how their positive feelings toward the vaccine would actually relate to the uptake of vaccination for their daughters.

Despite those limitations, our study found that the main facilitators of the acceptability of HPV vaccination were endorsement of the vaccine by the government and the desire to avoid of cancer. Major obstacles to acceptability included concerns about cost, side effects, and the conviction by parents that their adolescent daughters were unlikely to be sexually active. This work offers some initial insight into parental attitudes of HPV vaccination in a sample that has not previously been considered. Additional quantitative studies are now needed to understand further the predictors of HPV vaccine uptake among parents of adolescent girls in India.

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6

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P. Madhivanan et al. / Vaccine xxx (2009) xxx-xxx

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