# 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

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Growing evidence indicates that women in prison are particularly vulnerable to many negative health outcomes, including cervical cancer. The Papanicolaou (Pap) test is an effective tool to screen for this disease. To determine what is and is not working with the Pap test and follow-up treatment, we performed qualitative interviews with women prisoners and key informants at a California state women's prison. Our assessment revealed that the process of administering Pap tests at this institution was not meeting the health care needs of the women interviewed.

Women reported having negative experiences during the test and with their health care providers. Additionally the prison's culture and infrastructure create obstacles that hinder prisoners from receiving quality care and providers from delivering that care. In response, women prisoners use self- and community advocacy to meet their health care needs and cope with these challenges. (*Am J Public Health.* 2005;95:1712–1717. doi:10.2105/AJPH.2005.063677)

**WOMEN IN PRISON HAVE** unique reproductive health needs stemming from a variety of health matters.[1–4] Although specific data on the rates of cervical cancer among women in US prisons are not available, a confluence of factors place women in prison at high risk for this disease. First, compared with the general population, women in US prisons have high rates of substance abuse and mental health problems and a higher incidence of communicable diseases such as HIV, hepatitis C, and sexually transmitted infections.[3,5–7] Second, many of these women had limited access to quality primary and preventive health care before they were incarcerated.[2,6,7]

Finally, the race and ethnicity of women prisoners are contributing risk factors for cervical cancer. Although African American and Latina women represent just over a third of the women in the general population of California, they comprise over half of all women in California state prisons.[8,9] The incidence and mortality rates for cervical cancer in US women of color are higher than they are for White women.[10] Within California, Latina women have the highest incidence of cervical cancer among all ethnicities, and African American women have disproportionately high mortality rates.[11]

Quality, effective public health practice requires that preventive health care be coupled with clinical treatment. The controlled environment of correctional facilities presents a unique opportunity to provide quality screening and preventive health care, as well as appropriate follow-up treatment, to a population at risk for a variety of negative health outcomes, including cervical cancer.[2,6,7] Such comprehensive interventions have been successfully implemented in prisons to counter diseases such as hepatitis C and tuberculosis.[12,13] By linking comprehensive screening with treatment opportunities, these programs ensure continuity of care to high-risk individuals.[12,13] Integrating preventive health services such as regular Papanicolaou (Pap) tests with quality follow-up care into prison health care systems can potentially benefit individuals and communities by promoting health-conscious behaviors and reducing disease transmission and medical costs.[14,15]

Cervical cancer among women in US prisons is a significantly underresearched area. In the past 2 decades, very few published studies have examined Pap tests and cervical cancer in the prison setting, and none have been conducted in the United States. The studies that have been published were conducted in Canada, Spain, and the United Kingdom and were either epidemiological, examining prevalence and screening efficacy, or were clinical interventions.[16–20] No studies have qualitatively examined women's experiences with or perspective on the Pap test.

Because of the paucity of research on this topic, a qualitative community health assessment was conducted in fall 2004 to examine the experience of cervical cancer screening and treatment among women in prison in the California Department of Corrections (CDoC), a state system that operates the 2 largest women's prisons in the world.[21] The purpose was to determine what is and is not working with Pap tests and follow-up treatment at 1 California state women's prison. Studying the process can provide important insight into prevention within correctional facilities and can act as a point of departure for understanding women's experiences with other sensitive health matters, such as HIV and sexually transmitted infections.

The assessment aimed to investigate (1) the experiences of women in prison with the Pap test and follow-up treatment process, (2) medical and service providers' perceptions of that process, and (3) recommendations for improvements. Four Master of Public Health students

conducted the assessment as part of the Community Health Education program at San Francisco State University. The project was developed and implemented in partnership with Justice Now, an Oakland, Calif, legal advocacy organization specifically focused on women in prison, and served to inform their direct service, public policy, and human rights efforts.

## THE INTERVIEW PROCESS

The assessment used 2 sets of qualitative interviews—in-depth interviews with women prisoners and key informant interviews. The former were conducted with 35 women in prison, and the latter, with 10 individuals—6 women prisoners in leadership positions at the facility and 4 service providers and researchers. Interview questions can be found in Tables 1 and 2.

The qualitative interview methodology was chosen for 2 significant reasons. First, a primary aim of the assessment was to give voice to the experiences of women in prison, a population frequently excluded from the discourse on health. In-depth interviews were deemed the best way to elicit each woman's story. Second, the format of these interviews provided women the freedom to express their emotions and feelings about the Pap test and related topics, such as other reproductive health concerns, sexuality, interpersonal relationships, and past sexual abuse or trauma.

**TABLE 1—In-Depth Questions Posited to Women in Prison by the Assessment Team**

Process for Obtaining a Pap Test

1. Have you had a Pap smear since you have been at this facility?
2. What was the process by which you obtained Pap smears here?
3. What was communicated to you about getting Pap smears?
4. Who within this facility communicated with you about getting Pap smears?
5. If you failed to get one, what happened?
6. If you refused to get one, what happened?
7. If you avoid getting them, why?
8. If you wanted information about Pap smears, where would you go? Why?
9. What would make the process for obtaining Pap smears better?

Experience During the Actual Test

1. What was your experience like getting the actual Pap smear?
2. Who was there?
3. What were you told? And by whom?
4. What happened when you asked questions?
5. What did you feel about the experience?
6. What were your reasons for feeling (x)?
7. What would make the experience of getting a Pap smear better?

Follow-Up and Treatment Process

1. What happened after your exam?
2. What were you told about what would happen (i.e., next steps)? And by whom?
3. What actually happened?
4. How did you get your results?
5. Did you receive treatment or follow-up? How did that occur? Within what timeframe?
6. What did you feel about what happened after the exam?
7. What made you feel (x)?

**TABLE 2—Key Informant Questions Posited to Service Providers by the Assessment Team**

1. Please describe your role at this agency/organization and your agency's relationship to the facility.
2. How long have you been involved with this type of work?
3. What is the policy or standard procedure at this facility or within the CDoC for providing regular Pap smears?
4. What is the typical process by which women at this facility get a Pap smear exam?
5. What happens after a woman at this facility receives a Pap smear (e.g., results, follow-up treatment)?
6. How do women seek follow-up treatment if they have an abnormal Pap smear?
7. In your opinion, how often do the women at this facility have Pap smear exams?
8. Are there differences between the facility and other women's prison facilities in California in the Pap smear and follow-up treatment process?
9. What are some of the positive things about the health system in this facility with regard to women's health?
10. What is most challenging about the Pap smear and follow-up treatment process at this facility?
11. What are some recommendations you would suggest for improving the Pap smear and follow-up treatment process at this facility?
12. Now that you know what our research is about, is there anything I should have asked you but didn't?
13. Is there anyone you can think of that we can talk to who might add to our understanding of this topic or give us a different perspective?

To enhance the data collected in this assessment, the team chose to conduct key informant interviews in addition to in-depth interviews as a means of capturing experts' perspectives on Pap testing and follow-up care at this facility.

### Participants

In-depth interviews with women in prison comprised the bulk of the data collected in the assessment. The team conducted interviews over the course of 3 months with 35 women in 1 California state prison. Because of constraints on the assessment timeline and resources, it was not possible to interview more than 35 women, though many more expressed interest in participating. Over 70% of the interviewees were women of color. Their racial composition was 45% African American, 23% other (including mixed/biracial), 9% Latina, and 23% White. Their age ranged from 26 to 74 years, with a median age of 40 years.

A snowball sampling method, described next, was used to recruit these women. In this process, Justice Now referred half of the participants to the assessment team as women with whom the organization had a relationship. Additional interviewees were referred by the prisoners themselves. At the end of each interview, women were invited to provide referrals to other women in prison whom they believed would be willing to participate in the assessment.

Of the 10 key informants interviewed, 6 were women

selected by Justice Now on the basis of each woman's leadership role in the prison. Most of these women had been imprisoned for at least 5 years.

The remaining 4 key informant service providers and researchers were selected on the basis of their knowledge of women's health care in California prisons and specific experiences with this particular prison. Two were physicians; 1 worked extensively as a CDoC-contracted provider for 5 years, and the other specialized in jail and prison health care. Another key informant was a sociologist and researcher, and the fourth was a service provider at a local prison advocacy organization. None were CDoC employees.

The research team sought to include the perspective of key medical staff at the facility, as well as CDoC officials, in this assessment. However, these individuals failed to respond to multiple requests by phone, e-mail, fax, and letter for interviews.

### Procedure

All interviews were conducted individually, and notes were recorded by hand. The interviews with the women in prison were held in the general visiting room under guard supervision. Because the assessment was conducted in partnership with a legal advocacy organization, all prisoner interviews were conducted during legal visits under the coordination and supervision of Justice Now attorneys. Legal visits are held on specific days, independent of regular visiting hours.

Before each legal visit, letters of introduction were mailed to potential interviewees to provide a brief explanation of the project and its context within Justice Now's advocacy work. This information was repeated at the beginning of each interview. Every woman prisoner who participated in the project signed an informed consent authorizing her participation as well as the limited release of portions of her interviews in a manner that would not compromise confidentiality. All women were afforded full confidentiality as required under legal and professional ethics law in California.

Women prisoners who acted as key informants were interviewed using a set of qualitative, open-ended questions. Each interview lasted approximately 90 minutes. The information that was gathered contributed to the creation of the in-depth protocol used with other women in this facility.

Following the completion of these key informant interviews, the team began the in-depth interviews. On average, 12 women were interviewed during each of three legal visits. Each in-depth interview lasted approximately 60 to 90 minutes and used a standard set of qualitative, open-ended questions divided into 3 main sections—the process for obtaining a Pap test at the facility, the test itself, and follow-up and treatment.

At the close of each interview, women were presented with health education materials on Pap tests and other relevant women's health information. At that time, the women were also invited to request additional information on their specific needs. These materials were then mailed to each woman the following week.

Concurrent with the in-depth interviews, the team interviewed the service providers acting as key informants. These interviews were conducted one-on-one either at that person's office or home or by telephone and lasted approximately 90 minutes. With minor adjustments, the same qualitative open-ended interview protocol used with the women prisoners who acted as key informants was also used during these interviews.

### Data Analysis

Interviewers individually transcribed their handwritten notes within 48 to 72 hours after each legal visit. The interviews were then entered into NVivo, a qualitative data analysis program (QSR, Markham, Ontario, Canada). The assessment team collaboratively determined an initial set of codes for data analysis on the basis of the in-depth interview questions and augmented the codebook as the project progressed. Coding was done individually and was then verified by an additional team member before NVivo input. NVivo reports developed from specific selected codes were run, and the team analyzed these reports for content.

Each team member reviewed 1 set of reports and created a preliminary findings document. A thematic qualitative analysis approach was used to parse through the tremendous volume of data, and 5 main themes emerged: (1) women's experience during the test, (2) women's experience with the medical providers, (3) prison infrastructure—obstacles for women, (4) prison culture—obstacles for providers, and (5) opportunities for self- and community advocacy. Key informant interview data were then matched to these themes as a means of comparison with the in-depth findings.

## FINDINGS

In general, data from the assessment revealed that Pap testing and follow-up treatment at the facility were not meeting the health care needs of the women interviewed. Overall, women had negative experiences during the actual test and with their providers. The prison culture and infrastructure created obstacles that impeded women's access to quality reproductive health care and hindered providers from delivering that care. In response to these obstructions, women in prison increased their capacity and skill in self- and community advocacy as a way of coping with health care problems at the facility. Direct quotations from participants can be found in Table 3.

### Women's Experience During the Examination

Many of the women interviewed consistently described their experience with the test as painful and uncomfortable. They attributed their physical discomfort to both the provider's rough manner and to the inappropriately sized speculums used during the procedure. Further, the women commonly reported feeling a range of negative emotions during the test, including fear, embarrassment, and anger. Some even described the test as traumatic. Its sensitive and invasive nature, coupled with histories of sexual abuse and/or domestic violence, caused some women to feel violated.

Some women also expressed concern that the level of cleanliness in the examination rooms was inconsistent with their understanding of medical standards. Further, they noted that they were not afforded privacy during the examination.

**TABLE 3—Thematic Quotations From In-Depth and Key Informant Interviews: Community Health Assessment of Pap Tests for Women Prisoners at a California State Women's Prison**

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| Women's experience during the Pap test |
| "My last one . . . was extremely painful. He was cramming the speculum in like [a] Roto-Rooter." |
| "Ninety-nine percent of the women have been abused or raped. To have a man take us into an office the size of a closet . . . stripped down . . . [it's] rough and hurts us . . . it takes us right back to the beginning." |
| "It's really open . . . where they do the Paps. It has a lot of windows and see-through curtains. This needs to change." |
| "Even though I'm in prison, I'm a human being just like everybody else. I'm no different." |
| Women's experience with their medical providers |
| "Females have more understanding and can be more compassionate with Paps. It is kind of embarrassing for men to do it." |
| "I was never reassured by the doctor. There was no care and no time given to that aspect of my care. There was no overall [sic] humane treatment." |
| "They expect us to give them respect, but they don't respect us. They treat us like we are animals just because we are incarcerated." |
| Prison infrastructure obstacles hinder women's access to care |
| "I went through the right process and still couldn't see a doctor." |
| "Seventy-five percent of the women are illiterate. They don't know to put in a co-pay. They write 'pain down there' on their co-pay and are then misdiagnosed or just given medication." |
| "On a co-pay, in order to be seen, [you] should write that it's a dire emergency, can't get up, can't walk. You have to go the extremes." |
| "I never got no paperwork in the mail saying what happened. I got no results at all." |
| "I had a couple that weren't right [abnormal Pap test results]. No one said anything until a year later." |
| Prison infrastructure and culture hinder providers |
| "There does not exist the classic protective relationship between a doctor and their patient inside. . . . The doctors do not feel driven to take on any type of advocacy effort for a patient that they are unable to develop a doctor–patient relationship with. As a result, there is no one in the prison to support and take the side of the prisoner–patient."[a] |
| "[Providers] can get in trouble for being an advocate. . . . The system wants you to be mean to the inmates. . . . Employees can be written up for 'fraternizing' with the inmates."[a] |
| Self- and community advocacy |
| "We just try to take care of each other until we can't no more or figure out a way to fix it ourselves." |
| "A lot of women are scared to speak up. I used to be scared, but I'm not anymore." |
| "I would also like to see more empowerment for the women inside. It would be nice to see prisoner self-advocacy that doesn't equate to having conflict with one's doctor or being confrontational, but by gaining power through negotiation."[a] |

*Note.* [a]These quotations are from key informant interviewees. All other quotations are from women prisoners who participated in the assessment at this facility.

## Women's Experience With Their Medical Providers

In general, most of the women interviewed described their experience with medical providers during the Pap test as negative. They listed as possible causes the provider's gender and unprofessional demeanor and the lack of humane treatment. Almost all of the interviewees expressed aversion to being examined by a male physician and preferred the option of choosing a female physician or provider. Additionally, most of the women felt that the medical providers were unprofessional and sometimes rude, often lacking respect or compassion during the Pap test. As a result, some women stated that they have avoided or even refused Pap testing at this facility.

Women also commonly reported that communication with their providers during the Pap test was problematic. Providers gave little explanation of the process or its purpose and almost no explanation of follow-up treatment, if necessary. Further, some women felt that providers were not receptive to questions and comments during the Pap test. Women expressed a desire to receive health information from their providers respectfully and in language they could understand.

Finally, women reported that the follow-up care and treatment recommendations given by one provider were not always carried out by other providers, a practice that many women felt could ultimately compromise their health. According to some of the women, uncoordinated care could result in delays in communicating test results and the cancellation or alteration of a recommended course of treatment.

## Prison Infrastructure Hinders Women's Access to Care

The interviewees indicated that various aspects of the prison infrastructure impede women accessing Pap testing and follow-up care. Women discussed obstacles in scheduling a Pap test, obtaining results, and seeking follow-up treatment. Delays throughout these processes were a recurring theme.

In general, interviewees indicated that there is no standardized process for scheduling a Pap test at this facility. Consequently, many women wait extended periods for testing or do not obtain it at all. Some women are automatically called in for an annual Pap test, while others must proactively submit a written medical request form with a $5 fee to get a Pap test.

Women discussed concerns with the written request itself. First, it presents a financial hardship for many of them. Because a prisoner's average wage is 7 to 13 cents an hour, the $5 fee represents a significant proportion of their income.[21] Second, because obtaining a medical appointment often hinges on these written requests, the process requires a woman to be literate, fluent in English, and able to articulate her health care needs.

Many women also said that, more often than not, emergency cases are prioritized for appointments with providers. As a result, women felt that they had to embellish or exaggerate their health concerns to be seen by a physician. In

addition, some women indicated that they frequently did not receive their results in a timely or confidential manner.

The interviews also revealed that seeking follow-up treatment can be problematic. Some women spoke of long delays in obtaining treatment for gynecologic conditions after an initial Pap test.

### Prison Infrastructure and Culture Impede Providers From Delivering Care

The data suggest that the prison infrastructure and culture also hinder providers from offering quality medical care to women prisoners. Key informants indicated that the CDoC's punitive culture fosters antagonistic relationships between prison staff and women, discouraging physicians from advocating for their patients. Physicians who are viewed as being overly kind or helpful can be reprimanded for "fraternizing with the inmates." Interviewees also discussed understaffing as a contributing factor to tests' being rushed and medical providers' suffering from stress and burnout.

### Obstacles to Care Create Opportunities for Self- and Community Advocacy

Both women in prison and key informants emphasized women's capacity to use self- and community advocacy skills to meet their health care needs and cope with the challenges created by the prison infrastructure and culture. For example, to gain social support and receive health education, women rely on peer health educators and other women in leadership roles in the prison. They also offer one another emotional support and advice on how to navigate the health care system.

## ANALYSES

Since 1995, class action lawsuits have drawn public attention to negligent health care within the CDoC.[22,23] More recently, these lawsuits have been a catalyst for the establishment of performance standards and health care review processes within CDoC facilities.[22,24] These lawsuits aim to create substantive changes within the health care delivery system that will ultimately lead to the improved health of California state prisoners.[25]

Despite the changes brought about through litigation, significant hindrances to quality care persist. In June 2004, for example, California Governor Arnold Schwarzenegger's Corrections Independent Review Panel found the CDoC to be a defective system lacking accountability, uniformity, and transparency; moreover, its "insidious code of silence" continues to undermine its ability to care for and rehabilitate prisoners.[26] The panel has made restructuring the CDoC's health care system a top priority.[26]

The assessment findings substantiate many of the panel's conclusions. The women spoke of inconsistencies in the process to obtain Pap tests, the frequency of lost results, the lack of appropriate follow-up care, and significant delays throughout the spectrum of care. These data indicate that the facility does not have the infrastructure necessary to provide appropriate preventive reproductive care. The interviews also revealed that health care providers at this facility frequently fail to meet their patients' needs, specifically with regard to communication and sensitivity. Many women expressed aversion to being examined by a male physician and frequently connected memories of sexual abuse trauma with their experience during the Pap test. It is imperative that prison medical staff be trained to communicate effectively about the test and to understand the implications of sexual abuse and trauma for women's health care.

Finally, the negative effect of the CDoC's culture on health care delivery was another prominent theme throughout the interviews. The punitive nature of the system as a whole degrades doctor–patient trust and places providers and patients in adversarial roles.

The experiences revealed through this assessment indicate a need to create concrete procedural changes in the health care system, such as effective implementation of a medical scheduling and tracking system and specialized training on caring for women who have experienced sexual assault or trauma. Further, the data call for a macrolevel change in the CDoC's culture of punishment to create an environment that can provide quality, consistent reproductive care. In identifying the wide range of self-advocacy skills among women in prison, the assessment also encourages women to use these skills to transform the doctor–patient relationship into a relationship that promotes cooperation rather than antagonism.

Owing to the assessment's small sample size and its exploratory nature, the women interviewed are not representative of all women housed in this particular facility or within the CDoC. However, the assessment has served to highlight important topics of sensitivity, confidentiality, and communication within the Pap testing process that can potentially impact preventive care within prison systems. Furthermore, through a focus on qualitative data, the assessment highlights the significance of screening for cervical cancer for women in US prisons. It is hoped that these findings will initiate further research to advance an understanding of the problem, cultivate appropriate solutions, and include women prisoners in the process.

This assessment provides significant benefits for the public health field. The interdisciplinary collaboration between academic institutions and legal organizations presents an opportunity to exchange valuable skills, resources, and knowledge. The partnership between San Francisco State University and Justice Now provided unique access to a marginalized and isolated population of women at risk for preventable diseases such as cervical cancer. Also, the qualitative methodology used in the assessment gave voice to women typically excluded from the discourse on public health programs and policies that impact their lives. Studies that allow women to describe their own experiences are invaluable to health research. It is imperative that public health be informed not only by evidence-based research but also by the voices of the disenfranchised communities it aims to serve. ■


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*This article was accepted May 17, 2005.*

## Contributors

All of the authors conceptualized ideas; developed the assessment design; and implemented the assessment by collecting, coding, analyzing, and interpreting data. All authors also contributed to writing the article and reviewing drafts. J.R. Hult and C.G. Magee coordinated the development of the article.

## Acknowledgments

This community health assessment was conducted as part of the San Francisco State University Master of Public Health Practicum Experience in partnership with Justice Now, an Oakland, Calif., legal advocacy firm for women in prison.

The authors thank Justice Now staff for their support and resources, as well as the following San Francisco State University faculty members: Roma Guy and Jessica Wolin, for their academic instruction and guidance throughout the assessment design and implementation; Mia Luluquisen, for her consultation on data analysis and interpretation; and Lisa D. Moore, for her assistance and support in the publication process. We also thank everyone who generously participated in this assessment, especially the women in prison. Without them, this work would not have been possible.

## Human Subjects

This community health assessment was approved by the Committee for the Protection of Human and Animal Subjects at San Francisco State University.

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