

Methodological Challenges Encountered In a Study of Co-Payment Policies and The Health Of Women Prisoners

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Purpose of Paper

- To analyze the methodological challenges encountered in a qualitative, community-based participatory research project (CBPR) with formerly incarcerated women

Key Points

- Development the study & CAB (community advisory board)
- Formerly incarcerated women as participants
- Confidentiality
- Issues during focus groups
- Dissemination of findings

Development of Study

Preliminary Study

- Hatton, D. C., Kleffel, D., & Fisher, A. A. (2006). Prisoners' perspectives of health problems and healthcare in a US women's jail. *Women & Health, 44*(1), 119-136.

Preliminary Study: Findings

- Women prisoners suffered from a myriad of physical and mental health problems
- Co-payments were one factor hindering healthcare access.

“I’d rather have a box of cookies than pay for an appointment with a doctor who I’m not going to see when I need him.”

Community Based Participatory Research (CBPR)

- “...researchers and community participants seek to collaborate as full partners in every phase of the research process...”

- Metzler, M. M., Higgins, D. L., Beeker, C. G., Freudenberg, N., Lantz, P. M., Senturia, K. D., et al. (2003). Addressing urban health in Detroit, New York City, and Seattle through community-based participatory research partnerships. *Am J Public Health*, 93(5),p. 803

Community Advisory Board

- 11 members:
 - Former Prisoners
 - Advocates
 - Grass roots organization (3)
 - Attorney
 - Physician
 - Nurses

CAB Discussion

- Members most familiar with prison systems commented on co-payments
- Healthcare professionals, generally did not know about co-payments

“...people who may need care don’t get it cause they don’t have three bucks...” CAB member (former prisoner)

Why co-payments?

- Identified in preliminary study
- Identified by Community Advisory Board

Co-Payment Study AIMS

- Analyze women prisoners':
 - use of co-payment for health care
 - its effect on their access to health care
 - its impact on their health.

Co-researchers

- 2 members of a local grass roots organization
- 2 academic researchers
- Both groups involved in:
 - Project design
 - Implementation
 - Evaluation
 - Dissemination

Formerly Incarcerated Women As Participants

Limited Research with Women Prisoners

- Constraints
 - Prison bureaucracies
 - Institutional review boards
- More men than women in prison
- Maintains the invisibility of women prisoners and their health concerns

Women prisoners are “typically excluded from the discourse on public health programs and policies that impact their lives.”

Magee, Hult, Turalba, & McMillan, 2005, p. 1716.

Formerly Incarcerated Women

- Because of our concern for the vulnerability of imprisoned women including retribution for participation
- Problems of researcher access to this population

Two Major Assumptions of Our Research

1. Women prisoners are capable of participating in research
2. Women prisoners' right to health care

Characteristics of Participants (n=31)

Age (mean, range)	38.48 (20-59)
Education (mean, range)	12.32 (6-16)
Children (mean, range)	2.47 (0-5)
Past incarcerations/jail (mean, range)	6.13 (0-30)
Days incarcerated/jail (mean, range)	530.77 (0-7200)
Past incarcerations/prison (mean, range)	1.29 (0-13)
Months incarcerated/prison (mean, range)	29.03 (0-468)
Ethnicity	
African/American (n, %)	6 (19%)
Hispanic/Latina (n, %)	8 (26%)
White (n, %)	14 (45%)
Other (n, %)	3 (10%)

Confidentiality

Confidentiality

- Procedure during focus group
 - Reminder to participants hold comments of others in confidence
 - Encouraged not to reveal anything might be uncomfortable about later
- Certificate of Confidentiality from the National Institutes of Health
<http://grants.nih.gov/grants/policy/coc/>

Issues During Focus Groups

Focus Groups

- Provided a lens into the larger issues of the healthcare in jails and prisons

Invisibility of Prison Healthcare

- Medical care operations of the California prison system under a federal court receiver
- “By all accounts, the California prison medical care system is broken beyond repair. The harm already done in this case to California's prison inmate population could not be more grave, and the threat of future injury and death is virtually guaranteed in the absence of drastic action.”

California Prison Health Care
Receivership Corporation, 2007

Historically, too many people in California have not wanted to know what's going on in the prison system and that's from every governor for the last 30 years right on down through the legislators and the general public, ...It seems to me that if the unethical, immoral, illegal activities involving health care—just health care, especially medical care, mental health care—were known to the general public, they wouldn't have put up with it for this long...Because let me make it clear right from the start, it is a horrid, horrid health care system. Unnecessary deaths, unnecessary abuse, (and) clearly unnecessary, in my opinion, overcrowding. The living conditions, the medical conditions are just horrid and are not deserving of the State of California in any year, in any century, let alone the 21st century

R. Sillen: Federal Receiver for California's Prisons

Context of Prison Healthcare

- Our study of the co-payment policy became a lens to look at this larger context
- Participants' stories embedded in the larger problems of this troubled healthcare system

Dissemination Of Findings

Stigma

- Dissemination in process
- Issues around disclosure of former prisoner identity

Conclusion

- Community-Based Participatory Research (CBPR) is research with people rather than on people
- Obligations during dissemination phase