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### Acceptability of HPV Vaccine Implementation Among Parents in India

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## **Acceptability of HPV Vaccine Implementation Among Parents in India**

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*Due to high cervical cancer rates and limited research on human papillomavirus (HPV) vaccine acceptability in India, the research team examined parental attitudes toward HPV vaccines. Thirty-six interviews with parents were conducted to assess sexually transmitted infection (STI)-related knowledge and HPV-specific vaccine awareness and acceptability. Despite limited knowledge, parents had positive views toward HPV vaccines. Common barriers included concerns about side effects, vaccine cost, and missing work to receive the vaccine. Parents were strongly influenced by health care providers' recommendations. Our findings suggest that addressing parental concerns, health worker training and policies, and efforts to minimize cost will be central to successful HPV vaccine implementation.*

Cervical cancer is the most common cancer among Indian women, closely followed by breast cancer. In 2008, age-standardized incidence and mortality rate estimates cervical cancer in India were 27.0 and 15.2 per 100,000 women, respectively, which is considerably higher compared with the global estimates (15.2 and 7.8 per 100,000 women; Ferlay et al., 2008; [Globocan, 2008]). Nearly 60% of high-grade lesions and 80% of cervical cancers are due to HPV-16 and HPV-18. Organized cervical cancer screening programs have significantly reduced cervical cancer rates in developed countries. Although the National Cancer Program in India supports early screening and treatment of cervical cancer, implementations of screening programs are inadequate or nonexistent due to logistical barriers such as insufficiently trained staff and infrastructure (Bharadwaj, Hussain, Nasare, & Das, 2009).

Vaccinating against HPV infection, therefore, is a promising additional strategy for reducing cervical cancer rates. Vaccination may be especially relevant in India, home to one-fifth of the worldwide cervical cancer burden, which represents the largest burden in the world (Jemal et al., 2011; Sankaranarayanan, Budukh, & Rajkumar, 2001) and where screening programs are inadequate (Dabash et al., 2005). In 2008, the Indian Academy of Pediatrics Committee of Immunization, along with the Federation of Obstetric and Gynaecological Societies of India, and the WHO Strategic Advisory Group of

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DNA Fingerprinting and Diagnostics, Hyderabad, India: Gayatri Ramakrishna, Pavani Sowjanya, and Shantha Lakshmi; and SHARE INDIA Medici Institute of Medical Sciences: Research Administration: K. Vijayaraghavan, P. S. Reddy, Nitin Desai; Field staff: Mamatha D., Deepa K., Vasantha P., SriLaxmi K., Venkatlaxmi P., Bujji K., and Narendernath B.; Data Management: R. Purushotham Reddy and Chandana K.; Gynecology: Haripriya Vedantham, Karuna Bhawani P., Kalpana B., Rekha C., Meenakshi Jain, Lalitha J., Vidyadhari K., Malathi M. R., and Anitha; Pathology: Mrudula S., Rajani Kameshwari, Ratnakar C., Srilatha J. Goud, Kishore L., Ratnam B. Yesu, and Kauser Tahseem; and Microbiology: Manik S. Das, Anuradha M., Srinivas A., Anand Kumar R., and Goparani Bala.

Experts on Immunization, recommended HPV vaccine for 10–12-year-old females, with catch-up vaccination through age 26 (IAPCOI, 2008). The public health sector supports a childhood immunization program, which provides the Expanded Program on Immunization (EPI) in India for free, but other vaccines, like HPV vaccines, are solely available for purchase through the private sector. Compared with younger children, adolescents are traditionally underserved by India's health care system (Kumar, Prinja, & Lakshmi, 2008; Nath & Garg, 2008). In addition to parents (Bharadwaj et al., 2009; Das, Hussain, Nasare, & Bharadwaj, 2008), community perceptions, political will, provider support, and innovative delivery strategies will be important for acceptance and sustainability of HPV vaccination and adding the vaccine into the EPI schedule in India.

The context for HPV vaccination has been described in the developed (Brewer & Fazekas, 2007; Zimet et al., 2006; Zimet, Shew, & Kahn, 2008) and developing (specifically Asia) world (Basu & Mittal, 2011; Bingham, Drake, & Lamontagne, 2009; Dinh et al., 2007; Jacob et al., 2010; Kwan et al., 2008; Madhivan et al., 2009; Sam et al., 2009). A review of these studies indicates that government endorsement, cancer prevention, confidence in immunizations, and provider's recommendation are factors in vaccine acceptance. Major obstacles to acceptance are high cost and fear of side effects. There have been a few studies targeting parents in India (Basu & Mittal, 2011; Bingham et al., 2009; Jacob et al., 2010; Madhivanan et al., 2009). These researchers suggest a relatively positive response to vaccinating 9–15 year olds.

Understanding HPV vaccine acceptability in India is crucial given the enormous cultural, religious, and ethnic diversity and that relatively little research has been done in India (for exceptions see Basu & Mittal, 2011; Bingham, Janmohamed, et al., 2009; Jacob et al., 2010; Madhivan et al., 2009) compared with the extensive research done in England, Australia, and the United States (all much smaller countries with lower cervical cancer burden; Brewer & Fazekas, 2007; Zimet, Liddon, Rosenthal, Lazcano-Ponce, & Allen, 2006; Zimet, Shew, & Kahn, 2008). Since social practices in India not only differ from other countries, but also significantly differ across states and geographical regions, the purpose of this study was to use qualitative research methods to examine parental, particularly mothers', attitudes about HPV vaccine prior to its availability in perirural areas outside of Hyderabad, India.

## METHODS

### Study Design and Population

Parents were recruited in 2008 from Medchal Mandal and Shamirpet Mandal, Andhra Pradesh, India. The local private hospital is involved in community-based activities, including a population-based cervical cancer screening study, the Community Access to Cervical Health (CATCH) Study (Gravitt

et al., 2010). Villages in Medchal were selected based on their CATCH Study participation rates. Villages screening more than 45% of the population were considered high participation; villages screening under 45% were considered low. Three villages from both categories were purposively selected. In Shamirpet, with no active cervical cancer prevention activities, three villages were randomly selected. The Institutional Review Boards in India (SHARE India/MediCiti Institute of Medical Sciences) and the United States (Johns Hopkins University Bloomberg School of Public Health) approved the protocol.

A list of eligible mothers (with daughter(s) under 18 years old) in Medchal was generated using the hospital's computerized census database. Interviewers went to the house of every tenth person on the list and invited the mother (or father) to participate until topical saturation was reached. In Shamirpet, a convenience sample of 2–4 eligible parents were selected from each village. Thirty-six interviews were completed, including 20 mothers from Medchal (10 high participation, 10 low participation) and 10 from Shamirpet; 6 fathers were interviewed from Medchal Mandal. Participation was voluntary, and no incentive was provided.

### Data Collection

After slight modifications for cultural appropriateness, a semi structured interview guide from a U.S. study (Mays, Zimet, Winston, Kee, Dickes, & Su, 2000; Mays, Sturm, & Zimet, 2004) was used. The guide was translated into the local language of Telugu and back translated into English. The interviews were conducted in Telugu; informed consent was obtained orally from all participants.

Individual interviews explored the sociocultural environment and current vaccine infrastructure in Andhra Pradesh, India, with respect to (a) current vaccine utilization (e.g., Have your children received vaccines through the EPI program? What vaccines have they received?), (b) potential barriers to receiving existing and new vaccine (e.g., What are reason for not getting vaccines?), (c) knowledge of HPV and related diseases (e.g., What do you know about HPV? What are the potential outcomes related to HPV?), and (d) attitudes toward HPV immunization (e.g., Do you think an HPV vaccine is needed? At what age would you be willing to vaccinate your child for HPV?). Participants were asked about the current immunization programs and vaccine availability. Next, participants' knowledge regarding HPV infection, genital warts, and cervical cancer was assessed. Since pilot testing of the guide indicated very limited knowledge about HPV and HPV-related diseases, a script was developed to provide medically accurate information on HPV, HPV vaccine, and cervical cancer so participants could provide their opinions on HPV-vaccines. The interviewer verbally provided this information to every participant before eliciting opinions about HPV vaccination.

Demographic information (e.g., age, occupation, education, religion) were collected.

### Data Analysis

The interviews were audiorecorded, transcribed verbatim, and translated from Telugu into English. Prior to the analysis, all personal identifiers were removed. Qualitative data were managed using Atlas ti. 6.0 (Muhr, 2004). To analyze the interview data, a coding matrix was created based on the literature, interview questions, and preliminary readings of transcripts. Following constant comparison methodology, this coding structure was applied to the full transcripts and then transcripts, were searched for negative cases to identify exceptions to the initial themes; codes were modified as needed, with returns to the data for additional comparisons across parents (e.g., by gender; Glaser & Strauss, 1967). Emergent categories included the following: (a) STI, HPV, and cervical cancer knowledge; (b) general vaccine knowledge and behaviors; and (c) HPV vaccine preferences and acceptability. The researchers selected quotes that best represented the themes illustrating the commonalities and individual variation among the parents and were edited for readability and clarity.

## RESULTS

### Demographics

The participants were 19–62 years old (average = 30), and the majority were mothers (83%) and Hindu (81%). Education ranged from none to postgraduate degrees, and most (67%) were employed. Table 1 provides a complete description of relevant demographic information.

### Knowledge About STI, HPV, and Cervical Cancer

Parents had low levels of STI awareness with the exception of HIV/AIDS. Nearly all the respondents ( $n = 28$ ) reported HIV/AIDS knowledge with a high level of accurate information: “This infection affects people through multiple sexual contacts with unknown persons and also through injections” (mother, 35 years old). Conversely, seven participants reported not knowing about condoms (*nirodh*).

In contrast to high HIV/AIDS knowledge, only two parents reported any knowledge of HPV. All but seven participants had heard of cervical cancer; however, only one knew cervical cancer was associated with an STI: “Sometimes, some HPV types cause warts in the genital area called venereal or genital warts. It gets both in men and women. Sometimes, other HPV types cause cervical cancer” (mother, 28).

**TABLE 1** Participant Characteristics

Characteristic	<i>N</i>	%
Age (in years)		
Mean = 30		
<25	9	25.0
25–34	14	38.9
35–44	9	25.0
45+	2	5.6
DK/not reported	2	5.6
Gender		
Female	30	83.3
Male	6	16.7
Religion		
Hindu	29	80.6
Christian	5	13.9
Not reported	2	5.6
Education status		
None	13	36.1
1–8	12	33.3
9+	9	25.0
Missing	2	5.6
Occupation		
Not employed	12	33.3
Employed	24	66.7
Total number of children		
1	3	8.3
2	19	52.8
3	10	27.8
4+	4	11.1
Age of eldest daughter (in years)		
16+	7	19.4
9–15	12	33.3
<9	13	36.1
Missing	4	11.1
Vaccinated status of EPI vaccines		
Not vaccinated	4	11.1
Vaccinated	21	58.3
Don't know	11	30.6
All children vaccinated through EPI program		
Yes	35	97.2
No	1	2.8

### General Vaccine Knowledge and Behavior

Overall, parents understood that vaccinations were important “to have good health, to keep children healthy, and prevent disease” (mother, 20), with several parents ( $n = 7$ ) specifically stating that vaccines protect children’s health. One mother (28) added:

For the small children, vaccines are very much needed because, as we are educated, we know the importance of vaccines. It is important to

give vaccine to children because we've seen children who suffered from polio. To avoid getting polio and other diseases, we give these vaccines, to better their childhood and then the child will be healthy and safe.

Despite the awareness of vaccine benefits, understanding was low about specific illnesses that vaccines target. While the majority of parents ( $n = 35$ ) reported their children received complete vaccinations, they were less sure about what their children had been vaccinated against. Some mentioned diseases such as polio and hepatitis, other parents were uncertain: "I don't know the names, but my children they got vaccinated" (mother, 38). Several parents were unaware of need for vaccines to be given at older ages: "I don't know, nobody told me [about need to vaccinate at 5 and 10 years of age]" (mother, 30). Not surprisingly, given that the vaccine was not currently available, none of the participants knew about the HPV vaccine.

Most parents reported having access to the government supported childhood immunization program. The program includes a government health worker or auxiliary nurse midwife (ANM also called "government sister") traveling monthly to the villages to provide a variety of vaccinations to infants. All program vaccines are provided free of charge; however, some parents paid for specific vaccines (e.g., at private clinics or vaccines not included in the government program). There were some noted differences between private and government vaccine locations, as illustrated by a parent who said that "In private settings there is no guarantee, we have belief in government . . . if any problem comes also we have chance to ask them" (mother, 24).

Extensive vaccine programs resulted in vaccine behavior being heavily influenced by health professionals. Several parents ( $n = 8$ ) reported a willingness to do whatever the doctor or health worker instructs them: "She [ANM] says if we give the vaccine from childhood onwards then we can prevent certain diseases, so that's why we're prepared to give vaccines to children" (father, 38). Another father (35) commented that lack of education meant that they relied on the provided information:

We have not studied much and we don't have much knowledge about these things even. The doctor gives our treatment; we only accept it. That's all. We don't know what types of medicine are given, the only thing we do is we follow according to what were suggested to us to do, that's all.

Little emphasis was reported in helping parents understand the utility of the vaccines or the importance of booster vaccines for older children.



## HPV Vaccine Preferences and Acceptability

Despite low levels of knowledge related to HPV and the associated vaccine, most parents were willing to vaccinate their children against HPV, especially with a health worker recommendation. Many parents ( $n = 22$ ) reported acceptance of girls-only vaccination. Others ( $n = 12$ ), however, indicated that the vaccine would only be acceptable if it was given to both girls and boys. The gendered behavioral expectations were highlighted by one mother (28):

Why? Mostly boys do wrong and we don't know where he is going and what habits he has. Whereas girls' parents, at least for a while, we will be back of her tracking what she is doing. So in my opinion if the vaccine is given to boys it will be good because he will also get this virus if he has bad behavior habits.

Conversely, one mother (28) discussed vaccination in terms of boys' rights:

Parents will not accept, madam. Vaccine should be given to boys also. . . . Even they have the chance of getting this virus, right? First the virus will affect boys, right? So vaccine should be given to both boys and girls.

Preferences for HPV vaccine delivery included injection ( $n = 7$ ), drops ( $n = 5$ ), tablets ( $n = 4$ ), or a combination ( $n = 5$ ). All parents reported that they would vaccinate their children if the vaccines were free; 18 parents reported willingness to pay. Primary obstacles to vaccination were related to missing work for vaccine appointments and associated costs. Although vaccines were free (or low cost) the family still lost daily wages, as noted by one mother (28):

When we say to them that they need to get children vaccinated, they say that they have work. And even sometimes, if the parents show interest, then the government sister will not come on time promptly to the village. The parents had to wait all day and lost work for that day and lost one day wages because of the government sister's delay.

Overall, the most common barriers to HPV vaccination were work ( $n = 12$ ), cost ( $n = 6$ ), side effects ( $n = 3$ ), education ( $n = 3$ ), and other (e.g., effectiveness, karma;  $n = 9$ ). There was little concern related to transportation as most of the clinics were nearby or health workers came to the village.

## DISCUSSION

The purpose of the study was to assess parents' attitudes about HPV vaccine as well as general vaccine and STI-related knowledge in a specific region

of India. Our results indicated that among parents, STI- (with the exception of HIV/AIDS) and HPV-related knowledge were low, yet HPV vaccine acceptability was high. Parents acknowledged the importance of vaccines for children's health, which likely contributed to positive views of the HPV vaccine.

Similar to existing research (Basu & Mittal, 2011; Bingham et al., 2009; Dinh et al., 2007; Jacob et al., 2010; Kwan et al., 2008; Madhivanan et al., 2009; Sam et al., 2009), parents had not heard about HPV and had limited knowledge about cervical cancer. Although the relationship of HPV knowledge to vaccine acceptability varies (reviewed in Brewer & Fazekas, 2007; Trim, Nagji, Elit, & Roy, 2012), communities continue accepting vaccines with insufficient knowledge. This practice suggests that parental knowledge may not be essential for successful programs (Nichter, 1995); however, public health ethics highlight the need for better informed consent procedures. In contrast to results from another study (Krupp et al., 2010), parents indicated that health care personnel's recommendations and government endorsement play an integral role in vaccine behaviors (Basu & Mittal, 2011). Given the potential role of health providers and government officials, understanding their HPV vaccine attitudes should continue to be investigated.

Furthermore, there have been recent controversies in India over implementation of HPV vaccine studies (e.g., adverse event/side effects) resulting in the suspension of these projects (Choudhury & John, 2010; Larson, Brocard, & Garnett, 2010). Although the concerns were largely unfounded (Choudhury & John, 2010), these unfortunate events highlight the need for Indian health authorities and government officials to address people's concerns clearly and quickly to dispel fears based on misinformation and focus on improving the informed consent process (Larson et al., 2010).

Current immunization programs in Andhra Pradesh focus on children less than 2 years old. The majority of the households in our study reported that their children received at least one of the EPI vaccines. This immunization coverage aligns with previous data; less than 5% of children in Andhra Pradesh had not received any vaccines at all by 2 years of age (National Family Health Survey [NFHS], 2009). Boosters for 5 and 10 year olds are administered opportunistically at the primary health center, which may have implications for the addition of HPV vaccines to the expanded immunization program, given the later age of administration (9–26 years). While parental HPV vaccine acceptability was high, a primary challenge will be vaccinating adolescents who have less formal interactions with the health care system compared with existing vaccine for younger children.

The majority of parents reported acceptance of girls-only vaccination; however, some believed vaccines should be given to girls and boys. The interest in HPV vaccine for both genders is in line with the recent Food and Drug Administration (FDA) approval of vaccination for males in the United

States and needs to be explored further in Indian contexts as it has important implications for reducing HPV and cervical cancer rates.

Our data highlight parental concerns about vaccine-related side effects (Basu & Mittal, 2011). The most common side effects for HPV vaccines are pain at the injection site (local) and headaches (systemic; FDA, 2009). Although these side effects are not serious adverse events, they may represent concerns for the parents, be the basis for misinformation, and lead to negative HPV vaccine attitudes. It is important that personnel provide accurate information about safety and side effects to address potential concerns.

Several other issues were discussed as barriers to HPV vaccine acceptance, including cost, missing work and fitting into the existing program (Das et al., 2008; Jacob et al., 2010; Madhivanan et al., 2009; Sankaranarayanan 2009; Zimet et al., 2006, 2008). While parents expressed apprehension about a vaccine requiring payment, they were also concerned about lost daily wages when taking their children to receive immunizations. This may be a contributing factor for high dropout rates between the first and third doses for vaccines like DPT and polio (Gupta, Gupta, Gupta, Venkatesh, & Lal, 2006) and may be an issue for a multidose HPV vaccine. This is an important consideration when designing vaccine programs. Transportation was not identified as a barrier to HPV vaccine acceptance because health workers come to the villages. While this is how childhood immunizations are delivered, it might not be feasible to reach adolescents through the community-based program. If the vaccine is not directly provided in the villages, then transportation may become a barrier. The feasibility of incorporating HPV vaccines into immunization programs needs to be explored further.

Although the introduction of the HPV vaccine is expected to reduce cervical cancer rates; there continues to be a debate in India about whether prevention resources should concentrate on vaccine-based primary prevention or cervical cancer screening programs. Even in the presence of a strong health infrastructure and an inexpensive test, low compliance with screening continues to be a barrier (Dinshaw et al., 2007; Gravitt et al., 2010; Nene et al., 1996). Screening is still essential in cervical cancer prevention as the population impact of a vaccine-based program will not be apparent for at least 15–20 years and the vaccine is not completely protective against cervical cancer (Basu & Chowdhury, 2009). Women fear cancer diagnosis and frequently neglect their own health to take care of the family (Basu et al., 2006; Gravitt et al., 2010). Therefore, mobilizing mothers to vaccinate their daughters to protect against cancer may be more effective. A multipronged approach with comprehensive education messages that promote HPV vaccination for adolescents and increase awareness of cervical cancer screening may be the most efficient use of resources, especially in low resource settings.

Individual interviews helped delineate personal beliefs about vaccination, but the small sample size and demographics of the participants (e.g.,

majority Hindu compared with Muslim) may not represent the whole community's views. Potential religious differences and fathers' influences on vaccine acceptance should be explored more fully. The relationship of HPV vaccine acceptability to actual vaccine uptake and coverage may depend on a variety of factors such as mandatory vaccinations and vaccine delivery. HPV vaccine acceptance after programs are implemented needs to be evaluated.

Current HPV vaccine acceptability research has primarily been conducted in the United States, Europe, and some Asian countries (Bingham et al., 2009; Brewer & Fazekas, 2007; Dinh et al., 2007; Kwan et al., 2008; Zimet et al., 2006, 2008). Given the cervical cancer burden and the population density and diversity in India (and other developing countries), it is essential to get a better understanding of HPV vaccine acceptability. Programs that build on the strong infrastructure of the existing immunization program address parental concerns about vaccine safety and side effects, incorporate positive recommendation from health workers, have governmental policy support, and have efforts to minimize cost of HPV vaccine are essential for the successful implementation and uptake of the HPV vaccine in India. The vaccine delivery mode, number of doses, and other logistical concerns may affect HPV vaccine acceptance and utilization. Although extensive educational campaigns may not be extremely helpful, ethically, accurate information about HPV vaccines and cervical cancer should be provided. Such education programs may allow for development of a dialogue around the benefits of early protection from cervical cancer, thereby enhancing multipronged cervical cancer prevention.

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