“We brought our culture here with us”: A qualitative study of perceptions of HPV vaccine and vaccine uptake among East African immigrant mothers


Abstract

Background: HPV vaccine studies in East African communities are few and focus mainly on Somali women and girls. We examined how HPV vaccine perceptions and uptake are shaped among Somali, Ethiopian, and Eritrean mothers.

Methods: We convened three focus groups in Somali, Amharic, and Tigrinya with mothers of 11–17 year old children. The Socio-Context Framework (social, cultural, and religious factors) and Andersen’s Behavioral Model (predisposing, enabling, and need for care factors) informed question development.

Results: Negative vaccine perceptions, lack of HPV vaccine knowledge, and concerns about side effects emerged as predisposing factors. Having a provider who engages parents on HPV vaccination and takes responsibility for vaccine-related risks emerged as enabling factors. Availability of vaccine information resources (e.g., person-to-person, word of mouth education for parents) were also enabling factors. Need for care factors included having comprehensive vaccine information, strong recommendation from a doctor, and validation from a co-ethnic medical professional. Women exerted strong social influence on vaccine uptake (social), had concerns about pork gelatin in vaccines (religious), and felt discussions about sex with children were culturally unacceptable (cultural).

Conclusion: Strategies for vaccine uptake among East African immigrants need to address factors that shape HPV vaccine perceptions for adolescents, caregivers, and providers.

1. Introduction

In the U.S., adolescent human papillomavirus (HPV) vaccination coverage lags behind the Healthy People 2020 target of 80% [1]. In 2017, 69% of girls and 63% of boys (aged 13–17 years) had initiated and 53% of girls and 44% of boys had completed the vaccine series [2]. Uptake varies considerably by geographic area [2–4], income level [5,6], and racial/ethnic group [7–12]. A key paper on HPV vaccine initiation and completion across four major racial/ethnic groups reveals disparities for vaccine initiation (65% in Hispanics, 48% in non-Hispanic Whites, 56% in non-Hispanic Blacks, and 56% in non-Hispanic Asians) and completion (42% in Hispanics, 33% in non-Hispanic Whites, 32% in non-Hispanic Blacks, and 35% in non-Hispanic Asians) [12]. The paper, however, did not account for heterogeneity among population subgroups, thus overshadowing communities with lower uptake [12].

HPV vaccine uptake in U.S. East African communities is understudied, and most studies have focused on Somali women and girls [13–17] and explored barriers to HPV vaccination as part of a cervical cancer prevention study [13]. A small mixed methods study examining both general vaccine uptake and three specific vaccines (Pertussis/Tdap, Meningococcal/MCV4, and HPV) among Somali, Ethiopian/Eritrean, and Hispanic mothers conducted in 2013 showed that none of 55 Somali mothers and only 8 out of 50 (16%) of Ethiopian/Eritrean mothers reported vaccinating their children for HPV [17]. This study also relegated HPV vaccine perceptions to no or minimal HPV vaccine awareness, thus simplifying HPV vaccine experiences in these communities [17].

HPV vaccine uptake may present distinct challenges due to lack of school requirement [18], adolescent involvement in decision-making together with parents and providers [19], misconceptions about efficacy and safety [20–22], and cultural beliefs that vaccines normalize premarital sexual activity [15]. This study explores how perceptions of, and decisions around, HPV vaccine uptake are shaped among Somali,
Ethiopian, and Eritrean mothers.

2. Methods

Focus groups were conducted to inform development of a multi-level communication intervention to promote adolescent HPV vaccination in Somali, Ethiopian, and Eritrean communities in King County, Washington State. Intervention components included comic books for adolescents, educational forums for mothers and an online CME course for providers. Focus groups were structured to unveil factors that shape individuals’ perceptions and uptake of HPV vaccine, and provide feedback on comic book content and the interactive educational forums. Data were collected from February 2017–April 2017. The University of Washington Institutional Review Board approved this study. Participants received a $25 gift card.

2.1. Recruitment and data collection

We convened three focus groups, one each in Somali, Amharic, or Tigrinya (9–11 mothers per group, n = 30). We used purposive sampling to recruit mothers based on self-reported HPV vaccination status of their children, including up to 3 mothers with vaccinated children in each group. Eligibility criteria included fluency in the target language and having ≥ 1 child 11–17 years old. A bilingual (English and either Somali, Amharic, or Tigrinya) and bicultural research staff member (RSM) recruited women face-to-face at community meeting places or events, or by telephone. Community partners also provided contact information for potential participants. The RSM explained the study, noted languages spoken, and collected children’s (11–17 years old) age, gender and HPV vaccination status. Demographic and immigration information were also collected.

Sessions were facilitated by a bilingual/bicultural moderator trained by LKK. Written informed consent was administered in the participants’ native language prior to the discussion. Sessions lasted 1–1.5 h and were audio recorded and translated from Somali, Amharic, or Tigrinya into English.

2.2. Moderator guide

A moderator guide covered key HPV vaccine factors from the literature [23,24]. Two theoretical frameworks informed the development and analysis: Socio-Context framework and Andersen’s Behavioral Model of Health Services (Table 1). Integration of both frameworks was necessary to capture multi-faceted constructs (psychological, behavioral, and social) that contribute to vaccine uptake. The Socio-Context framework consists of the contextual forces (e.g., social, cultural, and religious) that shape day-to-day experiences that directly and indirectly affect health behavior [25,26]. Andersen’s Model proposes that health services utilization is determined by three factors: predisposing, enabling, and need for care factors [27]. Predisposing factors include demographics and health beliefs. Enabling factors enhance or impede ability to use health services, including family and community support. Finally, need for care includes perceived risk of illness [27]. RSMs reviewed questions for cultural appropriateness.

2.3. Data analysis

Focus group audio recordings were transcribed verbatim and translated into English. Data were coded using a template approach, with key themes emerging from the data, guided by a focus in the literature and the frameworks described above. Quotes for quotes are included in the results to ensure linguistic and cultural accuracy.

Table 1

<table>
<thead>
<tr>
<th>Social Context</th>
<th>Domains</th>
<th>Example of Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Context</td>
<td>What do you think is the role of family/friends in parents’ decision to vaccinate their children for HPV? Can you tell us about how family/friends may be helpful or not helpful in parents’ decision to vaccinate their children for HPV?</td>
<td></td>
</tr>
<tr>
<td>Cultural Context</td>
<td>Can you tell us about cultural beliefs in your community that can make it easy or difficult for adolescents to get vaccinated for HPV?</td>
<td></td>
</tr>
<tr>
<td>Religious Context</td>
<td>Can you tell us about religious beliefs in your community and how people’s beliefs play/do not play a role in parents’ decision to get their adolescent children vaccinated for HPV?</td>
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</table>

Andersen’s Behavioral Model of Health Services

<table>
<thead>
<tr>
<th>Healthcare Context</th>
<th>Predisposing</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>– Why do you think parents will/will not get their children vaccinated for HPV?</td>
</tr>
<tr>
<td></td>
<td>– What do you think is the role of the healthcare provider in parents’ decision to vaccinate their children?</td>
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<tr>
<td></td>
<td>– Need-for-Care – How much do you think people in your community understand about HPV vaccination?</td>
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</table>

Note. The Social context domains are from Pasick et al. [25] and Burke et al. [26]; the healthcare context domains are from Andersen’s Behavioral Model of Health Services, Andersen et al. [27].
2.3. Data analysis

Two researchers (LKK and HHD) independently reviewed each transcript to identify main ideas and meanings [28,29]. We generated tentative labels to capture each idea’s essence, and compared and contrasted notes. We then reviewed the data and clustered similar ideas into themes and codes representative of each theme. The coding scheme was refined throughout data analysis. We also created freehand domain charts mapping the interrelationship between concepts. Focus group data were organized using ATLAS.ti, version 7 (Scientific Software Development, Berlin, Germany, 2013).

3. Results

Table 2 reports participant demographics. Fig. 1 provides the pictorial overview of our results. The four outer boxes denote the four factors (predisposing, enabling, need for care, and contextual) that shape East African mothers’ HPV vaccine perceptions and decisions around uptake. Within these boxes are key factors mothers identified as influencing the larger factors affecting vaccine perceptions and uptake. Starting with the predisposing factors in the upper left corner of the figure and moving clockwise, we discuss each in turn.

3.1. Predisposing factors

3.1.1. Vaccine perceptions

Across groups, many women indicated general concerns about vaccines and associated vaccination with disease risk. Risk perception was shaped by healthcare experiences in home countries. When discussing the HPV vaccine, an Eritrean woman bluntly out “vaccine is terrible;” another woman in the same group elaborated this fear:

"...Our people are afraid of vaccines, I, myself, am afraid of vaccines. For example, I never get my children a flu shot and I also have never taken flu shots in my life.

Ethiopian women shared similar sentiments about flu shots indicating that they began getting flu after getting flu shots in the U.S. and “back at home in Ethiopia” they never caught the flu. Women’s experiences in their home country seem to affect their healthcare decisions in the U.S. An Eritrean woman said “childhood upbringing from back home” affects parents’ health decisions for themselves and their children. Others thought the U.S. healthcare system was too dependent on medications and vaccines, leading to negative health outcomes, thus questioning HPV vaccine efficacy. Another Eritrean woman said:

It is...what we see around us. There are people who are dependent on medication and/or vaccines. Some are anxious and can’t function without a medicine. It makes me wonder if the HPV vaccine would really help my children. There are more illnesses and death in this country than back home...

3.1.2. HPV vaccine knowledge

Most women did not know about the HPV vaccine. Some confused HPV with HIV; others asked for more information about symptoms and transmission. When the moderator explained that transmission was via sexual contact, some expressed concerns regarding children’s sexual behavior and abstinence. A Somali woman emphasized the importance of ‘understanding’ vaccine efficacy in shaping mothers’ HPV vaccine perceptions and decisions to vaccinate their children:

When you understand...that it’s for your kid’s health. And when you understand what it’s preventing. Then that mother will be convinced and will vaccinate her child, but only if she understands. But if she doesn’t understand then she won’t allow it.

3.1.3. Side effects

Across all groups, the topic of vaccine safety made for dynamic discussion. There was an overall sentiment of fear for vaccine side effects. Women shared experiences of witnessing sickness, fever, and fainting in children after vaccination. An Ethiopian woman said she would not vaccinate her children “if it has side effects,” and would “if it doesn’t have side effects.” An Eritrean woman shared similar sentiments about vaccine safety and how her fear delayed her children’s future clinic visits and ultimately her decision to not vaccinate her children:

When they [her children] were younger, the doctor told me [about the HPV vaccine]. Then we did not go back. When we went back later, the doctor explained the vaccine to my children, but they [my children] decided against it. I am kind of scared because I am concerned about the side effects. Because of that, I did not push them to do it.

An Ethiopian woman shared that healthcare providers need to be transparent about side effects. Another woman from the same group said decisions ultimately come after weighing vaccine pros and cons, corroborating the importance of having side effect information.

3.2. Enabling factors

3.2.1. Healthcare provider responsibility

Many women discussed experiences communicating with providers about HPV vaccine. There was lively cross talk among women about the provider’s role. Most said providers were ‘information givers’ but decisions rested with parents. The topic of ‘provider responsibility’ naturally emerged in the Ethiopian focus group (i.e., who should take responsibility for “risk of the vaccine”). Some saw this as doctors’ responsibility, while another woman from the same focus group said risk-taking was parents’ responsibility. Regardless, there was consensus that providers need to engage parents in communicating about the vaccine. A Somali woman stated:

I asked him [the healthcare provider] to explain so I could understand every step well. She brought me a translator in person, not by phone. He [the translator] came and explained well and I decided to vaccinate myself and my daughter.

3.2.2. Community resources

Across all groups, women shared the need for information from multiple sources including healthcare providers or media, such as DVDs. DVDs were noted as helpful tools to engage children on the topic of sexual health as it is difficult to broach the topic. Peer-to-peer information sharing emerged as more relatable to children and an opportunity to empower adolescents to ask their mothers to take them to
3.4.2. Cultural and religious factors

A Somali so, you heard from the doctor and asked your friend, right? A Somali woman emphasized the need to receive information by word of mouth. A Somali woman said:

We’re an oral society. If you write something on a paper and put it on the wall we just pass it by. But if you say come here look at this paper and you are told something verbally then you’ll listen. It's our culture. We'll listen if you tell us something verbally. But if you hand me a bunch of paper, I'll throw it away. It ends up in the trash.

3.3. Need for care factors

3.3.1. Vaccine uptake needs

Mothers discussed how their need for HPV vaccination is elevated when they are informed of the vaccine's purpose, importance, efficacy, and side effects. Women also stated that a strong recommendation from a co-ethnic or culturally sensitive provider elevated their need for vaccination. An Ethiopian woman shared her thoughts on the kind of word of mouth. A Somali woman said:

We’re an oral society. If you write something on a paper and put it on the wall we just pass it by. But if you say come here look at this paper and you are told something verbally then you’ll listen. It's our culture. We'll listen if you tell us something verbally. But if you hand me a bunch of paper, I'll throw it away. It ends up in the trash.

3.4. Contextual factors

3.4.1. Social factors

The social influence women exert with one another in their daily lives through shared experiences emerged in all groups. A Somali woman said, “We always talk about our children.” Women also discussed how their friends serve as sounding platforms to validate or invalidate doctors’ recommendations, with friends’ advice trumping doctor recommendations. An Eritrean woman shared how she reconciles information from her doctor and her friends:

At first, when the doctor told me, I was scared. I asked my friend, and she explained it to me. I thought about it and went back to my doctor. I told my doctor that I need time to think about it.

Another woman from the same group validated her point saying: “so, you heard from the doctor and asked your friend, right?” A Somali woman was more specific about how she weighs information:

…If the doctor tells me to vaccinate my children...and the doctor hasn’t explained, I will consult with another mother. If I ask her about the vaccine and she says she vaccinated her kids, it’s a good thing and that her doctor explained it to her and she tells me what it prevents, then, I will change my mind about it. I will trust her since I know her...I know that she wouldn’t tell me something bad and wouldn’t harm her child... I will be influenced by seeing mothers like myself.

3.4.2. Cultural and religious factors

There was crosscutting discussion of culture and religion when the topic of culture emerged. Women from all groups used the terms interchangeably. As shown in the literature, Somali women corroborated concerns of “pork gelatin” in medicines [30]. One Somali woman resolved confusion among the group by saying gelatin content was on the “outer capsules of medicines,” not vaccines. An Eritrean woman shared that culture and religion impact healthcare decisions, extending to non-compliance with prescription medication. Ethiopian women disagreed:

Definitely our culture and religion doesn’t affect our decision...The only thing is that we do not have the information.

The same woman later shared her community’s utter beliefs that everything is in God's hands, unknowingly suggesting the concept of fatalism. In all groups, women shared that it was culturally unacceptable to engage in discussions about sex with their children and that “anything that has to do with man and woman relationship is a secret.” An Eritrean woman noted that their health behaviors in the U.S. are shaped by their culture, saying, “we brought our culture here with us.”

4. Discussion

This study examined how HPV vaccine perceptions and decisions around uptake are shaped among Somali, Ethiopian, and Eritrean mothers. General vaccine perception is first shaped in the home country, and brought over when immigrating to the U.S. There was overall mistrust for vaccine safety rooted in experiences from home country and views of the U.S. healthcare system’s dependency on medicine and vaccines. Vaccine mistrust within African countries ties to “Western Plot” theories that suggest vaccines are ploys to sterilize or infect non-western communities [30-36]. Vaccine mistrust may play a bigger role for non-mandated vaccines such as HPV and flu. In fact, during one focus group, women expressed concerns with the study's specific interest in East Africans. Our findings suggest that providers should be aware of strong, pervasive vaccine mistrust among some members of the East African communities, and address vaccine safety when communicating about the HPV vaccine.

Social, cultural, and religious factors affect women's decisions to vaccinate children. Relational interdependence among immigrants has been widely reported in the literature [25,26,37,38], where decisions around breast cancer screening among Hispanic and Filipina women occurred within the context of group interconnectedness [25,26,37,38]. Our study shows friends exert similar influence among East African women, and their decisions to vaccinate their children is co-constructed with their friends’ advice, even trumping providers’ recommendations. Fathers, on the other hand, appear to have a lesser influence on mothers’ decision to vaccinate their children. Although a few mothers mentioned that they discuss their children's health issues with their husbands, others relegated fathers' roles to providing general support for children when mothers were not available.

Religion and culture seem to be co-constituted in these communities as they used the terms interchangeably. Religion and culture directly influence Somali and Eritrean women's health decisions; however, influence was less direct for Ethiopian women. Context framework literature corroborates our findings where social, cultural, and religious dimensions are conceptualized as formed in relation to, and by, each other, and often influence people in ways they are not consciously aware [25,26,37,38]. Research shows that the single most important factor influencing parents’ decision to vaccinate their children is physicians’ recommendation [17]. Our findings show that decision-making for vaccination among East African mothers is more complex, and providers need to be strategic. Providers may want to connect with East African mothers at a level familiar to them (for example, shared goals to protect their child’s health) and view mothers beyond the role of a patient’s mother, but also a potential “social influencer” who can champion vaccine uptake in the community.

Our participants demonstrated limited knowledge of HPV vaccines yet had abundant information/misinformation about overall vaccine side effects. Community resources need to leverage community-trusted sources, such as churches, community centers, and use electronic
media, word-of-mouth to inform parents, and peer-based education for their children. Rather than providing generic information on the HPV vaccine, use of universal metaphors, such as the use of water to note a vaccine may have stronger cultural resonance to East African women.

Andersen’s Health Model conceptualizes need for care as perceptions of disease status or risk [27]. Need for care was challenging to capture because our participants had low awareness of HPV. However, our findings show that need for care emerged when women had access to information that counter-balanced their fear of side effects, and strong vaccine endorsement from a co-ethnic or culturally sensitive provider. This form of capturing need for care may be relevant for ‘emerging’ health problems where people’s perception of illness is not yet construed.

This was the first study to explore HPV vaccine perceptions in three East African communities: Somali, Libyan, and Eritrean. Another strength is the exclusive focus on the HPV vaccine enabling us to capture unique perspectives, values, and experiences not reported in prior research. A limitation is that only one focus group was conducted per community. Although we believe we reached saturation and themes were validated by our bilingual/bicultural RSM, future studies should further explore other contextual forces. Finally, participants were from urban settings; those from non-urban settings may show different perceptions of HPV vaccines.

5. Conclusion

Promotion of vaccine uptake among East African communities is an important step towards reaching the Healthy People 2020 goal. Our study highlights unique factors that consciously or unconsciously shape HPV vaccine perception and decisions around HPV vaccine uptake among Somali, Ethiopian, and Eritrean communities. Strategies for vaccine uptake among East African communities need to address these factors and use trusted community resources and healthcare providers for vaccine promotion.

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Competing interests

None.

References


