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Challenges to Pap Smear Follow-up among Women in the Criminal Justice System

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Abstract

Women involved in the United States criminal justice system face a variety of challenges in maintaining their health. Histories of sexual abuse, early initiation of sex, and substance abuse are reflected in more negative reproductive health outcomes, including cervical cancer, than those found among non-incarcerated women. Little is known about how to close this health gap. The present study assessed what incarcerated women perceived to be facilitators and inhibitors of obtaining recommended follow-up for abnormal Pap tests. In-depth individual interviews were conducted with 44 women in an urban county jail about experiences with Pap tests and how they followed-up on abnormal results. We analyzed data using the process of thematic content analysis. Four themes were found, *Pap test abnormality as an all-inclusive phrase for women's health problems, unstable lives, the structural challenges of money,* and *competing demands*. Women with criminal justice histories have numerous and complex challenges in following-up abnormal Pap test results, as well as other health problems. Understanding the context around the follow-up for abnormal Pap tests in this population may increase providers' ability to help women effectively obtain cancer prevention care that can be life-saving, as well as to more effectively provide care for other health problems.

Keywords

Cervical cancer prevention; Incarcerated populations; Women's health; Qualitative research

Background

Cervical cancer, the result of a sexually transmitted infection, is disproportionately present in the lives of women involved in the North American criminal justice system [2]. Examination of the backgrounds of women in this population provides some insight into the origins of these poor health outcomes. Individually or in combination, mental illness, sexual and partner abuse, substance use, and trauma resulting from incarceration—represent

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formidable barriers to self-care and follow-up of health problems outside of carceral settings.

Among the 13,000 new cases of cervical cancer reported each year in the U.S., the rate among women in the criminal justice system is four–five times greater than among non-incarcerated women [1, 2]. The few investigators who have studied this problem in jail/prison populations have found that although many women get screened for cervical cancer, less than half gain access to recommended follow-up for abnormal Papanicolaou (Pap) tests results, which may involve human papilloma virus (HPV) typing, colposcopy, removal of precancerous tissue or cervical cancer treatment [3]. A number of factors have been found to be related to low rates of follow-up among non-incarcerated women, including lack of health care provider encouragement to get Pap tests and follow-up, lack of understanding of the abnormal results and the purpose of colposcopy, fear related to procedural pain and the potential diagnosis of cancer, forgetting appointments, low health literacy and low levels of education [4–7].

Little is known, however, about the particular barriers that incarcerated women face, during incarceration or following release that contribute to their very low rate of follow-up for abnormal Pap results. For most women, the days, weeks, or months after leaving jail are chaotic, as they struggle to navigate housing, child and partner reunification, and income needs [8]. In this context, preventive health care often has low priority.

The goal of our study was to assess the interpretation of “abnormal Pap test findings” among incarcerated women and what they perceived to be facilitators and inhibitors of obtaining recommended care. If providers can understand the context surrounding the gap in follow-up for abnormal Pap tests in this population, they may be able to help women to more effectively obtain cancer prevention care, as well as care for other health problems.

Methods

We conducted in-depth interviews with 44 women in an urban county jail. The Institutional Review Boards of both the University of Kansas Medical Center and the University of Missouri-Kansas City provided approval to conduct the study.

Setting/Recruitment/Sample

Data collection occurred at an urban county jail in the Midwest U.S. On any given day about 100 women are incarcerated in this facility, with turnover of about half the population occurring every 2 weeks. Most of the women incarcerated were charged with non-violent crimes. We recruited participants by posting flyers in the female housing units that stated the inclusion requirement and invitation, “Have you had a Pap test or cervical cancer screening in the last 5 years that came back ‘abnormal’? Researchers from the University of Kansas would like to talk to you about your experiences getting an abnormal Pap result.” No further definitions of Pap, cervical cancer screening, or “abnormal result” were provided.

Interested women were escorted to a special programs room where a researcher answered questions about the study and had participants sign consent forms. Interviews were

conducted in this programs room, with a jail staff member present for security about 30 feet from researchers and participants. Interviews were audiotaped with a digital recorder. While thematic saturation was reached after approximately 30 interviews, additional women were anxious to discuss this topic with us, so we interviewed all who expressed interest and met eligibility criteria.

Interview Guide/Data Analysis

Questions were based on key outcomes of interest described above and included an assessment of knowledge of Pap test screening; recommended follow-up; types of follow-up events; location of follow-up care; features of the medical encounter; and barriers to screening, follow-up care, or access to health care in general. Interviews were transcribed by a research assistant and transcriptions checked against the original recordings to ensure accuracy. Researchers went through several steps of data management and thematic analysis, a tool that can be used in conjunction with various methodologies or as an approach in itself [9]. This analytic strategy involves searching across a data set to identify repeated patterns of meaning. Researchers began by familiarizing themselves with the data, immersing themselves through repeated readings of the transcripts. They identified initial themes and constructed tables (data displays) including summaries of data from each interview, arranged according to initially identified themes, with representative quotes [10]. During the next stage, researchers used iterative analysis, or comparing back and forth between interviews to further refine themes that were both relevant to the research questions and that adequately represented the data set as a whole. Direct quotes were extracted from the interviews to illustrate the main themes.

Results

The average age of the 44 participants who made up the sample of this study was 34 years (range 19–53). The majority were Caucasian (n = 25, 62.5 %) or African–American (n = 17, 42.5 %). Other demographics are listed in Table 1.

Four overarching themes were identified within the data and relevant to our research question. These included:

- Pap test abnormality as an all-inclusive phrase for women's health problems,
- unstable lives,
- the structural challenges of money, and
- competing demands.

Pap test abnormality as an all-inclusive phrase for women's health problems: Despite a clear request in recruitment materials, restated before the signing of the consent form, only 10 of the 44 participants clearly had, and four others perhaps had, an abnormal Pap test. As illustrated in the accounts below, women viewed the Pap test as indicated for any number of women's health problems, and sought a Pap in response to a variety of symptoms including abnormal bleeding, itching, or vaginal discharge. Although most women voiced knowledge

that these tests should be done on a regular basis (every 1–3 years), a full 60 % of the reported Paps in these interviews were sought in relation to gynecologic symptoms rather than asymptomatic screening. The women often interpreted any pelvic exam as being a Pap test, whether or not a this screening test was actually done or indicated. There was also evidence of the women misinterpreting a cervical or uterine biopsy as a Pap test. They considered an "abnormal Pap test" to include not only findings that would medically be considered an abnormal Pap result, such as precancerous or cancerous cervical cells, but also incidental findings from the pelvic exam such as abnormal bleeding (n = 7), sexually transmitted infections (n = 6), bacterial vaginosis (n = 3), yeast infections (n = 3) and and palpable ovarian cysts (n = 8).

> They said I had a yeast infection, so I knew I had a problem. Something wasn't right."
>
> "I went to the emergency room and they did a Pap smear. I was scheduled for surgery for an ovarian cyst that same day. I was told I was at high risk for vaginal cancer."
>
> "I had heavy periods and they took tissue from my cervix."
>
> "I had a miscarriage and they did a Pap test. When I returned to see if the baby was completely gone from the uterus, they performed another Pap."

Unstable lives was a broad category that suggested why women might not follow-up on screening tests. Release from jail and re-entering the community required renegotiating housing, parental and partner relationships, and finding jobs despite a record of recent incarceration. Returning to previous social networks often included resumption of abusive drug behaviors, which complicated decision making, finances, willingness to seek medical help or apply for jobs, and also put them at risk for reincarceration. For those that did seek health care before, during, or after a jail term, the health team's ability to follow-up with them was compromised by frequently changing residences. In addition to the 18 women who mentioned new addresses, phone numbers, and/or unstable housing, jail recidivism made follow-up contact difficult.

> "I was supposed to go to a follow-up in 6 months…so it'll be this month and I'm in jail, so it'll have to be when I get out."
>
> "[I was supposed to follow-up], but I didn't. At the time I was homeless … I was sleeping here and there and I was living here and there. I was more concerned about that than my body."
>
> "I actually set up an appointment. I just never went to it. I had kids and an old man and then we started getting high again and it just really kind of faded to the back of the priority level."
>
> "I got into a drug addiction and at the time, it was helping me hide my fear. I tried to put [the need for surgery to remove ovarian cysts/masses] behind me, making myself believe it would go away, which knowing in reality, I knew it wouldn't, but on drugs your mind seems to think other ways."

> "I haven't been back… Since then I've got a new number and I've moved so I don't know [the results of the last test.]"

The structural challenge of money within the context of basic survival and the hard, cold reality of financial cost for health care were mentioned specifically by 14 women in this study. Because low-income women in the state where the jail was located were able to get Medicaid only when they were pregnant, few had coverage; only one participant interviewed stated she had health insurance. The fear of how much a visit, procedure, or medication would cost seemed to plague the women in this sample. The Medicaid structure also sets up a potential motivation to get pregnant in order to get coverage, despite already overwhelming financial stress. The costs of owning and maintaining a car or purchasing transportation to get to health care was another essential basic. Nine women discussed transportation issues.

> "It's hard for me because I don't have insurance or anything so … not knowing, well how much is this going to cost? Worrying about how much that's going to cost. It's just pretty scary."

> "[After being given abnormal Pap test results], I asked her, 'Ok how much is it [the follow-up]?' When she told me, I asked, 'Any payment options? And she said, no, not really.'"

> "They told me I could also go to [the community health center], and see if I qualified for Medicaid, and if I qualified then I could get it [the colposcopy for Pap test follow-up]. But I don't qualify for Medicaid because my son doesn't live with me and I'm not pregnant."

> "I don't have health insurance, and…I think that's a lot of young people's problem right now, cause I know a couple of girls in this pod [jail unit] that don't have health insurance, they're pretty young…and they can't go and get the help they need."

> "I don't have medical insurance. I did have Medicaid at one point in time, but I can't get Medicaid now… unless I get pregnant."

> "Just like the transportation thing. I think that if we're either low income or no income…we should be able to …have some kind of transportation, because a women's health is very important."

Competing demands included a variety of other life complications that can happen to anyone, particularly single mothers, but on top of the issues already discussed related to re-entry and recidivism, these new hurdles presented even more challenges that the women had to negotiate before they could consider caring for themselves.

> "I had a car wreck and I've been having to go to a whole lot of other stuff like, physical therapy."

> "I've got doctor's appointments or dentist appointments, my kids, they gotta get out of school. Somebody's gotta be home."

"Sometimes it's just taking care of three kids on my own, and their father is in prison."

"Mental health issues and dealing with my son's death. He was hit on a motorcycle and we had to bury him 14 days later."

Discussion

The overall goal of this qualitative study was to learn more about how incarcerated women understand Pap test abnormalities, and the inhibitors and facilitators related to subsequent follow-up. Only one of the identified themes was specific to Pap tests and the meaning of abnormal results. *Pap test abnormality as an all-inclusive phrase for women's health problems* conflated pelvic exams, STI testing and Pap smears. Similar results have been reported by numerous studies over many years, in various populations, and without apparent improvement over time [6, 11–17]. In conducting focus groups with an earlier sample of incarcerated women, we also found that women perceived all gynecological health exams to include a Pap test and that all gynecological problems were reflected as an abnormality in this test [18].

The other three identified themes were associated with cervical cancer disparities and are relevant to real life difficulties encountered by these women when trying to follow-up on any medical problem. *Unstable lives* and *competing demands* reflect the many personal challenges in the lives of women in this study when they are released from jail. Recent ethnographic work provides stark narratives on the post-incarceration challenges to family dynamics, housing, and employment that are reflected in the comments of the participants in this study [19]. Understanding the context in which they live, with minimal social support and concrete assistance lends insight into their difficulty in focusing on a personal health goal such as the following up of any abnormal medical test.

Women with criminal justice histories have tremendous instability around physical space and continuous housing. Close to 40 % of women in one study returned to jail or prison within a year of release; another study found 46 % of women were homeless immediately before incarceration, and a quarter were still homeless 6 months after release from jail [4, 20]. These factors certainly complicate vulnerable women's ability to address any health screening, including that for cervical cancer, much less to coordinate follow-up appointments after abnormal test results [12]. They also pose significant challenges to health care providers trying to contact them with information, findings, and instructions for recommended next steps.

The reality of the cost of health care in the United States presented itself in the theme of *the structural question of money* for women in this study. While a variety of publicly supported programs are available for the initial screening for cervical cancer, these same programs are rarely available for follow-up tests for definitive diagnosis and treatment. This violates a key component of the long-accepted ethics of screening, that is, that adequate resources for treatment should be available for all those who are found to have the condition of the condition [21]. While the existence of these financial factors as barriers to treatment for

cervical cancer is not new, neither has it been generally acknowledged as a serious problem [22].

Given their general poverty and the challenges these women face with employment and household demands, it is difficult for them to expect them to justify spending limited resources on potential problems that are not symptomatic and that do not interfere with daily life. This phenomenon is described by epidemiologists as the “breakpoint of illness” or the point at which it is legitimate to tap into resources for health care [23]. In cultures of poverty, it is common to wait until symptoms are significant, while in cultures of abundance (including health insurance), one often goes to the doctor for conditions just short of perfect health. While this idea was conceived before the passage of the Affordable Care Act in the United States, an unfortunate reality is that the state in which the present study was conducted was one of 22 that have refused Medicaid expansion, making health insurance coverage and the resources available with such coverage an elusive quest for many women in these communities [24]. When there is no insurance, and programs that pay for screening do not pay for treatment, why seek early identification of an illness for which you, within your economic means, can do nothing?

This study has several limitations. We were unable to access medical records for each participant to verify whether women had had an abnormal Pap test and what follow up they had. The convenience sample was recruited from one facility, which limits the broad application of results to other incarcerated women’s populations.

Conclusion

The results of this study provide insights about strategies needed to reduce health disparities among women in the criminal justice system. Access to screening tests for any health problem, while an important initial step, is insufficient to have an impact on the health status of any group. Policies that ensure access to both screening and treatment through the Affordable Care Act and Medicaid expansion can address some of the structural financial barriers for the many women in the jails and prisons in the United States. Public health programs such as the provision of case management services would provide concrete support for women as they negotiate their many post-incarceration demands. Clinical practitioners should routinely provide women with clear and complete information about what is occurring during pelvic exams.

From both an individual, a family and a community perspective, time in jail in the U.S. penal system represents a vast loss of potential. Families are disrupted and children separated from the incarcerated parent, often placed into the foster care system [25]. Low-income urban communities suffer from the frequent removal and reincarceration of their members [26]. Local jail facilities have variable programming that might enhance outcomes for their populations [27]. Programs to address substance abuse, increase health literacy and to better navigate the world upon release could create productive vs wasted time for inmates, and productive outcomes for individuals and society. Ultimately, considering incarceration as an opportunity to intervene with a very vulnerable population has the potential to improve health at multiple levels.

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Table 1

Characteristics of sample (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 *, no. (%)	4 (8.9)
Uninsured *, no. (%)	21 (46.7)
Had a primary care provider *, no. (%)	17 (37.8)

* Prior to incarceration