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## Incarcerated women's HPV awareness, beliefs, and experiences

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### Abstract

**Purpose**—The purpose of this paper is to explore incarcerated women's awareness, beliefs, and experiences with human papillomavirus (HPV) infection and vaccination.

**Design/methodology/approach**—Researchers conducted focus groups with 45 incarcerated women in an urban Midwestern US jail to assess how women talked about their Papanicolaou (Pap) test screening and abnormal Pap test follow-up experiences. Some focus group questions specifically assessed individual awareness, beliefs, and experiences with HPV infection and vaccination. Based on these data, the authors described participants' awareness of HPV, as well as used open coding to ultimately extract themes related to beliefs and experiences with HPV infection and vaccine.

**Findings**—While all 45 participants reported experiencing an abnormal Pap test event within the last five years, only two-thirds of participants ( $n = 30$ ) reported having heard of the HPV infection. Several themes emerged from the analysis of the data: the women's beliefs about cause and severity of HPV; frustration with age requirements of the vaccine; varied experiences with vaccinations for themselves and their children; the impact of media exposure on knowledge; and desire for more HPV infection and vaccine information.

**Originality/value**—Incarcerated women's awareness and limited experiences with HPV infection and vaccination may be a barrier to adequate screening and cervical cancer prevention. This study has implications for the development of cervical health education for this high-risk group of women, who are four to five times as likely to have cervical cancer as non-incarcerated women.

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<sup>1</sup>Pseudonyms used to identify participants.

## Keywords

Criminal justice system; Correctional health care; Post-release care; Women's health; Health promotion; Sexual health

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## Introduction

Women incarcerated in jails and prisons report multiple risk factors for human papilloma virus (HPV) and cervical cancer – histories of multiple sex partners (Binswanger et al., 2011; Fogel and Belyea, 1999), sexually transmitted infections (STIs) (Hale et al., 2009; Hogben et al., 2001), exchanging sex for money, drugs, or life necessities (Bond and Semaan, 1996; Magura et al., 1993), and tobacco use (Cropsey et al., 2004). Prevalence studies of HPV in correctional settings have shown rates ranging between 27 and 46 percent (Bickell et al., 1991; de Sanjosé et al., 2000; González et al., 2008). Indeed, over the last 40 years incarcerated women have been four to five times more likely to have cervical cancer compared to non-incarcerated women (Binswanger et al., 2009; Moghissi and Mack, 1968).

Cervical cancer prevention requires identification of high-risk HPV types and appropriate follow-up, or historically regular attendance at Papanicolaou (Pap) test screenings and follow-up of abnormal Pap tests. Women with criminal justice histories report varying levels of being up-to-date on Pap test screenings (Binswanger et al., 2005; Nijhawan et al., 2010; Plugge and Fitzpatrick, 2004; Ramaswamy et al., 2011), in addition to which, follow-up rates for appropriate care are generally low (Clarke et al., 2007; Martin et al., 2004, 2008). Ongoing periods of criminal justice involvement (James, 2004), low rates of health insurance coverage or primary care coverage in the community (Lee et al., 2006; Ramaswamy et al., 2011), and low cervical health literacy (Ramaswamy et al., 2014) may, in part, explain the disproportionate cervical cancer burden that incarcerated women face.

Given the changing global landscape of cervical cancer screening and the inclusion of HPV typing as a primary screening tool (Food and Drug Administration, 2014; Ronco et al., 2014), many vulnerable women may miss the opportunity for important education related to new technologies and procedures for screening. The purpose of this study was to generate baseline information about the high-risk group of incarcerated women's awareness, beliefs, and experiences with HPV infection and vaccination as a way to inform future public health education efforts for such vulnerable groups. To our knowledge, little to no information is available about incarcerated women's awareness of HPV, despite their risks.

In the general "free" population, greater awareness about HPV is typically exhibited among individuals who are older, female, and sexually active, and those with a history of genital warts and/or cervical dysplasia (Gerend and Magloire, 2008). An examination of Australian women's knowledge regarding HPV infection, cervical cancer, and vaccination showed that among a group of 90 women aged 18-30, 89 percent had heard of HPV and 94 percent of participants understood the purpose of the Pap test and its recommended frequency (Giles and Garland, 2006). However, a survey among over 1,200 women in the USA between 18 and 75 years of age demonstrated that fewer than 2 percent of respondents correctly answered questions measuring HPV knowledge and <50 percent of women had heard of

HPV. Moreover, less than half of the women who had heard of HPV knew that it could cause cancer (Daley et al., 2010). A Swedish study similarly found that less than one-third of participants had ever heard of HPV, but of those who had heard of HPV, in that study between 56 and 82 percent knew that it could cause cervical cancer (Dahlström et al., 2012). Another study among 1,106 Italian participants who had recently visited a sexual health center reported that only 36.5 percent of participants knew of an HPV vaccine (Capogrosso et al., 2014).

Prior research also reveals racial/ethnic disparities in awareness and knowledge of the infection. Several recent studies concluded that Hispanic and non-Hispanic Black women in the USA were significantly less aware of both the HPV infection and vaccine compared to non-Hispanic White women of the same age (Ford, 2011; Gelman et al., 2011). Low-income women also appeared to be disproportionately affected by the HPV infection (Kahn et al., 2007). Lower levels of HPV awareness among these groups is of particular concern for this study, considering that the majority of incarcerated women in the USA, the site of the present study, are low-income, racial/ethnic minorities (Greenfeld and Snell, 1999). A secondary goal of this study was to see whether these low levels of awareness and knowledge were ubiquitous – or perhaps unique – to the high-risk group of incarcerated women. Given incarcerated women’s multiple risks for HPV and cervical cancer, they certainly have more at stake when it comes to awareness, beliefs, and experiences with HPV infection and vaccination.

We estimate that one-fifth of women in the US criminal justice system are eligible for HPV vaccination based on age recommendations in the USA, and about 70 percent of incarcerated women have children under age 18, many of whom would be eligible for vaccination (Centers for Disease Control and Prevention, 2014; Greenfeld and Snell, 1999). In addition to their need for information, and risks for HPV and cervical cancer described above, we were interested in whether a group of incarcerated women were current on the changing recommendations for cervical cancer screening and prevention, including new information on HPV typing and vaccination technologies. Therefore, the objective of this study was to provide a preliminary assessment of incarcerated women’s awareness of the HPV infection and vaccine. We further sought to elicit women’s general beliefs about HPV and their experiences with the infection and vaccination, which may inform future efforts at targeting a high-risk group of women in the criminal justice system with HPV and cancer prevention messaging.

## Approach

Over a four-month study period from 2011 to 2012, we conducted four focus groups assessing incarcerated women’s interpretation of abnormal Pap test screening events and subsequent follow-up with a sample of 45 women in a Kansas City, Kansas jail in the USA. The goal of this larger parent study was to better understand the processes that affect women’s ability to access cervical cancer prevention and follow-up (Ramaswamy et al., 2014). Included in the focus groups were questions that specifically addressed HPV awareness, beliefs, and experiences. This subset of data is the focus of the present study.

## Procedures

Participants were recruited with flyers posted at the facility and through word of mouth recruitment in each housing unit by the special programs coordinators. On any given day, about 300 men and women, total, were housed in the jail facility. About 10 percent of the average daily population was female and the average length of stay was 13.6 days. Any woman experiencing an abnormal Pap test screening result in the last five years was eligible and invited to participate, based on the aim of the parent study. Only those women who volunteered were included as participants. Recruitment occurred approximately once per month over the four-month data collection period to ensure new samples of women participating in each focus group. The special programs coordinator recruited a maximum of 13 eligible women for each focus group on a first-come-first-serve basis.

The focus group moderator read the study consent form to all potential participants in English. After women signed the informed consent document and agreed to participate in the study, we conducted a 60-90 minute audio-recorded focus group. All focus groups were conducted in the law library of the jail, where the moderator, participants, and other study staff sat around rectangular tables. Each participant received a \$20USD gift basket with snacks and hygiene products of equivalent value as compensation for participation. The protocol for this study was approved by the University of Kansas Medical Center Institutional Review Board.

## Data collection

Prior to beginning each focus group, participants provided the following demographic information: race and ethnicity, age, level of education, number of children living at home under age 18 and under age five prior to incarceration, marital/partner status, employment status prior to incarceration, health insurance coverage prior to incarceration, and whether they had a regular health provider prior to incarceration.

For this secondary data analysis, we focussed specifically on the focus group probes related to awareness, beliefs, and experiences with the HPV infection and vaccination. For example, prompts of interest included, “What do you know about the human papillomavirus, also known as HPV?” and, “Have you ever heard of the HPV vaccine? If so, have you been vaccinated?” We asked participants to self-report an HPV diagnosis, if applicable. This study did not measure HPV knowledge. Rather, we were most interested in assessing women’s understanding of the infection and vaccine, or lack thereof. We did not expect to reach thematic saturation with this secondary data analysis – the analysis presented here is exploratory and meant to guide future research.

## Data analysis

Descriptive statistics such as means, standard deviations, and percentages were calculated for demographic characteristics. All focus group recordings were transcribed and checked against the original recordings to ensure accuracy. A five-step process was used for the analysis:

1. focus group probes about HPV, specifically, were used to guide a research assistant's initial analysis of selected sections of data and identify levels of awareness of HPV;
2. open coding was then used to delineate conceptual categories in selected sections of data;
3. dominant themes were extracted from the data related to beliefs and experience with HPV infection and vaccination;
4. data were extracted and organized according to the emerging themes selected; and
5. two other researchers, including the principal investigator, reviewed transcripts, codes, and themes to verify interpretation of data.

## Findings

The 45 women who participated in this study were, on average, 34.0 years old ( $SD = 9.9$ ). More than half of participants were non-Hispanic White ( $n = 25$ , 55.6 percent), and the remaining women were non-Hispanic Black ( $n = 16$ , 35.6 percent) or American Indian/Alaskan Native ( $n = 3$ , 6.7 percent). Participant characteristics are described fully in Table I.

Awareness of the HPV infection was explored by asking focus group participants to raise their hands if they had ever heard of the human papillomavirus, also known as HPV. Across the sample of 45 women, who had self-reported an abnormal Pap test event in the previous five years, only two-thirds ( $n = 30$ , 66.7 percent) of participants reported an awareness of the HPV infection. The remaining one-third of women reported never having heard of the HPV infection. Two participants out of 45 reported a current cervical cancer diagnosis. Less than 10 percent ( $n = 4$ ) self-reported a past diagnosis of HPV.

Throughout all four focus groups, less than one-quarter of women ( $n = 10$ , 22 percent) indicated a provider-based knowledge of the HPV infection and/or Gardasil vaccine, which is the vaccine most commonly used in the USA. Of those ten women, one completed the HPV vaccine series and two women completed two out of three shots in the Gardasil series. Two women indicated an awareness of the HPV infection stemming from a close friend or relative who had been diagnosed with HPV and/or cervical cancer. Several women indicated that although they had heard of HPV, they did not know what it was, but rather only remembered having previously heard the term.

Across the four focus groups of 45 women, only two women were able to articulate a good understanding of the importance of: Pap tests; and the Gardasil vaccine, in relation to HPV detection and cervical cancer prevention, respectively. Vickie[1], a cervical cancer survivor and mother of three, explained, "It's also good to get Pap smears because it can find out if you have HPV, which the HPV causes the cervical cancer. Well, some HPV causes cervical cancer. Then you can get the Gardasil shot to help."

Casey, a 22-year old, reflected on her primary care provider's recommendation to her saying, "It would be good now if you want to start. If you got the three sets of Gardasil shots just to prevent it [cervical cancer]." The participant went on to describe how she visited her

doctor's office every three months to get the three series vaccine to "prevent HPV and cervical cancer." Both participants appeared to have received information from medical providers about HPV, though only one clearly understood that the vaccine for HPV was preventative.

### **Beliefs about cause and severity of HPV**

Several women accurately described the HPV infection as the most common STI, as becoming more and more widespread among the general population, and as capable of producing warts and/or cervical cancer. Beliefs about HPV were informed mostly based on the experiences of others or what participants had heard from medical providers. For example, Randy, a woman in her mid-40s who spoke of a niece recently diagnosed with HPV, compared the infection to a terminal illness. She said, "I mean, it's like once you get it, it's like AIDS. For real. You don't get rid of it, you know what I mean? And you have to do regular Pap smears and have these doctors probing you. And if you're gonna have sex, you gotta tell the partner. Then some guys are like 'Eh eh, I'm not foolin' with you.' And you know, my niece had to go through all of that, and it ain't good."

Paula, a 39-year old, said that she learned about the HPV infection through a local medical provider during her daughter's pregnancy. The participant went on to describe how, according to the physician, "Young women are more liable to get cervix cancer because they mess with older men that's penises are way too big." Fellow focus group members were highly critical of this particular comment and quickly expressed their disagreement to such a claim.

Barbara, a 24-year old, shared that during her last well woman's exam roughly six months prior, "It was really stressed to me about the vaccine and about the HPV virus and just how big it is now and how widespread." Barbara indicated that she did not get vaccinated after this visit to her medical provider.

Jennifer, a 26-year old, also had personal experience with HPV. She said, "I got it from my ex-husband. Between our oldest and our middle child, I tested for pre-cancerous cells after I gave birth to my second child and it went away. And then I went back, cause I had my kids back to back. I got an eight-year old, seven-year old, six-year old. But the cancer came back when I was pregnant with my last child and the HPV, my doctor said it was HPV, and that men carry it and they don't know. They won't know about it cause they won't get sick from it or anything but it cause me to almost lose my baby. I had to have a partial hysterectomy done, and a cone biopsy and all that fun stuff. So, I can't have kids anymore so that really sucks."

The women's accounts of HPV experiences above indicated that most understood HPV was sexually transmitted. But they seemed to lack information about the severity of HPV and potential for cervical cancer. Only Jennifer, who appeared to have a cervical cancer experience, was clearly able to trace the severity of the disease and its real-life implications.



### Knowledge of dosing and barriers to continuing vaccine

Even among women who reported an awareness of the HPV vaccine, some lacked knowledge about the specific parameters of the Gardasil vaccine (i.e. a series of three doses that is maximally effective when administered before the age of 26). For example, two out of the three women reporting an HPV vaccination history expressed uncertainty about whether or not they were fully protected against the HPV infection. In both instances, the women had only received two out of three shots in the Gardasil series, yet did not know whether they would have to begin the series all over again, or if they could still complete the series by getting the third and final shot. Ivy said, “One thing led to another and then I’m locked up again and this and that, so I mean, I’ve just had the two [shots], so that means nothing?” Similarly, Kim, a 21-year old, said “By the time it was time to get the third shot, I wasn’t able to make it on the exact date so, do I have to get all the shots again?” Both women were outside of their respective dosing windows.

### Feeling left out of the benefits

Several women expressed frustration about the Gardasil vaccine and its inability to protect all women against HPV. For example, Carla, a 51-year old, took issue with the age limit of the vaccine (currently set at 26 years of age) when she responded, “Yea okay, people at 50 have sex you know.” Another woman commented about feeling “cut out of it” because of her age. Additionally, several women became upset when informed that the vaccine did not offer lifetime protection. For instance, Barbara protested that, “They should be able to do it forever,” referring to the longevity of the HPV vaccine. Others agreed that the vaccination should protect women for the duration of their lives upon administration.

### Vaccination of children

Six women (<10 percent) reported having one or more of their adolescent and/or teenage daughters initiate the vaccine series. Their accounts reflected both the experience with preventive pediatric care, as well as the desire to better understand the need for vaccine. For example, one mother explained, “I had both my kids do the Gardasil shots. You know, there is three of them. I started my oldest one when the first thing came out, um, commercial on television. And then my youngest one wasn’t old enough yet to get it. And at 16, I started her Gardasil. So both of them have been protected from that.”

Another mother of three, Jennifer, said, “I was also told that cause I have two girls, that I’m supposed to get them checked as soon as they start their periods and for the Gardasil and all that fun stuff.” She had been instructed to get her son and daughters vaccinated after being personally diagnosed with HPV. Upon hearing about the HPV vaccine and its importance among adolescent and teenage girls, several women expressed interest in learning more about its applicability in their own children’s lives. For example, a 36-year old mom, Jo, inquired, “My daughter is gonna be 17, so she should get it?”

In this context, as well as in others, we found that the women who openly spoke of personal experiences with HPV or cervical cancer encouraged the other participants to ask questions. The focus group format illustrated how our participants’ sharing of experiences led other participants to express a desire for more information.

### HPV media exposure

Several women vocalized their chronic exposure to advertisements of the Gardasil vaccine through US media outlets such as television and radio. Some women were even cognizant of the advertisers' intended audience. Barbara correctly identified a popular HPV vaccine campaign targeting adolescent and teenage girls when she said, "The 'One Less Commercials,' that's about getting vaccines for HPV, right?" She went on to explain how, "You can tell that's where the commercials go because it's like really young girls. They want to do it [vaccinate] before they're sexually active or whatever." When members of one focus group were probed about what was known about the HPV infection, another woman similarly responded, "Just that it's maybe in the younger girls, 'cause I thought that's who they focus on basically."

### Wanting more information

During discussions surrounding the HPV infection and vaccine, many women felt the need to broaden their understanding of the topic by asking various questions. Questions included how specifically to classify HPV (e.g. how life-threatening is this STI), transmission of the infection if it is transmitted through bodily fluids, skin contact, etc.), vitality after diagnosis (e.g. what is the impact of the infection on an individual's lifespan), and what women should ask their medical providers once they were released from jail in order to protect themselves from the HPV infection. Even Vickie, who was diagnosed with cervical cancer and relatively knowledgeable about the HPV infection, inquired about whether the HPV infection she had during two of her pregnancies could have been passed to her children. Upon receiving a response to her inquiry, she commented, "I didn't know. I had never asked that until now."

The women we conducted focus groups with explicitly requested more information about HPV infection and vaccine when it came to their own preventive efforts, as well as for their children. As described above, the women eagerly probed us about the details of severity, cause, and prognosis of HPV.

### Discussion

Despite our recruitment of women with high risks for HPV – those with a recent abnormal Pap test history – only two-thirds of participants reported awareness of HPV infection or vaccine. We also found that even when women had learned about HPV through their medical providers, our probes still elicited many questions about the specifics of disease severity and vaccination requirements, for example. Our findings mirror the work of others who have found that participants with personal experience with cervical cancer have more knowledge (Gerend and Magloire, 2008) and that awareness and knowledge, in general, vary significantly across samples (Capogrosso et al., 2014; Daley et al., 2010; Dahlström et al., 2012). Ours is one of the few studies to specifically examine incarcerated women's awareness, beliefs, and experiences with HPV infection and vaccine, and on the surface, our sample of women with criminal justice status have no greater or fewer deficits in knowledge compared to samples of women without criminal justice involvement.



This forces us to return to the question of why women with the unique experience of criminal justice involvement may be more vulnerable for HPV and cervical cancer outcomes. Indeed, the cervical health disparities between incarcerated and non-incarcerated women have been demonstrated (Binswanger et al., 2009; Martin, 1998; Moghissi and Mack, 1968; Ramaswamy et al., 2011), as well as the co-occurrence of HPV and multiple other risks factors for cervical cancer and poor health outcomes (Bickell et al., 1991; de Sanjosé et al., 2000; González et al., 2008). Incarcerated women in the USA, the site of our study, are on average 35 years old – old enough that a portion may be out of the loop of current communications about HPV typing and vaccination as part of routine cervical health care. At the level of the data, though participants seemed to understand the infectious nature of HPV, they demonstrated a lack of information about the severity of HPV and its potential for cancer. A persistent thread throughout the analysis was the desire for more information and requests for clarification. We believe this last thread was a result of the focus group format and its potential for encouraging conversation and sharing (Hollander, 2004), rather than something specific to the sample.

Two of our participants also talked about the specific experience of incarceration as a barrier to completing the HPV vaccination series. The barrier of ongoing and short stints of criminal justice involvement to completing the HPV vaccine series is an example of how this group of women may have unique risks for cervical cancer compared to women without criminal justice histories. Women incarcerated in the USA are on average 35 years old, though in this sample, in particular, about one-third of the women were 26 years or less – eligible for the HPV vaccine in the USA. Had the women under age 26 not been vaccinated as children, their adult criminal justice involvement may have precluded continuity of preventive care or vaccine completion. Though this conclusion may not apply to the majority of women, this problem was certainly reflected in the conversations with our participants, as illustrated above.

The small literature on HPV and cervical cancer among incarcerated women describes other risks for HPV and subsequent health problems: co-infection with HIV, high rates of injection drug use and sex risk behaviors that may lead to HIV and thus, HPV (Bickell et al., 1991; de Sanjosé et al., 2000; González et al., 2008), and then the burden of follow-up after cervical cancer screening (Clarke et al., 2007; Martin et al., 2008). Though the literature focusses specifically on follow-up care after Pap test screening (Clarke et al., 2007; Martin et al., 2008), future studies will have to take into account new trends in HPV typing as a primary cervical cancer screening tool (Food and Drug Administration, 2014; Ronco et al., 2014). The literature also points to opportunities for intervention behind bars (Clarke et al., 2007; Martin et al., 2008; Plugge and Fitzpatrick, 2004), with which we agree with and advocate for.

Several limitations surrounding this exploratory investigation are worth noting. This investigation took place among a small convenience sample of participants. The thoughts and opinions expressed among the 45 women participating in the four focus groups discussed here may not reflect other groups of incarcerated women. Therefore, findings may not be generalizable. Data were also collected as part of a parent study examining abnormal Pap test experiences, not HPV experiences, specifically. Nevertheless, we were able to

collect data relevant to the women's health care access experiences, as it relates to Pap tests and other reproductive health screening, which is appropriate for an exploratory study. Given the exploratory nature of the study, we certainly acknowledge that we could have missed important information about the women's experiences as it relates to HPV awareness, beliefs, and experiences. Focus group moderators were all trained in public health, nursing, or medicine, and did not abstain from answering participant questions if or when they arose. As a result, moderator-based knowledge and information-sharing may have influenced participants' willingness, need, or desire to contribute to the focus group dialogue. In order to adequately assess women's baseline perceptions and attitudes, to the extent possible, focus group moderators waited until discussion topics were exhausted before answering participant questions regarding the HPV infection and vaccine. Further, given the sensitive subject matter, as well as the presence of jail staff, it is possible that women felt uncomfortable openly sharing their awareness, beliefs, or experiences with HPV infection and vaccination.

## Implications

Women with ongoing criminal justice involvement may be at increased risk for HPV infection and cervical cancer. This study has implications for the development of cervical health education for the high-risk group of women moving through the criminal justice system, and we suggest that future programs take the following approach:

- target young women, as well as those women with children of vaccinating age;
- provide more information about the severity and implications of HPV and cervical cancer, understanding that the public health education role is to supplement the limited information women hear from community-based medical providers;
- focus specifically on new technologies around HPV typing along with Pap test screening;
- address the confluence of risks: sex, drug, tobacco use, and HIV; and
- capitalize on jail and prison settings for intervention.

In doing so, at least at the individual level, such efforts may serve to close the cervical health gap between incarcerated and non-incarcerated women. At the population level, broader efforts are needed to reach audiences with new information on the rapidly changing technologies for cervical cancer screening and prevention.

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**Table I**

## Participant characteristics

	n/Mean	%/SD
Age	34.0	9.9
Race/ethnicity		
White	25	55.6
Black	16	35.6
American Indian/Alaskan Native	3	6.3
Unknown	1	2.2
High school graduate or equivalent diploma	26	57.8
Children under 18 living at home	1.4	1.6
Children under 5 living at home	0.9	1.4
Partner status as single	18	40.0
Employed prior to incarceration	4	8.9
Health insurance coverage prior to incarceration	24	53.3
Regular health provider prior to incarceration	17	37.8

Note:  $n = 45$