HHS Public Access

Author manuscript

J Health Care Poor Underserved. Author manuscript; available in PMC 2015 November 30.

Published in final edited form as:

J Health Care Poor Underserved. 2015 ; 26(4): 1265–1285. doi:10.1353/hpu.2015.0130.

"The Vagina is a Very Tricky Little Thing Down There": Cervical Health Literacy among Incarcerated Women

Megha Ramaswamy, PhD, MPH [Associate Professor] and
Preventive Medicine and Public Health, University of Kansas School of Medicine

Patricia J. Kelly, PhD, MPH, APRN [Professor]
School of Nursing, University of Missouri-Kansas City

Abstract

The objective of this study was to understand factors associated with women's ability to engage in cervical cancer prevention and follow-up care given ongoing criminal justice involvement. We conducted four focus groups with 45 incarcerated women to assess barriers to cervical health promotion, and used a grounded theory method to analyze data. We administered the Short Test of Functional Health Literacy in Adults to assess general health literacy as a standalone factor related to cervical health promotion. Ninety-one percent of participants had adequate health literacy scores. However, we found that the women had varying levels of cervical health literacy, which we operationalized as knowledge, beliefs, and self-efficacy related to cervical health promotion. Practitioners should establish broader interventions to empower women with criminal justice histories to take control of their own cervical health and focus on communicating updated recommendations to improve cervical health understanding, beliefs, and practices among high-risk women.

Keywords

Cervical cancer prevention; health literacy; jail health; incarcerated women

The one million women under correctional supervision in the U.S. are four to five times as likely to have cervical cancer as non-incarcerated women.[1-3] Between 25%–66% of incarcerated women have had an abnormal Papanicolaou (Pap) test.[4-7] Many women with criminal justice histories bear the burden of multiple risk factors for cervical cancer, including histories of multiple sex partners;[8] sexually transmitted infections (STIs),[9-10] trading sex for drugs, money, or life necessities;[11-12] high rates of tobacco use;[13] and human papillomavirus (HPV) infection.[14-16] Given this backdrop of risk for cervical cancer, the objective of our study was to understand factors associated with women's ability to engage in cervical cancer prevention and follow-up care in both jail and community settings, given the women's ongoing criminal justice involvement.

Correspondence about this article may be sent to Megha Ramaswamy, 3901 Rainbow Boulevard, MS 1008, Kansas City, KS 66160, or by mramaswamy@kumc.edu..

Though several studies have reported high cervical cancer screening rates for this group of women,[7,17,18] follow-up care after initial screening is suboptimal.[5,19,20] Beyond describing cervical cancer risk and follow-up trends, few studies have fleshed out possible causes for cervical cancer disparities between incarcerated and non-incarcerated women. Research with samples of non-incarcerated people suggests that low levels of health literacy may be associated with cancer risk,[21-25] though health literacy levels have gone largely unmeasured among incarcerated women.

Cancer prevention requires knowledge about sexual health, commitment to and self-efficacy for screening and follow-up, and high levels of health literacy in interactions with health care providers and the broader health care system.[22,25] Some studies have found that low health literacy is a better predictor than education level or ethnicity of low cervical cancer knowledge and screening rates.[21,23-24]

Women in the criminal justice system may be dually burdened by low health literacy, as well as the instability of movement between jails and communities. Jails in the U.S. house women awaiting adjudication, sentenced to terms of one year or less, along with probation and parole violators.[26] Therefore, women leave jails days, weeks, or months after arrest. This creates significant challenges when it comes to addressing ongoing health care needs that compete with family, income, housing, and criminal justice, in addition to potentially low levels of health literacy. Prior studies have demonstrated that women in jails receive Pap tests while incarcerated, and those women were more likely to be up-to-date on Pap test screenings, as well.[17] However, given the short-term nature of these jail sentences, continuity of care in the community and commitment to cervical health follow-up remains a challenge. We argue here that high levels of health literacy are needed for women to be able to navigate the challenges of community reentry and engage in preventive health behaviors. To our knowledge, no one has conducted an assessment of health literacy among incarcerated women, especially as it relates to cancer prevention.

A lack of health literacy, defined as "[t]he degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions,"[27[p. 2]] has been associated with numerous adverse health outcomes, including chronic disease, risky health behaviors, hospitalizations, and cancer risk. Low health literacy has been associated with cancer risk, in particular, because it affects communication during cancer care;[22] creates inequality in access to information and medications;[28] is associated with distress, which may be a barrier to seeking cancer care;[29] and has also been associated with failure to follow up after an abnormal Pap test.[30] Yet interventions that build health literacy in the area of cancer prevention are rare,[31-34] and much rarer in the case of health literacy among incarcerated women.

Going into this study, there was scant evidence about the levels of health literacy among incarcerated women, though at least one investigator identified less than complete knowledge about cervical cancer screening.[17] Based on this and our own experiences with data collection about Pap tests among incarcerated women,[7] we hypothesized that low health literacy, in particular cervical health literacy, may be one factor driving the cervical cancer disparity between incarcerated women and women without criminal justice histories.

Ultimately, this was an under-researched area as it related to cervical cancer prevention. Therefore, using qualitative methodology and a standardized measure of general health literacy, we sought to understand factors associated with women's ability to engage in cervical cancer prevention and follow-up care in both jail and community-based settings (given frequent movement in and out of the criminal justice system). Understanding barriers to cervical cancer prevention and the possible contribution of low cervical health literacy to risk among this group of women could contribute to the development of novel interventions to reduce the cancer burden among this already disadvantaged group.

Methods

Sample and recruitment

Over a four-month study period from fall 2011 to winter 2012, we conducted four focus groups with a sample of 45 women in an urban county jail in Kansas City to assess the women's interpretation of abnormal Pap test events and any subsequent follow-up. Participants were recruited through word-of-mouth in each housing unit by the special programs coordinator and with flyers posted at the facilities that said. "Have you had a Pap test or cervical cancer screening in the last five years that came back 'abnormal'? Researchers from the University of Kansas would like to talk to you about your experiences getting a Pap screening and then getting an abnormal result." We chose five years as a cut off so that our participants' responses would reflect relatively recent experiences that we could inquire further about during focus groups.

Thus, any woman self-reporting an abnormal Pap test result in the last five years was eligible and invited to participate. A limitation of this self-identification for eligibility was that we ended up with a sample in which less than half of participants truly had an abnormal Pap test event, based on their individual accounts. Instead, many of the women thought they had an abnormal Pap but actually had some other abnormal gynecologic finding, such as cysts, sexually transmitted infections, or ectopic pregnancy. As a result, our data about barriers to cervical health promotion apply to women self-identifying as having had an abnormal Pap test, even if they misunderstood the term or had other motivations for participating.

On any given day, about 300 men and women in total were housed in the jail facility. About 10% of the average daily population was female, and their average length of stay was 13.6 days. Recruitment occurred approximately once per month over the four-month data collection period to ensure new samples of women participating in each of four focus groups. Recruitment strategies resulted in a maximum of 13 eligible women for each of four focus groups on a first-come-first-serve basis. We estimate that we recruited a little less than half of the women incarcerated at the jail facility on each of the four focus group days. Because only women who volunteered were included as participants, we do not know whether our sample was any different from the group of women who did not participate (e.g., more literate).

Focus group procedures

At the beginning of each of the four focus groups, the moderator read the study consent form to each group of potential participants in English. After women in each group signed the informed consent document and agreed to participate in the study, we conducted a 60- to 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 $20 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.

Once participants consented, we collected sociodemographic data for each participant, asking her age, race/ethnicity, marital status, number of children under 18 years of age, educational attainment, employment prior to incarceration, and health insurance status prior to incarceration, as well as whether participants had a primary care provider prior to incarceration. Participants filled out the questionnaire themselves, while the moderator read each question and answer response.

Then we administered the Short Test of Functional Health Literacy in Adults (STOFHLA)[35] in a group context, although each participant completed the assessment individually. Participants were asked to read the instrument to themselves, in keeping with instrument instructions. This 36-item instrument includes two functional health reading comprehension passages and takes seven minutes to administer, versus the 22 minutes needed for the full Test of Functional Health Literacy in Adults (TOFHLA). The spearman correlation between the STOFHLA and the TOFHLA is 0.91. When administered among 211 patients in an Atlanta hospital, reliability for the STOFHLA (Cronbach's Alpha) was 0.97.[35]

The STOFHLA awards one point for each correct response and zero points for incorrect responses, resulting in a sum score of 0–36. In the few cases where participants had difficulty completing the form, they were instructed to skip questions or stop completing the assessment. Any skipped responses received zero points, in keeping with the scoring instructions. Based on test scores, individuals are considered to have inadequate (0–16), marginal (17–22), or adequate (23–36) functional health literacy. Individuals with marginal or inadequate functional health literacy are more likely to misunderstand health materials, take medications incorrectly and deviate from treatment plans. According to the U.S. Department of Education's National Adult Literacy Survey report, 23% of American adults are functionally illiterate and 28% are marginally illiterate.[36]

Once the sociodemographic and STOFHLA data collection were completed, we began focus group sessions. The focus groups sought to assess participants' knowledge and awareness around Pap tests, abnormal Pap test events, the human papillomavirus (HPV) vaccine, Pap test follow-up requirements, types of follow-up events, location of care, features of the medical encounter, and general barriers to screening, follow-up care, or access to health care (see Appendix). We chose focus groups as a methodology to see how women produce knowledge as part of a shared meaning-making process.[37] Such a methodology would give us clues as to how and where we might develop interventions to address cervical health promotion in jails, particularly in a group setting. Conducting interventions with groups is

both an accepted and effective strategy.[38] Our prior experience conducting focus groups[39] also suggested that such a methodology was appropriate, and the sample size selected was sufficient to meet our analytic goals.

Data management and analysis

Participant and STOFHLA data were entered directly into SPSS. Descriptive statistics such as means, standard deviations, and percentages were compiled for demographic characteristics and health literacy scores.

All focus groups were audio-recorded, transcribed by two graduate-level research assistants who conducted the focus groups, and checked against the original recordings to ensure accuracy. Using a grounded theory method to analyze data, the principal author and one research assistant open-coded data independently to delineate conceptual categories.[40] Areas of disagreement between the two coders were resolved by discussion. Once data were coded, it became very clear that the women's narratives about Pap test and follow-up experiences were a reflection of what we conceptualized as low cervical health literacy. This ultimately became our guiding theoretical framework with which to examine the data. In the second step of analysis, we toggled between the emerging themes from the data and the standing literature about health literacy,[27,41] which we thought might help explain the women's cervical health-related experiences. Finally, the authors collaborated to extract themes and supporting data that would best illustrate and summarize the women's experiences in engaging with cervical health promotion. Thus, the three themes presented here were the women's (1) knowledge, (2) beliefs, and (3) self-efficacy related to cervical health promotion, including their ability to navigate the stigma of their ongoing criminal justice involvement in health care encounters, all of which we judged made up the women's cervical health literacy. We wish to note that we presented what the women said, even if their narratives reflected misunderstandings of, for example, Pap test procedures.

Results

The 45 women who participated in this study were 34.0 years old, on average (sd=9.9) (Table 1). The majority were White (n=25, 55.6%), and the remainder Black (n=17, 37.8%) or American Indian/Alaskan Native (n=3, 6.7%). We had no Latina participants in this study, though about 10% of female inmates in this facility were Latina.

Participants' average functional health literacy score was 32.1 (sd=5.3) on a scale that ranged from 0–36 (Table 2). The majority of women (n=41, 91.1%) had scores high enough to indicate "adequate" health literacy. Two participants had marginal health literacy, and two had inadequate functional health literacy scores.

There were three distinct themes found from the analysis of the focus groups: 1) knowledge about Pap test procedures, purpose, and cervical cancer etiology; 2) beliefs about Pap test screening, results, and cervical cancer prevention; and 3) self-efficacy for cervical health promotion and navigating the stigma of criminal justice involvement.

Knowledge about Pap test purpose, procedures, and cervical cancer etiology

Cervical health knowledge assessed during focus groups revealed considerable variability. While some women accurately described what happens during a Pap test, others expressed confusion about the purpose of the test. For example, Dana,* a 46-year old, clearly and accurately described what happens at a doctor's visit during a Pap test, as did six other participants who either explicitly referred to the "duck bills" (speculum) or "Q-tip brush thingy" (cytobrush) used during the procedure.

> You go see your gynecologist. He puts you on the table. You put your legs up in the stirrup. He's got these clamps and he opens you up. And he's got these long cotton swabs and he swabs your vagina. Just to make sure, he puts it on slides to make sure you don't have any cancer cells or any diseases—you know, sexually transmitted diseases or anything like that. Cervical cancer would be one of the things he'd be looking for. That's where they can also start your birth control. They get your birth control started by swabbing your cervix.

Though Dana's response reflects understanding of what happens during the procedure, she indicated that cervical cancer is only one of the things the health care provider would be looking for during a Pap test, in addition to looking for sexually transmitted diseases or initiating birth control. This quotation also illustrates how a Pap test may not have been the initial reason to see a provider, but rather a byproduct of a visit for another reason, such as birth control initiation.

We also captured this exchange between two participants that indicated a different understanding about the purpose of a Pap test, one that reflected the reality of our sample's lives—where concern about sexual assault is common and easily conflated with health screenings during medical encounters.

> Yolanda: Don't they do different kinds of Paps? For instance, if you have been fondled, they can do a Pap smear to see if you have been raped. Or a rape kit.
>
> Tracy: *A rape exam is totally different.*
>
> Yolanda: *But they still do a Pap smear.*
>
> Tracy: Yeah, to determine if you have been messed with. They can find semen up there.

Other women, however, did clarify that the Pap test is specifically for cancer screening. For example, Tracy, a 48-year-old woman, said, "I think they are going up there scraping your cervix to see if there's cancer," when asked what happens during a Pap test. Seven participants correctly identified the Pap test as a way to identify abnormalities on the cervix, though three of the seven said this was only one purpose of the Pap test. The range of other responses to our questions about the procedure, its purpose, and the cause of cervical cancer are listed in Box 1.

*Pseudonyms used for all participants

As for the purpose of the Pap test, the women characterized it as a screening tool for any number of conditions—including STIs, pregnancy, and cancer cells.

Alice, a 36-year-old woman, said that her last Pap test solved a range of problems, such as diagnosing bacterial vaginosis and trichomoniasis, while providing an opportunity to get the full range of hepatitis shots. Alice received sexual or reproductive health care every one to two years and said she had no problem following doctors' recommendations because she doesn't like things to be "wrong with her vagina." She considered it a matter of responsibility and neatly surmised, "The vagina is a very tricky little thing down there."

Similarly, when asked what purpose the Pap test serves and why it's important, one participant responded, "Some [women] go to see if they are pregnant. Some go to make sure they're disease-free. And some go to make sure they don't have any health problems, like cancer." Reflecting the belief that a Pap test is a general screening tool, another participant said, "It saved my baby from being blind. I was pregnant and my husband gave me chlamydia."

In each of the four focus groups, when we asked participants what causes cervical cancer, someone always said that it was hereditary—as did Anita, who said, "[It's] hereditary. [You] get it from your parents' genes, your grandparents'." Three other women in the focus group agreed with this statement. Other responses to our questions about the etiology of cervical cancer included older age, bodily "decay" (two participants referred specifically to decay), scar tissue, and a history of anemia. Additionally, several women indicated a relationship between cervical cancer and sexual behavior—in particular, number of sex partners, penis size, and STIs. Of the 45 women in our study, only one, Alexis, said explicitly that HPV causes cervical cancer. She was a participant who had actually had cervical cancer, possibly accounting for her knowledge of the connection.

Some women expressed confusion over the issue of sexual health risk and cervical cancer. Seeking clarification during a focus group, Mindy, a 45-year-old woman, said, "I have a question. Does your sexual [activity]—say you're promiscuous, okay, and you have um … you've acquired some kind of inflaming in your uterus—does that cause you to have cancer? Does it build up is what I'm asking?" Mindy had never heard of HPV and was a fairly quiet participant during the focus group. She had a positive STI test and when we recruited her, she assumed that was her abnormal Pap test event that would make her eligible for the study.

Even Alexis, the sole participant who explicitly stated there was a connection between HPV and cervical cancer, expressed some confusion and misinformation about the disease. She said, "My doctor told me you don't have to get it just from having sex. You can get it from like somebody who's … if they have it and they're really sick with it, and they cough in your face, you can get it that way … or if blood-to-blood. I don't know."

It was this type of confusion that we heard throughout the focus groups—where women were either blatantly confused or stopped to ask if they were "on the right track" in their explanations. To us, this represented the degree of their knowledge, and spoke to the role that low cervical health literacy may have in cancer prevention behaviors.

Beliefs about Pap test screening, results, and cervical cancer prevention

The women in our study had various beliefs about screening, their feelings after getting Pap test results, and cervical cancer prevention (Box 1). In particular, the participants had a variety of personal rules and practices related to frequency of screening, but also perhaps to the complexity of their sexual and reproductive health issues.

Frequency of screening, which ranged in our participants from a reported “monthly” to once a year, depended on age and frequency of sexual activity (i.e., more sex meant necessity for more frequent screening, according to some). For example, one participant said, “Younger women [need them] maybe every six months, depending on how active you are.” Another said, “You’re supposed to get your vagina checked twice a year.” A third participant said, “I get it [Pap test] like every six months or whatever because I’m sexually active and you never know. Like, just because you might be in a relationship with one person doesn’t mean that that person is. So I do it just to make sure that I’m clean and ain’t nothing going wrong with my body.” Frequency of screening may have been confused by a couple of issues: Mistaking a Pap test for a pelvic screening, or citing the six-month recommendation for follow-up of abnormal Pap tests (we estimate that half of our participants had an abnormal Pap test in the last five years based on review of their narratives). Indeed, the participant who said that you are supposed to get your vagina checked twice a year was accurately informed, if she were referring to abnormal Pap test follow-up recommendations.

Participants’ responses to receipt of results generally reflected one or two feelings: “If it ain’t broke, don’t fix it;” or the feeling that receiving Pap test results was ambiguous enough to make it scary. For example, Barb, a 51-year-old, said: “I received mine [Pap test result] by mail and I was kinda afraid. Then the way I felt about it was, well whatever it is, it’s not bothering me so why should I bother it? You know?” Sally, another participant, interjected: “If it ain’t broke, don’t fix it.” Barb continued, “Any diagnoses—if it’s not hurting me, I’m not going. If I start bothering it, it might start bothering me.”

In addition to fear and ambivalence about screening and follow-up, the woman had a sense of the sexually transmissible nature of HPV, and thus, spread of cancer (see Box 1). Given the variability in their knowledge, we were surprised to note their beliefs about partners’ roles (and blame) in disease transmission. All of these factors related to beliefs about cancer screening and prevention seemed both modifiable and potentially related to the women’s ability to navigate the health system for cancer prevention—an important component of cervical health literacy.

Self-efficacy for cervical health promotion and navigating the stigma of criminal justice involvement

Self-efficacy is commonly defined as a person’s judgment of their own capabilities for performing tasks or functions[42]—in this case, related to cervical cancer prevention. Among participants in this study, we found that self-efficacy was often overshadowed by tangible barriers to health (e.g., no money for transportation, lack of health insurance, repeated incarcerations, drug use)—all of which were cited as problems (Box 1). For example, in an

exchange among eight women led by Bryn, age 24, various issues were cited in response to the question about barriers and facilitators of cervical health promotion:

> I think that there are things offered to those in a better social economic status than those who aren't. 'Cause I mean, I don't have any kids, I don't have insurance, I don't have income, and I'm not gonna be able to pay for any doctor's visit. [Erin: I don't either, but you can go to the health department.] Okay, you can go to the free clinics. But say you don't have a car, you have no money for bus—what are you gonna walk? You're not gonna go unless you're dying." [Alice: I promise I'll school you on the resources when we go back to the room. They will pick you up, they have a van that'll come get you and take care of you.] [Angel: If you need a van to come pick you up, how are you gonna get a hold of them?] *Are you gonna call them on your phone?* [Jo: *Gonna waste your minutes?*] [Barb: *You don't have a phone. No money.*] [Unknown: *No money.*] [Carly: *Don't have a cell phone*].

This exchange not only revealed the variety of barriers to self-efficacy for cancer prevention, but also the extent to which knowledge-sharing occurred among the women during the focus groups. From an analytic standpoint, it showed the variability in knowledge and self-efficacy, but also the potential for the women to help each other navigate health systems.

Finally, we heard from several women in conversations about their relationship with medical providers that their criminal justice history was a barrier to receiving care in the community, specifically in the emergency department setting. Lamenting the loss of her primary care provider, Yolanda said the following about the local academic medical center:

> I don't know where he's [the health care provider] at now. Now I just go to [academic medical center's] *emergency room. But I done got scared now cause* [academic medical center] *has changed so much."* [Moderator: *What are you scared of?*] 'Cause I don't know if I'ma go in there and come out in handcuffs. [Moderator: *What do you mean by that? Come out in handcuffs?*] *'Cause they like to run your name.* [Tracy: *Right.*] When I was there … Okay. 'Cause when I was there, this was the last time, when I got hit in the head with a bat, you know. I was in there for seven days. And while I was in there for seven days, I missed my court date. I was hit in the head with a bat! You know, I was unconscious for a few days. And as soon as I got released, Bam! I was sitting here [in jail]" [She indicated that someone from the hospital had shared the fact of her hospitalization with the police.]

Other women in our sample shared similar perceptions of this particular emergency department, per the following conversation with four women led by Bryn:

> *I like* [academic medical center]." [Barb: *I like it too*] I like it other than if you have warrants—they'll take you to jail." [Agreement about warrants and hospital from Barb, Joe, and Carly] They will take you. They will have security take you. [Unknown: If you got warrants, you're going straight to booking.] [Barb: That's what I'm saying. They'll work on everything! They work on your physical and your criminal.]

Our analyses demonstrated that some components of self-efficacy for cancer prevention, or health care seeking in general, may be unique to women with criminal justice histories. In addition to balancing the multiple barriers to preventive health related to socioeconomic status, our sample of women were acutely aware of the stigma associated with criminal justice involvement and how that relates to health care seeking behaviors. Thus, the factors that may comprise their cervical health literacy—in this study their knowledge, beliefs, and self-efficacy related to cervical cancer prevention—may serve to explain the higher rates of cervical cancer morbidity among women with criminal justice histories.

Discussion

Women with criminal justice histories are unique in their elevated sexual, reproductive, and cervical health risks. They consistently have worse sexual and cervical health outcomes compared to women without incarceration histories.[1,9,10] But to our knowledge, no one has investigated the role of health literacy in these disparities, and this could be a modifiable area that cuts across the range of women's health seeking behaviors. As we explored how women engaged in cervical cancer prevention, it became clear to us that one important explanatory factor could indeed be cervical health literacy— that is, knowledge, beliefs, and self-efficacy related to cervical cancer prevention practices.

We found that on a measure of general health literacy, the majority of women did have the capacity to "obtain, process, and understand"[27] basic health information in order to make appropriate preventive and treatment health care decisions. However, when we qualitatively probed into their experiences, we found that the women had varying capacities for cervical health promotion, some of which were out of their control. Ultimately, we became much more concerned with the women's functional health literacy, which included their knowledge, awareness, and beliefs about cervical health risk, in addition to their ability to navigate health systems for cervical health promotion.[43]

Our study is not the first to document varied levels of cervical health knowledge among women in the criminal justice system, in particular. Binswanger and colleagues[17] found that only 61% of women in jails could describe how health providers screen for cervical cancer. Her findings as well as other studies[7] call into question women's reporting of screening, arguably the most preventive behavior for cervical cancer prevention. Though researchers have reported overall high rates of screening,[7,17,18] the way women talk about screening in a qualitative study, such as the present one, may reveal misreporting of these women's engagement in cervical cancer prevention.

While conducting this study, and based on other previous research,[7,17] we have also wondered whether low cervical health knowledge is an issue unique to the high-risk group of incarcerated women. A review of the literature shows almost definitively that women in the U.S. and abroad have varying levels of knowledge about cervical health and cancer prevention, regardless of social or criminal justice status.[44-50] This finding points to a much broader problem of communication between providers, public health advocates, and citizens when it comes to cervical cancer health information.

To some extent, our findings on the women's beliefs about Pap tests and follow-ups mirror findings in the existing literature—particularly the notion of discomfort and fear surrounding Pap tests.[51-52] Less common in the cancer prevention literature, however, is our finding on the women's beliefs about frequency and need for Pap tests, which seemed to be tied more to sexual practices and their ideas about sexual risk—although this connection (between sexual practices, risk, and cervical cancer) has been previously documented.[53]

Our findings about cervical health promotion self-efficacy seemed very particular to the sample under observation—in that their histories of poverty, drug use, and criminal justice involvement often served as barriers to continuity of care. A unique contribution of our study is the documentation of the perception of stigma as a barrier to self-efficacy. Several of our participants indicated fear of arrest while seeking emergency department care, a finding that has been documented in other recent research, but remains under-investigated.[54] Distrust at any level of the system could result in reduced health care utilization and preventive behaviors both inside criminal justice facilities and the community.

Our study had limitations. We had no validated quantitative measure of cervical health literacy, though one has since been published.[43] Our qualitative study, however, potentially measures disease-specific health literacy (operationalized as knowledge, beliefs, and self-efficacy) in a way that standardized measures—designed for use across various samples, health conditions, or cancer types—cannot capture. Secondly, we can only make subjective judgments about cervical health knowledge, beliefs, and self-efficacy based on our conversations with our sample. The value of qualitative research is that we can still present the data so that readers can also make subjective judgments. Our participants' descriptions about the frequency of their Pap tests also highlight a limitation of focus groups and self-reporting, which are subject to bias and recall issues.[55-58] Another limitation of our study was the failure to recruit Spanish speakers, a high-risk group for cervical cancer in the U.S.[59]

A final limitation of qualitative research in general is the failure to produce generalizable results. However, our results are transferable—that is, the findings can be taken for their individual context and, subsequently, lessons can be transferred to other similar groups and contexts by readers. This was ultimately a heuristic approach to research.[60] Our goal was to capture the participants' narratives about cervical cancer screening and follow-up experiences, letting them lead the conversation as appropriate. It was important to highlight their words and their experiences, even if the results were not generalizable to other groups. This was a small-scale pilot study that was designed to lead to future studies and programming. We sought to draw connections among the women's narratives and begin to inform future work.

Implications for practice and research

Findings from this study as well as others may inform future directions for public health, clinical practice, and research, and include the following areas for greater programmatic and research emphasis:

Interventions that address cervical health literacy for institutionalized women—Jails, prisons, therapeutic communities, transitional living centers, residential drug treatment facilities, or other institutions that house high-risk women provide unique 'windows of opportunity' for delivering public health programming.[61] Public health practitioners could tailor cervical health education materials so that they address incarcerated women's barriers to knowledge and information, their unique cultural beliefs, and their self-efficacy as it stems from poverty and stigma based on ongoing criminal justice involvement.[62]

Research on structural discrimination in health systems—Research about surveillance of racial minorities in health care systems is starting to emerge.[54] Participants in our study have also echoed the finding of others that surveillance and police reporting is widespread in hospital-based settings, particularly emergency departments. Such discriminatory surveillance practices create an unfair burden on the most disadvantaged patients and may even deter people from seeking health care. Whether policies or informal practices drive structural discrimination at all levels of the health system is an open question ripe for further investigation.

Communication and dissemination of information about changing cervical cancer screening and prevention guidelines—Though there have been significant changes in cervical cancer screening recommendations,[63] our sample of high-risk women has not yet understood the practical implications. Research among other diverse samples of women also seems to point to the same lack of translation from updated recommendations to improved understanding and practice among women in the general population.[44,47-49] Specifically for high-risk women—such as those who move through the criminal justice system—public health, policy, and clinical professionals should focus on uniform messaging about new screening recommendations that increase access to prevention services for vulnerable groups. Doing so would help high-risk women take an informed approach to balancing health needs against many other competing priorities. Free cervical cancer screening and HPV vaccination for eligible women will be made widely available through provisions of the Affordable Care Act in the U.S.,[64] and public health advocates would do well to take advantage of increased access to services with targeted messaging about cervical cancer screening.

In following these recommendations, public health practitioners, clinicians, and researchers may work together in reducing the cervical health disparities between women with criminal justice histories and their counterparts in the free community.

Acknowledgments

This work was supported by National Cancer Institute (NCI) 1R03CA162869-01. The principal author was also supported by a Clinical and Translational Science Award from the National Center for Advancing Translational Sciences (NCATS) awarded to the University of Kansas Medical Center, Frontiers: The Heartland Institute for Clinical and Translational Research # KL2TR000119. The contents are solely the responsibility of the authors and do not necessarily represent the official views of NCI or NCATS.

Appendix

Focus Group—Moderator's Guide

Thank you for attending this focus group. My name is _____, and this is my colleague, _____. We are from the University of Kansas Medical Center and the University of Missouri-Kansas City. We are here to do a focus group with you to ask you about your past experiences getting Pap tests. We are interested in knowing how you felt about your Pap screenings and what steps you had to take to see a doctor or nurse when you got the Pap tests and had follow-up appointments. So that's what we're here to do today. You don't have to answer a question if you don't want to. I just ask that you be respectful so if someone else is talking. you don't talk over them. There are no right or wrong answers, and I'm interested in hearing everyone's opinions. If it's ok with everyone here, I'd like to audio record this group. That way I don't have to take notes while everyone is talking, and I won't have to stop the conversation to make sure I've gotten everything written down. I can go back later and listen to the recording and write things down then. When I do that I won't use your names or identify who said what. It'll just be, "One participant said this, and another said this …" Sound good? Please feel free to interrupt me if you have any questions at any point.

Focus Group Probes

Describe to me what happens when you get a Pap test.

What kinds of places do you usually go to get a Pap test, like a hospital, clinic, or health department?

Why do you think it's important to get Pap tests, and what purpose do they serve?

Tell me about the last time you had a Pap test:

- Where did you get it?
- What did the doctor or nurse do?
- If it was uncomfortable, what made it uncomfortable?

What do you know about human papilloma virus?

- What do you know about the HPV vaccine?

What do you think causes cervical cancer?

What do you think can prevent cervical cancer?

What would make it easy or hard for you to prevent cervical cancer?

Tell me about how you usually get your Pap tests results.

When you got your last "abnormal" Pap test result, how did you get the result?

- By mail?
- By calling to check up on the result?

- Face-to-face with a doctor or nurse?

How did your doctor or nurse describe the abnormal result?

- What did he/she say to you?
- How did you interpret the result? What did it mean to you?

What did the doctor or nurse say to do about the abnormal Pap test result?

- Did you do what the doctor or nurse said?
- What made it easy for you or difficult to do what the doctor or nurse said after your abnormal Pap test result?

How would you describe your relationship with the doctor(s) or nurse(s) who did the Pap tests, gave you the results, and did any follow-up care?

- Did they make it comfortable for you? If so, how? Or how did they make it difficult?
- Tell me: How satisfied were you with how they explained everything to you?

Tell me: How satisfied were you with how much respect they showed to you in the clinic?

What kinds of things would make the Pap test and follow-up stuff easier for you to do?

Has being in jail or prison ever gotten in the way of you getting a Pap test, your results, or follow-up care?

- If yes, how has it gotten in the way?
- Or how has it made it easier to get care?

Do you have any questions for us?

References

1. Binswanger IA, Krueger PM, Steiner JF. Prevalence of chronic medical conditions among jail and prison inmates in the USA compared with the general population. J Epidemiol Community Health. Nov; 2009 63(11):912–9. Epub 2009 Jul 30. [PubMed: 19648129]
2. Bureau of Justice Statistics. Correctional populations in the United States, 1997. Bureau of Justice Statistics; Washington, DC: 2000.
3. Moghissi KS, Mack HC. Epidemiology of cervical cancer: study of a prison population. Am J Obstet Gynecol. Mar 1; 1968 100(5):607–14. [PubMed: 5638481]
4. Binswanger IA, Mueller S, Clark CB, et al. Risk factors for cervical cancer in criminal justice settings. J Womens Health (Larchmt). Dec; 2011 20(12):1839–45. [PubMed: 22004180]
5. Clarke J, Phipps M, Rose J, et al. Follow-up of abnormal pap smears among incarcerated women. J Correct Health Care. Jan; 2007 13(1):22–6.
6. Martin RE. A review of a prison cervical cancer screening program in British Columbia. Can J Public Health. Nov-Dec;1998 89(6):382–6. [PubMed: 9926496]
7. Ramaswamy M, Kelly PJ, Koblitz A, et al. Understanding the role of violence in incarcerated women's cervical cancer screening and history. Women Health. Jul 22; 2011 51(5):423–41. [PubMed: 21797677]
8. Fogel CI, Belyea M. The lives of incarcerated women: violence, substance abuse, and at risk for HIV. J Assoc Nurses AIDS Care. Nov-Dec;1999 10(6):66–74. [PubMed: 10546175]

9. Hale G, Oswalt K, Cropsey K, et al. The contraceptive needs of incarcerated women. J Womens Health (Larchmt). Aug; 2009 18(8):1221–6. [PubMed: 19630555]
10. Hogben M, Lawrence J, Eldridge G. Sexual risk behavior, drug use, and STD rates among incarcerated women. Womens Health. 2001; 34(1):63–78. http://dx.doi.org/10.1300/J013v34n01_05.
11. Bond L, Semaan S. At risk for HIV infection: incarcerated women in a county jail in Philadelphia. Women Health. 1996; 24(4):27–45. http://dx.doi.org/10.1300/J013v24n04_02. PMid:9104763. [PubMed: 9104763]
12. Magura S, Kang SY, Shapiro J, et al. HIV risk among women injecting drug users who are in jail. Addiction. Oct; 1993 88(10):1351–60. [PubMed: 8251872]
13. Cropsey K, Eldridge GD, Ladner T. Smoking among female prisoners: an ignored public health epidemic. Addict Behav. Feb; 2004 29(2):425–31. [PubMed: 14732432]
14. Bickell NA, Vermund SH, Holmes M, et al. Human papillomavirus, gonorrhea, syphilis, and cervical dysplasia in jailed women. Am J Public Health. Oct; 1991 81(10):1318–20. [PubMed: 1928533]
15. de Sanjosé S, Valls I, Paz Canadas, et al. [Human papillomavirus and human immunodeficiency virus infections as risk factors for cervix cancer in women prisoners]. Med Clin (Barc). Jun 17; 2000 115(3):81–4. [PubMed: 10965480]
16. González C, Canals J, Ortiz M, et al. Prevalence and determinants of high-risk human papillomavirus (HPV) infection and cervical cytological abnormalities in imprisoned women. Epidemiol Infect. Feb; 2008 136(2):215–21. Epub 2007 Apr 20. [PubMed: 17445312]
17. Binswanger IA, White MC, Pérez-Stable EJ, et al. Cancer screening among jail inmates: frequency, knowledge, and willingness. Am J Public Health. Oct; 2005 95(10):1781–7. [PubMed: 16186455]
18. Nijhawan AE, Salloway R, Nunn AS, et al. Preventive healthcare for underserved women: results of a prison survey. J Womens Health (Larchmt). Jan; 2010 19(1):17–22. [PubMed: 20088654]
19. Elwood Martin R, Hislop TG, Grams GD, et al. Evaluation of a cervical cancer screening intervention for prison inmates. Can J Public Health. Jul-Aug;2004 95(4):285–9. [PubMed: 15362473]
20. Martin RE, Hislop TG, Moravan V, et al. Three-year follow-up study of women who participated in a cervical cancer screening intervention while in prison. Can J Public Health. Jul-Aug;2008 99(4):262–6. [PubMed: 18767267]
21. American Medical Association. Health literacy: report of the Council on Scientific Affairs. Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical Association. JAMA. Feb 10; 1999 281(6):552–7. [PubMed: 10022112]
22. Davis TC, Williams MV, Marin E, et al. Health literacy and cancer communication. CA Cancer J Clin. May-Jun;2002 52(3):134–49. [PubMed: 12018928]
23. Lindau ST, Tomori C, Lyons T, et al. The association of health literacy with cervical cancer prevention knowledge and health behaviors in a multiethnic cohort of women. Am J Obstet Gynecol. May; 2002 186(5):938–43. [PubMed: 12015518]
24. Rudd, R.; Kirsch, I.; Yamamoto, K. Literacy and health in America: policy information report. Center for Global Assessment Educational Testing Service; Princeton, NJ: 2004.
25. Sparks L, Nussbaum JF. Health literacy and cancer communication with older adults. Patient Educ Couns. Jun; 2008 71(3):345–50. Epub 2008 Apr 18. [PubMed: 18374536]
26. James, DJ. Profile of jail inmates, 2002. U.S. Department of Justice; Washington, DC: 2004. 2004. Available at: http://www.bjs.gov/content/pub/pdf/pji02.pdf
27. Nielsen-Bohlman, L.; Panzer, AM.; Kindig, DA. Health literacy: a prescription to end confusion. National Academies Press; Washington, DC: 2004.
28. Rust C, Davis C. Health literacy and medication adherence in underserved African-American breast cancer survivors: a qualitative study. Soc Work Health Care. 2011; 50(9):739–61. http://dx.doi.org/10.1080/00981389.2011.585703. PMid:21985113. [PubMed: 21985113]
29. Sharp LK, Zurawski JM, Roland PY, et al. Health literacy, cervical cancer risk factors, and distress in low-income African-American women seeking colposcopy. Ethn Dis. Fall;2002 12(4):541–6. [PubMed: 12477141]

30. Lindau ST, Basu A, Leitsch SA. Health literacy as a predictor of follow-up after an abnormal Pap smear: a prospective study. J Gen Intern Med. Aug; 2006 21(8):829–34. [PubMed: 16881942]
31. Coughlin SS, Costanza ME, Fernandez ME, et al. CDC-funded intervention research aimed at promoting colorectal cancer screening in communities Cancer. Sep 1; 2006 107(5 Suppl):1196–204. [PubMed: 16802326]
32. Hendren S, Griggs JJ, Epstein RM, et al. Study protocol: a randomized controlled trial of patient navigation-activation to reduce cancer health disparities. BMC Cancer. Oct 13.2010 10:551. [PubMed: 20939928]
33. Kim SP, Knight SJ, Tomori C, et al. Health literacy and shared decision making for prostate cancer patients with low socioeconomic status. Cancer Invest. 2001; 19(7):684–91. http://dx.doi.org/10.1081/CNV-100106143. PMid:11577809. [PubMed: 11577809]
34. Mabiso A, Williams KP, Todem D, et al. Longitudinal analysis of domain-level breast cancer literacy among African-American women. Health Educ Res. Feb; 2010 25(1):151–61. Epub 2009 Oct 27. [PubMed: 19861639]
35. Baker DW, Williams MV, Parker RM, et al. Development of a brief test to measure functional health literacy. Patient Educ Couns. Sep; 1999 38(1):33–42. [PubMed: 14528569]
36. Kirsch, IS.; Jungeblut, A.; Jenkins, L., et al. Adult literacy in America: a first look at the results of the National Adult Literacy Survey. National Center for Education Statistics, U.S. Department of Education; Washington, DC: 1993. Available at: https://nces.ed.gov/pubsearch/pubsinfo.asp?pubid=93275
37. Hollander JA. The social contexts of focus groups. J Contemp Ethnogr. Oct; 2004 33(5):602–37.
38. Freudenberg N, Ramaswamy M, Daniels J, et al. Reducing drug use, human immunodeficiency virus risk, and recidivism among young men leaving jail: evaluation of the REAL MEN reentry program. J Adolesc Health. Nov; 2010 47(5):448–55. [PubMed: 20970079]
39. Ramaswamy M. Progressive paths to masculinity for young Black and Latino men in an urban alternatives-to-incarceration program. West J Black Stud. Winter;2010 34(4):412–24.
40. Charmaz, K. The grounded theory method: an explication and interpretation. In: Emerson, RM., editor. Contemporary field research: a collection of readings. Waveland Press, Inc.; Prospect Heights, IL: 1983. p. 109-26.
41. Berkman ND, Sheridan SL, Donahue KE, et al. Health literacy interventions and outcomes: an updated systematic review. Evid Rep Technol Assess (Full Rep). Mar.2011 (199):1–941. [PubMed: 23126607]
42. O'Leary A. Self-efficacy and health. Behav Res Ther. 1985; 23(4):437–51. http://dx.doi.org/10.1016/0005-7967(85)90172-X. [PubMed: 3896228]
43. Williams KP, Templin TN. Bringing real world to psychometric evaluation of cervical cancer literacy assessments with Black, Latina, and Arab women in real-world settings. J Cancer Educ. Dec; 2013 28(4):738–43. [PubMed: 24072456]
44. Brown D, Wilson RM, Boothe MA, et al. Cervical cancer screening among ethnically diverse black women: knowledge, attitudes, beliefs, and practices. J Natl Med Assoc. Aug; 2011 103(8):719–28. [PubMed: 22046849]
45. Dahlström LA, Sundström K, Young C, et al. Awareness and knowledge of human papillomavirus in the Swedish adult population. J Adolesc Health. Feb; 2012 50(2):204–6. Epub 2011 Jun 25. [PubMed: 22265119]
46. Ford JL. Racial and ethnic disparities in human papillomavirus awareness and vaccination among young adult women. Public Health Nurs. Nov-Dec;2011 28(6):485–93. Epub 2011 Jun 6. [PubMed: 22092458]
47. Head KJ, Cohen EL. Young women's perspectives on cervical cancer prevention in Appalachian Kentucky. Qual Health Res. Apr; 2012 22(4):476–87. Epub 2011 Nov 7. [PubMed: 22068039]
48. Montgomery K, Smith-Glasgow ME. Human papillomavirus and cervical cancer knowledge, health beliefs, and preventive practices in 2 age cohorts: a comparison study. Gend Med. Feb; 2012 9(1 Suppl):S55–66. [PubMed: 22340641]
49. Ogbechie OA, Hacker MR, Dodge LE, et al. Confusion regarding cervical cancer screening and chlamydia screening among sexually active young women. Sex Transm Infect. Feb; 2012 88(1):35–7. Epub 2011 Nov 28. [PubMed: 22123163]

50. Reis N, Bebis H, Kose S, et al. Knowledge, behavior and beliefs related to cervical cancer and screening among Turkish women. Asian Pac J Cancer Prev. 2012; 13(4):1463–70. http://dx.doi.org/10.7314/APJCP.2012.13.4.1463. PMid:22799349. [PubMed: 22799349]
51. Fylan F. Screening for cervical cancer: a review of women's attitudes, knowledge, and behaviors. Br J Gen Pract. Aug; 1998 48(433):1509–14. [PubMed: 10024713]
52. Magee CG, Hult JR, Turalba R, et al. Preventive care for women in prison: a qualitative community health assessment of the Papanicolaou test and follow-up treatment at a California state women's prison. Am J Public Health. Oct; 2005 95(10):1712–7. [PubMed: 16186450]
53. Vanslyke JG, Baum J, Plaza MO. HPV and cervical cancer testing and prevention: knowledge, beliefs, and attitudes among Hispanic women. Qual Health Res. May; 2008 18(5):584–96. Epub 2008 Mar 12. [PubMed: 18337618]
54. Goffman A. On the run: wanted men in a Philadelphia ghetto. Am Soc Rev. 2009; 74(3):339–57. http://dx.doi.org/10.1177/000312240907400301.
55. Hewitt M, Devesa SS, Breen N. Cervical cancer screening among U.S. women: analyses of the 2000 National Health Interview Survey. Prev Med. Aug; 2004 39(2):270–8. [PubMed: 15226035]
56. Howard M, Agarwal G, Lytwyn A. Accuracy of self-reports of Pap and mammography screening compared to medical record: a meta-analysis. Cancer Causes Control. Feb; 2009 20(1):1–13. Epub 2008 Sep 19. [PubMed: 18802779]
57. Klungsoyr O, Nygard M, Skare G, et al. Validity of self-reported Pap smear history in Norwegian women. J Med Screen. 2009; 16(2):91–7. http://dx.doi.org/10.1258/jms.2009.008087 PMid: 19564522. [PubMed: 19564522]
58. Newell S, Girgis A, Sanson-Fisher, et al. Accuracy of patients' recall of Pap and cholesterol screening. Am J Public Health. Sep; 2000 90(9):1431–5. [PubMed: 10983202]
59. Hunter JL. Cervical cancer educational pamphlets: Do they miss the mark for Mexican immigrant women's needs? Cancer Control. Nov; 2005 12(Suppl 2):42–50. [PubMed: 16327750]
60. Kleining G, Witt H. The qualitative heuristic approach: a methodology for discovery in psychology and the social sciences. Rediscovering the method of introspection as an example. Forum: Qual Soc Res. 2000; 1(1) Art. 13.
61. Ramaswamy, M.; Freudenberg, N. Health promotion in jails and prisons: an alternative paradigm for correctional health services. In: Greifinger, R.; Bick, J.; Goldenson, J., editors. Public health is public safety: improving public health through correctional health care. Springer Publishing Company; New York, NY: 2007. p. 229-48.
62. Ramaswamy M, Simmons R, Kelly PJ. The development of a brief jail-based cervical health promotion intervention. Health Promot Pract. May; 2015 16(3):432–42. Epub 2014 Jul 25. [PubMed: 25063589]
63. American Congress of Obstetricians and Gynecologists (ACOG). New cervical cancer screening recommendations from the U.S. Preventive Services Task Force and the American Cancer Society/ American Society for Colposcopy and Cervical Pathology/American Society for Clinical Pathology. ACOG; Washington, DC: 2012. 2012. Available at: http://www.vcom.edu/obgyn/files/New%20Cervical%20Cancer%20Screening%20Recommendations%20March%202012.pdf
64. Preventive health services for adults. U.S. Centers for Medicaid and Medicare Services; Baltimore, MD: 2012. HealthCare.govAvailable at: http://www.healthcare.gov/news/factsheets/2010/07/preventive-services-list.html#CoveredPreventiveServicesforWomenIncludingPregnantWomen

Box 1

KNOWLEDGE, BELIEFS, AND SELF-EFFICACY FOR CERVICAL HEALTH PROMOTION AMONG WOMEN IN JAIL

KNOWLEDGE

What happens when you get a Pap test?

"When you get a Pap test, they put you on a table, they tell you to get naked, they give you a gown. Am I going the right way so far?"—Alice

"They're looking at your cervix and see if they see anything abnormal on your cervix."—Barb

"Yeah, inside you, they open you up, use a Q-tip brush thingy, microscope, and test them for any bacteria, like for trichomoniasis, or whatever. Different types of bacteria, and they do like a cell take or whatever. It's a long strip and it's got like jagged edges, and they go, it goes, cuts into your uterus."—Paula

"They'll take their duck bills, put it inside of you, scoot it to the edge of the table and look. I wish I could look down there and see, what was going on, you know?"—Unknown participant

Why do you think it's important to get Pap tests?

"Make sure you don't have any diseases or nothing like that."—Carly

"It can show the abnormal cells or the pre-cancerous cells."—Alice

"Early, early detection."—Karen

"Just to prevent cancer from spreading, basically."—Carrie

What do you think causes cervical cancer?

"Cancer is, uh, it's hereditary. I think it comes from the blood, or it's the body decaying. Especially in your older people. It seems like cancer is just killing our older crowd, the body decaying."—Tracy

"Scar tissue. I mean, would scar tissue be one of the answers? Let's say you have an STD, and you leave it in too long, your ovaries, your tissue's getting scarred. Okay a lot of women can't have babies because their tissues get all scarred up by not going to get their treatment for STDs. So that puts scar tissue up there and so that leads to um, I don't know. I'm just talking (laughing)"—Dana

"Maybe undetected diseases and just not getting the proper medical care for it."— Barb

"Rough, unprotected sex."—Karen

"I've been told that too many sex partners can cause it too." [Yolanda: Big penises] "STDs, repeated STDs."—Paula

BELIEFS

What happens when you get a Pap test?

"The little thing they put on your private parts, I don't like that. That thing hurt. I've heard it's called a duck bill."—Carly

"Sometimes those clamps, clips right on your, it hurt."[Asha: Yeah, I feel violated] [Ellen: Yeah, it hurts] "And I don't like when they get to doing all that and they want to use their little finger." [Dana: Yeah, they sure do. Yup]—Lily

Why do you think it's important to get Pap tests?

"It's also good to get Pap smears because you can find out if you have HPV. The HPV causes cervical cancer, well some HPV causes cervical cancer. Then you can get the Gardasil shot to help."—Alexis

"Once a year is what I'm supposed to do it. You know, once a year is your average time. I try to do it around my birthday and that just gives me, telling me it's my turn, time to go get my Pap smear cause it's my birthday and it's a once a year thing. I'm 46 years old and that's what I've always learned, that you get one once a year." [Moderator: And why do you think it's important to do that?] "Just to make sure there's no cancer cells and things like that, that I'm healthy. It's something I'm supposed to do. It's a womanly thing."—Dana

"It's real important to go get your Pap smears done cause you can have an STD or whatever for a long time before. And a man will know immediately before a woman, right? [Kim: I've heard that men carry a disease called HPV that gives women cervical cancer and they don't know it. Cause that's what happened to me (said under her breath)] —Lilly

"I get them [Paps] once a year up until like last year cause I thought if I went to my doctor's office (laughing) I would probably go to jail." [Kelly: Hey I be thinking that, too, though (laughing)]—Rita

When you got your Pap results how did they present it and how did you feel about it?

[Erin: I mean if it's abnormal that ain't, something's not right.] "And you're pretty sure that you're not the one that made it abnormal. It's your other partner. [Moderator: What does that mean? Explain that] "I felt because I stayed, I was always home, work, taking care of my kids, taking care of my man, all right? He may not be always at work where he's supposed to be or wherever else." [Jo: You feel betrayed] "But he's always out there kickin' it with the boys." [Bryn: They be kickin' it with some girls] [Barb: We know how it happens] "If I ever come back with a problem I said, and it comes to me, we're gonna have problems because I don't mess around."—Sally

"I received a little card at first saying that it was abnormal. And they wanted me to come back in and so, then whenever I come back they did that biopsy thing and it hurt like hell and then um, I went um, I left the office or whatever and they, I believe they called me into tell me that they wanted to do the laser surgery and everything. But they didn't explain too much about it or anything. I was just like, 'Well, whatever, I'm getting stuff laser surgeried off.' And he called it some other name, and I don't … I'm not sure … I

just went along with it (laughing). [Moderator: So you feel like during that time you weren't exactly sure what was going on?] Um, yeah, what I got out of it was some kind of pre-cancerous cells and I like had to pull that out of them. I don't remember exactly what they called it or what not, but they didn't explain it too much. But I was like, 'Whatever, it's got to be done.' [Moderator: And what was your reaction to that initial card you got in the mail?] "Um, I was a little nervous and everything, cause I mean like, I had just been with just one person. I mean, you know, in that time frame. So I didn't know what was going on with it. And my mom, she had to have a full hysterectomy too, and so it kind of made me a little bit nervous after I did find out and everything. And I should go back for another one, but, I haven't."Carrie

What was your reasoning for not going back to a follow-up appointment?

"Whatever they keep saying is not bothering me. You done gave me the ablation and it didn't work. I'm still bleeding like a dog and I am not … " [Carly: Going back] "Right, because even after that now I'm taking iron twice a day, I'm doing things I wasn't doing, so whatever you seeing is not hurting me, so I'm not going back to fooling with it anymore." [Carly: That's it] "Over." [Carly: Back on the bus] "Back on the bus." [Women laughing]—Barb

SELF-EFFICACY

What are some of the things that make it easy or hard to prevent cervical cancer?

"It depends on what kind of mental status you in, because if you're out there on that stuff you're not likely to go to the doctor."—Barb

"It doesn't matter if you're not clean or sober because I'm not the perfect one. I party like a rock star when I'm here or not here and so I still get my checkup. No matter what's going on in my life I still gets my check up."—Alice

"I believe it comes with having kids. I've had three kids and your have to go to the doctor and you have to keep up."—Erin

"If you have a job that gives you insurance, there you go. But I mean, there's no jobs and anyway to make any kind of money is illegal. [Barb: Right] "If you do make money you're not gonna spend it on the doctor." [Carly: I know that's right. You just keep putting it on the table.] "And I guarantee you that is one of the biggest things why this shit is more you know with women in jail. Because of their economic status."—Bryn

What are some of the reasons that make it easy or hard to go back and do what the doctor told you to do?

"After I had a partial hysterectomy they had me go back in for another Pap smear and they did another biopsy to make sure they had gotten all of the cells. And I still go back and get checked because I got kids. You know, plus my grandparents died of cancer and my mom had cervical cancer and I'm so scared that's gonna be what gets me. So I take every precaution cause I got four little, you know, little babies all in diapers. If I'm not here they ain't got nobody." [Erin: I totally agree with that. Pretty much to the same, to the same tee.]—Angel

"When they called actually I didn't have to go back to the office. Cause she [provider] asked if I could come in for an appointment and I was like, 'No.' I was like, 'Well I don't have a way to get to the office.' She's like, 'Well I can come to you.' I was like, 'Oh, okay.'—Tricia

"I was supposed to go back, well, I have since gone back, but at that time I was supposed to go back and get another one, another Pap done, I just didn't go back. [Moderator: Was there a particular reason or factors that …] Life. Too busy. It was a lot of drugs and a lot of alcohol and I was busy doing other things. So I just didn't go back. Now I've been back since then and had normal ones. But that abnormal one, I didn't want to hear about it. So I just … didn't."—Charlene

"Like when you go to the welfare office to try to get Medicaid, if you don't have a kid or you're disabled in some way, they don't give it to you. So probably cost has a lot to do with why a lot of women ain't, I mean, Is not, you know, getting themselves checked out because you can't afford it."—Ronnie

"Cost is a big thing, but the health department is like 30 bucks. If you don't have the 30 bucks, they bill it to you and they can never deny you. They cannot say, 'Oh, you owe too much money, we can't see you,' or 'You can't have a Pap smear.' But cost is really a big thing and it is really hard to get on Medicaid unless you're dying, you got a disease, you got kids, or you're disabled." [Brooke: Or you're in foster care until you're 18]—Alexis

"You know, drugs and alcohol play a big part when you're in the streets. A lot of females don't go for um, you know, whether it's turning days, I mean, all the money is going to another source, you know? So it makes it not a top priority, you know?"—Landry

Table 1

SAMPLE CHARACTERISTICS (N=45)

Age (mean, SD)	34.0 ± 9.9
Non-Hispanic, Black, No. (%)	17 (37.8)
Non-Hispanic, White, No. (%)	25 (55.6)
Single, No. (%)	18 (40.0)
Children at home under age 18 (mean, SD)	1.4 ± 1.6
≥ High school diploma/GED, No. (%)	26 (57.8)
Employed full-time prior to incarceration, No. (%)	4 (8.9)
Uninsured prior to incarceration, No. (%)	21 (46.7)
Had a primary care provider prior to incarceration, No. (%)	17 (37.8)

Table 2
FUNCTIONAL HEALTH LITERACY CHARACTERISTICS (N=45)

Total score[a] (mean, SD)	32.1 ±5.3
Adequate, No. (%)	41 (91.1)
Marginal, No. (%)	2 (4.4)
Inadequate, No. (%)	2 (4.4)

Note

[a]Short Test of Functional Health Literacy for Adults (STOFHLA) total score range= 0–36.