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## Conducting Research as a Visiting Scientist in a Women's Prison

Mary Woods Byrne, PhD, PNP, MPH, FAAN\*

\* Professor, Columbia University School of Nursing, New York, NY.

### Abstract

Incarcerated populations have disparities in health risks and illness conditions meriting study, but the history of prison research is marred by unethical conduct. Ethical participation strategies are discussed in the context of studies implemented by the author in a state prison system. This study used ethnographic approaches, observed adherence to federal and institutional review board regulations and corrections department directives, and maintained continuous communication with vested interests to provide entry and long-term access for studies on female prisoners and their civilian infants. A culture clash between the punitive restrictive environment that serves the custody–control–care mission of corrections systems and the open inquiry environment needed for conduct of health research exists. Federal regulations protect prisoners as human subjects but additional vigilance and communication by researchers are required. Gaining and maintaining access to prison inmates for nursing research are leadership challenges that can be met within the caring and collaborative paradigm of nursing.

### Index words

Incarceration; Ethical conduct; Female prisoners

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RESEARCH HAS BEEN conducted inside prison environments in the United States for more than a century. Unfortunately, the history of prison research has been scarred by human subjects' abuses particularly before the 1970s when the federal government began to initiate protective guidelines and regulations (Kalmbach & Lyons, 2003). Ethical issues remain at the forefront of concerns for conducting prison research, but at the present time, there are comprehensive and explicit federal regulations that do protect prisoners' rights as research subjects. Other important research issues have received less attention. These include gaining access to a prison or jail system, establishing research rigor within the constraints of prison or jail security regulations, maintaining access and interest over periods for longitudinal studies, and establishing relationships with interfacing systems (corrections, media, philanthropic) in such a way that they are supportive and preserve appropriate research autonomy.

This author has conducted research in a maximum and a medium security prison for women in one state and is currently conducting a longitudinal study in these settings funded by the National Institutes of Health/National Institute for Nursing Research (Maternal and Child Outcomes of a Prison Nursery Program, ROIN00778). In addition to strict adherence to federal guidelines, including special regulations related to prisoners as subjects, other strategies for providing a respectful study environment and maintaining access have been devised in the course of study implementation.

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Address correspondence and reprint requests to Dr. Byrne: PhD, Professor, Columbia University School of Nursing, 617 West 168 Street, New York, NY 10032. E-mail: mwb4@columbia.edu.

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The purpose of this article is to share those learned strategies so that other researchers can draw implications useful to studies in prison environments, especially studies requiring long-term access and focusing on multiple-factor human phenomena. To achieve this purpose, a context will be provided by a review of health-related disparities that merit research in a women's prison system, a summary of the troubled history of prison research, and an introduction to the series of studies undertaken by this author. The use of federal requirements as well as optional measures to provide human subject protection within these studies will then be reported, followed by a discussion of additional learned strategies to enhance respectful, beneficent, and just participation by study enrollees as well as practical aspects to protect continued study implementation.

## Health Disparities of Incarcerated Women

### VIOLENCE, ADDICTION, INFECTIOUS DISEASE, AND MENTAL ILLNESS

Incarcerated women as a group experience violence victimization, drug involvement and addiction, sexually transmitted diseases, and HIV infection at disproportionately greater rates than the general population. In a sample of 66 Philadelphia jail inmates, one half had a history of sexual abuse and three quarters had been physically beaten by a boyfriend or spouse (Bond & Semaan, 1996). In North Carolina, pregnant prisoners were compared with pregnant patients seen in the health department and found to be twice as likely as the community women to have experienced both physical and sexual violence and more than three times likely to have experienced both types of violence (Sable, Fieberg, Martin, & Kupper, 1999).

Incarceration of women for drug-related charges doubled from 1990 to 1997 and is exceeded by the number of women who report drug use (DeGroot, 2000; U.S. General Accounting Office, 1999). In a convenience sample of 158 women in a New York City jail, three quarters had used crack and one quarter had used other drugs, chiefly heroin, three or more times a week during the month preceding imprisonment (el-Bassel et al., 1996).

Compared with free women, incarcerated women have repeatedly been shown to have high rates of sexually transmitted diseases, cervical cytological abnormalities, and gynecologic infections (Flanigan et al., 1999; Fogel & Belyea, 1999; Richie & Johnsen, 1996). The proportion of all female inmates with HIV has been reported to be more than 30 times higher than that of the general population (3.5% vs. 0.1%) and substantially higher in the northeastern United States where 13% of women in state prisons are HIV-infected (DeGroot, 2000; U.S. General Accounting Office, 1999).

Sixty-two incarcerated women in Boston reported an average of 10 stressful life events in the year prior to imprisonment, and the number of life events significantly correlated with depression in prison. The group had high levels of depression (mean, 31 [on the Center for Epidemiologic Studies Depression Scale, which has a cutoff of 16 or 20]) and anxiety. Female inmates in Alabama ( $N = 198$ ) were reported to have significantly higher mental distress compared with male inmates. Mental health for pregnant inmates is uniquely stressed. In a midwestern facility, in-depth interviews with 12 pregnant inmates concluded that all but 1 inmate perceived prenatal care to be adequate but that all had knowledge deficits and all reported the need for more psychological support (Shelton, Armstrong, & Cochran, 1983). An ethnographic study followed 26 pregnant inmates through delivery in two midwestern correctional facilities and all perceived the experience as a strongly negative one associated with feelings of stigma, deprivation, and anger that were exacerbated when they were separated from their infants within hours following their birth (Shelton & Gill, 1989). The Kentucky Commission on Women (1982) reported that for all imprisoned mothers with children of any age, the most traumatic aspect of their incarceration was separation from their children. Most

newly delivered prisoners are separated from their infant within hours after birth with minimal or no opportunity for even a brief reunion.

## **PREGNANCY, PARENTING, AND MINOR CHILDREN**

Pregnancy is not generally an indication for prison release, yet few prisons offer comprehensive prenatal care. Pregnant and parenting adolescents confined in juvenile criminal justice facilities were rarely offered parenting classes, and prenatal care was fragmented and dependent on access to community providers (Breuner & Farrow, 1995). Pregnant inmates tend to be in higher perinatal risk groups at the time of their incarceration and to have later initiation of prenatal care (Cordero, Hines, Shibley, & Landon, 1992; DeGroot, 2000; Martin, Reiger, Kupper, Meyer, & Qaqish, 1997). One advocacy report describes deaths of unborn and newborn children in prisons as a result of inadequate prenatal care, improper infant care, and long delays waiting for escorts by corrections officers and secure transportation when medical emergencies arise (Lays, 1992).

Most incarcerated women of all ages are mothers of children younger than 18 years and most of them resided with their children prior to incarceration (DeGroot, 2000; Women Offenders: Bureau of Justice Statistics Special Report, 1999). Minimal attention has been given to children of incarcerated women. The National Council on Crime and Delinquency in New Jersey reported more than 25 years ago that when a mother is incarcerated, her children demonstrate more frequent disruptive behaviors, illnesses, and poorer self-image; the situation was unchanged when the council revisited the issue in 1993 (Bloom & Steinhart). The Child Welfare League characterizes children with parents in prison as “in crisis” and at risk for hardship, substance abuse, and delinquency (Beatty, 1997). The Center for Children of Incarcerated Parents, a national advocacy group, points out that, although small in scale, all studies consistently demonstrate poor outcomes for these children in terms of poverty, diminished physical and mental health, and risk for intergenerational criminality (Simmons, 2000). For the most part, children of incarcerated women have not been the recipients of special assessments or interventions but have become invisible to society. Most children of incarcerated mothers live with extended family members or become part of a state foster care system, and 56% of female inmates do not see their children at all during their entire term of incarceration (U.S. General Accounting Office, 1999). Residential programs for infants now exist in only 11 states and a few federal prisons (DeGroot, 2000); many of these have short and interrupted histories, limited resources, and minimal programs to support new mothers’ health needs. Even demographic data for these programs are sparse and no rigorous evaluations are available.

## **Troubled History of Prison Research**

Minimal public attention was given to prison research during most of its first century in the United States. During this time, diseases were induced for study purposes (Leopold, 1958; Reich, 1995) and up to 85% of all drug toxicity clinical trials were conducted with prisoners (Hoffman, 2000; Kalmbach & Lyons, 2003). As the public became aware of similar research with vulnerable civilian populations, the government finally responded by forming the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (NCPHSBBR) and passing the National Research Act in 1974 with additional protections added later for pregnant women, prisoners, and finally children.

An early recommendation of the commission was to discontinue all prison research on the assumption that informed consent could never be elicited in an intrinsically coercive environment. This debate continues but, currently, the Code of Federal Regulations (Title 45, Part 46 [45 CFR 46]) for Protection of Human Subjects now provides explicit regulations governing human research in all federally funded studies and commercially sponsored drug

studies. Notably, regulations are specified for research involvement of prisoners. The code has become increasingly specific regarding informed consent, institutional review boards (IRBs), and quality assurance oversight by the new Office for Human Research Protections (OHRP). In response to specific abuse allegations settled in courts in the past, informed consent must specify that a subject is not waiving any legal right and research participation will have no effect on parole board decisions. Research conditions are compared with usual living conditions of incarceration and must not provide undue incentives. Institutional review boards must have at least one member who is a former prisoner or prisoner advocate. Research subject matter is limited to four areas: (1) causes, effects, and process of incarceration or criminal behavior; (2) prisons as institutions or prisoners as incarcerated persons; (3) medical conditions affecting prisoners as a group; and (4) practices with the intent or probability of improving the health or well-being of participants.

Some researchers think that the pendulum has swung so far that prisoners are overprotected as a subject group with the unanticipated result of actually discouraging their participation in studies that have critical implications for their welfare (Moser et al., 2004). Others point out lingering limitations in human subjects protection for prisoners and for all groups for which the ability to make decisions freely might be questionable (Hoffman, Schwartz, & DeRenzo, 2000; Kalmbach & Lyons, 2003).

### Studies in a Prison Nursery

The studies that provide the context for this article have been conducted since 2000 in two correctional facilities for women in a northeastern state prison system. The focus is unique in that the subjects include female inmates convicted of felony crimes and their civilian infants who arrived in the prison because their mothers were pregnant when incarcerated. A statute in this state provides infants with protection against arbitrary separation from their mothers. Because this is one of the few corrections systems that has a prison nursery option, these inmates can apply for it and, barring past history of child-related crime, child maltreatment, or serious disciplinary issues during incarceration, they are accepted and reside inside the prison with their infants for up to 18 months. This is all the more remarkable because these are maximum and medium security facilities. The nursery has existed for more than 100 years, but this is the first time that an outside scientist was permitted to research its outcomes. Following ethnographic and cross-sectional descriptive studies ( $N = 118$ ), a longitudinal study on 100 mother/infant dyads ( $N = 200$ ) is currently in progress.

### Use of Mandated and Other Human Subject Protections

All 45 CFR 46 requirements were observed for these studies. In addition, the option to apply for a certificate of confidentiality that provides a researcher with the right to resist most legal requests for disclosure of subject information was exercised. Although the 45 CFR 46 protections have been described as “exhaustive” (Kalmbach & Lyons, 2003), a researcher must still confront additional concerns in day-to-day implementation of research. The broader ethical principles articulated in the Belmont Report (NCPHSBRR, 1979) provide the guidance needed to address ongoing issues in these complex human research situations. The principles of respect for persons, beneficence, and justice are imbedded in the ethnographic orientation, the attention to repeated explanation of the consent content and the study components, and other strategies used to address research issues that are detailed below.

The Department of Correctional Services (DOCS) in the state in which these studies were conducted required a research application to the central administration in the capital city and a subsequent contract outlining researcher responsibilities to the department. Unfailing compliance with the security regulations of the prison system was stressed. There was also a clause requiring a review of all manuscripts that hint at a historical fear of bad publicity

(Newman, 1958). The IRB of this researcher's medical center clarified that this review must be limited to comments on accuracy about the prison system and could not incorporate any type of censorship.

## Strategies to Optimize Ethical and Continuing Participation of Prisoners in Research

The researcher, who has complied with all federal regulations and achieved IRB and OHRP approval for a study as well as a corrections department's permission to do research in its facilities and who also has acquired the necessary funding and resources, must still confront a series of potential obstacles to the implementation of the approved research. These obstacles are associated with the realities of multiple gateways guarded by state and local administrators with varying understanding of research, diverse vested interests held by formal and informal gatekeepers, security issues related to inmate access, the forensic orientation of a prison system, and existing suspicions of prison administrators, staff, and inmates derived from any negative experience with the media, medical personnel, and system politics. These obstacles are intensified for a visiting civilian scientist and research team who come from the outside community and are not part of the corrections system.

Strategies used in this researcher's studies to address these issues include ethnographic orientation, participatory input of inmates, acquiring knowledge of criminal justice and specific prison systems, consistent compliance with security regulations, awareness of and repeated dialogue with vested individuals and groups, clarity of research goals, participatory input of inmates, and constant vigilance.

### ETHNOGRAPHIC ORIENTATION

This series of multimethod studies used ethnography as one method but also maintained an ethnographic orientation throughout. By ethnographic orientation, this writer means arranging to collect, record, and interpret data so that they preserve the perspective and the cultural fabric of those whose human experience is being studied. This researcher was already trained as an ethnographer so it may be that this orientation would have been inevitable especially in research encounters that last over long periods. At any rate, this outlook served the studies in several ways. The ethnography as an initial study design established collaborative respect for all involved persons and especially for the inmates. The ethnography findings suggested a theory of parenting specific to incarcerated women and directed the researcher to the significant themes of attachment and separation for the current study. Conducting an ethnography is a long-term project, and the longevity provided the advantage of thoroughly acquainting the researcher with the environment over the first 2 years as well as creating a continued presence during which trust with subjects and staff could be achieved.

As an ongoing orientation, the ethnographic perspective inspired numerous strategies for full and respectful continuing participation of vulnerable research subjects. Inmates who could serve as study consultants and provide insight into access to participants and productive data collection methods were identified. These inmates were key informants, certainly not in the prison sense of an *informer* but in the best ethnographic sense, which means that they were seen as leaders within their own inmate community and so could speak knowledgeably about their own perspective but also speak for the group. Early in the research, they provided input on understandability of quantitative instruments, feasibility of scheduling for repeated data collection, and spreading word of the research to all eligible inmates. Their feedback kept the researcher aware of the subtle shifts of dynamics in the prison community that had implications for recruitment and continuation of participation in the studies.

## COMPLIANCE WITH SECURITY REGULATIONS

Prisons are primarily custodial institutions responsible for the confinement of sentenced individuals. The mission of a corrections department is contained in three *c*'s: custody, control, and care. The obligation is to keep incarcerated individuals in custody, to control behavior so that no further harm is done, and to provide adequate basic care for those in keeping. These are challenging demands and it is documented that violence and crime do exist inside prison walls and that prisoners often reside in substandard living conditions.

The first and continuous reminder of prison security is the gate check prior to entry. This process was facilitated for this author's studies through the prison's volunteer program that provided the vehicle for background check, fingerprinting, and photo identification needed to achieve regular entry into the prison. The rigor of gate entry procedure is not disturbing to a researcher who appreciates the value of detailed protocol, but the occasional excessive intrusiveness and the unfailing unpredictability of the procedures can be jarring. One can be prepared with open bags only to be waved quickly through on one occasion and to be detained, scrutinized, and questioned or even ignored and left waiting on another. Not knowing quite what to expect is a security strategy used to deter carelessness visitors might assume over time. Researchers must learn to limit all items to the minimum needed for a visit. beepers, cell phones, and other conveniences accepted as routine in civilian life are forbidden, as are large sums of money, credit cards, and any breakable item. The extraordinary permission to bring in a video camera, tape recorder, and battery-operated infant state monitor was granted to this researcher but special permission must be confirmed each time entry is made with any of these contraband devices and allowing extra time to be cleared at the gate is always recommended. Although recognition as a volunteer expedited routine entry, that status does not truly incorporate the research role and was not sufficient to maintain entry during the national security crisis that followed the attacks on our country on September 11, 2001. Working closely with the DOCS medical director was instrumental in solving this dilemma when he consulted with other top-level administrators in the prison system and secured a letter of entry for the research team covering all times including "code orange" designations so that recruitment and data collection could continue on schedule.

**Dialogue with all Vested Interests**—This is a dramatic example of the need to repeatedly dialogue with prison administrators. Although the need for such communication seems obvious, the few early articles on prison research methods actually warned against it, advising that prisoners should see researchers as separate and aloof from prison personnel (Newman, 1958). This has some merit but can be accomplished without relinquishing essential open communication with administration or pretending to inmates that it does not have to occur.

The range of vested individuals who and groups that take formal or informal interest in prison research goes well beyond administrators and behooves the research to be aware of all of them. It was surprising to this researcher how many such people there are. Approvals received at the state capital level were based on feedback from individual prison superintendents but additional meetings with these local administrators, their deputy superintendents, and their staff were crucial to explain the study details and secure cooperation at the local prison level. In addition, there was a significant civilian staff contracted to administer the children's center of which the prison nursery was one program component. The civilian staff members are deeply involved in the programs for the nursery mothers and their awareness and support for the study have been important. They direct emerging questions or concerns to the researcher, suggest best access times, and help secure appropriate spaces for all aspects of data collection with both the women and the infants. This program-oriented prison system also uses large numbers of civilian volunteers who observe the study activities and inquire about them.

Another vested interest group that emerged early and required careful interface is the media. The nature of these studies is intriguing to local and national news reporters among others. It is important to understand their agenda and to be wary of misrepresentation, whether intentional or a function of story angle. Skills in preparing comments for telephone interviews, in gaining access to a prepublication draft for accuracy, and in developing judgment about which interviews to accept or decline are critical for all research but especially so for prison research. Problems this researcher confronted included impatience of reporters with the need to protect the privacy of inmates and their children when their requests for detailed information and photographs had to be denied, eagerness for definitive study results while the study is in progress, and attempts to fit interview comments into preconceived positive or negative notions about infants raised in prison.

Personnel changes were not uncommon at all levels and necessitated another round of explanatory meetings. Troubleshooting meetings remain important and are arranged by the researcher whenever potential difficulties can be anticipated and circumvented. During the first 4 years of these studies, there have been four changes in superintendents, four changes in deputy superintendents, six changes in nursery manager, and countless changes in corrections officers and their assigned posts.

### **KNOWLEDGE OF CRIMINAL JUSTICE AND PRISON OR JAIL SYSTEM**

Acquiring knowledge of the specific prison system in which one's research will be conducted is a requisite to understanding how to gain and maintain access and to tailor data collection procedures. To interpret data within context, it also becomes important to have knowledge of criminal justice. Both factual and cultural knowledge are needed. The former is abundantly accessible through texts, literature, and online information in this growing field. The problem is one of absorbing so much information. Consultants from the field of criminal justice have been a major asset to this author's studies. Cultural knowledge is less readily available and learned more slowly through observation and listening while "inside" as well as exposure to prisoners' journals, poetry, and other writings and sensitivity to prison as a metaphor in art, history, and biography. Throughout these studies, inmates engaged in dialogue with the two research team members allowed inside the prison and shared their stories, opinion, and writings.

Routine is a significant component of prison culture. For more than 60 years, it has been mentioned as a consideration that prison researchers must regard as inevitable (Farber, 1941; Newman, 1958). In this author's studies, it was important not to disrupt inmate participation in either required or optional prison programs that would be considered in their parole board evaluations. It was also essential to know where and when inmates could be accessed and crucial to not expect access during the mandatory count times four times each day when prisoners are locked in their cells.

Rumor and innuendo are also an inescapable cultural component of prison life. Inmates' experiences with a researcher, however privately arranged or cursory, can be expected to become known to other inmates. The very presence of an outsider in the prison is an event noted and evaluated. Long-term prisoners are eager to receive another reflection of life and of themselves through a new outsider. In these studies, to meet the ethical obligation of including all eligible inmates, one strategy was to meet with the entire group of women accepted in the prison nursery at any point in time and to present the research opportunity to them. In the very first such meeting 4 years ago, there were 17 women in the nursery and 16 of them chose to enroll in the study. However, the only inmate who declined observed the research process over time and spontaneously encouraged all newly confined nursery mothers to participate. A single inmate with influence among peers can either strengthen or undo a study, especially one that depends on long-term participation. On the other hand, it is crucial not to violate promised

confidentiality and to be on guard about what information is shared and what is appropriately always kept private.

### **CLARITY OF RESEARCH GOALS**

By the time one completes applications for IRB, DOCS, and funders, it would seem that clarity of goals is a given. However, the range of persons to communicate with in the prisons, from administrators to corrections personnel to civilians and the inmates themselves, necessitates the clearest use of lay terms suitable to the education and background of each person as well as highlights the need to repeat explanations over time and to be consistent. One must also develop a savvy for those who need information and at what depth. The greatest effort should be put into informing inmates so that they can adequately consent and participate. Research administrators need sufficient detail to comprehend and support a study. Casual observers only need to know that a researcher is conducting an authorized study. Providing isolated details, especially if conveyed in a hurried encounter or out of context, carries the risk of misinterpretation and inappropriate involvement.

### **CONSTANT VIGILANCE**

The prison is notoriously a scene of boredom, repetition, and dull sameness. Yet changes that impact research suddenly can occur. Changes in key personnel have already been mentioned. There can also be sudden transporting of study subjects to distant prison sites as part of the draft system used to control housing density and security. Scheduling of parole decisions is fairly predictable but budgetary and other influences beyond the scope of a researcher can sometimes result in more rapid prisoner release than anticipated or loss of follow-up opportunity through deportation proceedings. For study designs that include postrelease follow-up, it is important to elicit a wide range of contact information with each subject's permission as early in the study as feasible. There is also a need to be vigilant with regard to persons who and groups that do not want the research to continue. A researcher must evaluate the power and authority of such interests and the need to negotiate or circumvent their influence.

### **Discussion**

Following decades of prison research without scrutiny and a brief period of virtual halt, there seems to be renewed interest in prisons and jails as research settings and in incarcerated persons as subjects. Search of the CRISP retrieval system reveals four times as many National Institutes of Health-funded studies in this area during the last decade than in all the years since its inception in 1972. Nursing and health literature are beginning to reflect study outcomes. A review of MEDLINE, PsychINFO, and CINAHL literature systems do show however that there is a reporting lag, with more funded studies being experimental and more publications reporting descriptive or predictive studies or focused on ethics and societal issues related to incarcerated persons.

It is a welcome new direction that prisoner and jail research must now be justified and that prisoners are not merely used as a convenient, homogeneous, and inexpensive sample for any study that needs to be done (Kalmbach & Lyons, 2003). Articles exploring ethical and social issues are also a welcome corollary to the research literature and serve to remind investigators that although health disparities are indisputable in incarcerated populations, their existence alone does not justify research (Carlen, 1994). The process of implementing prison research unwittingly opens the mind to the more compelling questions of what research can contribute not only for a single study question but also in the larger contexts of prisons' effects on the imprisoned and prisons' place in society. Research barriers can be overcome with thoughtful strategies so that research can include ethical and full prisoner participation. The larger sets of societal questions engendered by prison research do not have easy and obvious answers.



## Summary and Conclusions

There is an intrinsic culture clash between the punitive and restrictive environment that exists within the custody–control–care mission of correctional systems and the open inquiry environment needed for conduct of research by health care professionals. Federal regulations now protect prisoners as human subjects but additional gatekeeping and communication by researchers are required continuously. Assessment of obstacles and implementation of strategies are an ongoing and dynamic process that make possible the conduct of prison research with full and ethical participation of subjects and robust results.

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