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# HIV/AIDS Research in Correctional Settings: A Difficult Task Made Even Harder?

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# **Abstract**

Housing a large number of individuals living with or at risk for HIV/AIDS, correctional settings have considerable potential for epidemiological, prevention, and treatment research. However, federal regulations and institutional challenges have limited the extent and types of such research with prisoners. This study examines the degree to which HIV/AIDS correctional researchers report greater challenges than do their non-correctional counterparts. Results indicated that correctional researchers reported significantly more frequent challenges than those in noncorrectional settings, even after controlling for experience; with the dominant difference related to challenges due to the research setting. These findings add empirical data and support previous research in the field; however, additional research should include correctional staff and incarcerated individuals, and explore whether these differences extend to other research topics.

## **Keywords**

HIV/AIDS Research; Correctional Settings; Prisoner Research; Research Challenges

# Introduction

The Centers for Disease Control and Prevention (CDC) estimates that more than 1.1 million people in the U.S. are currently living with HIV, with 18.1% unaware of their infection, and an additional nearly 500,000 individuals with confirmed AIDS (CDC, 2012; CDC, n.d.). Correctional settings are disproportionately affected by HIV/AIDS with 1.4% of all male, and 1.9% of all female prisoners reported to be HIV positive or have confirmed AIDS, as compared with 0.7% of the U.S. population at large (Maruschak, 2011; World Health Organization, 2013). With over 1.6 million people incarcerated in federal or state prisons, this translates to more than 20,000 (1.5%) confirmed to be living with HIV/AIDS (Guerino, Harrison, & Sabol, 2011; Maruschak, 2012). Indeed, an estimated 16.9% of all Americans

with HIV and 11.9% of individuals with confirmed AIDS were incarcerated at some point in 2006 (Spaulding et al., 2009). Furthermore, in addition to the prevalence of individuals with HIV/AIDS in correctional settings, an important consideration is the continuous stream of more than nine million individuals entering and being released from correctional institutions every year (CDC, 2001; Leh, 1999). For example, Spaulding et al. (2009) estimated that, in 2006, 14% of all individuals with HIV/AIDS in the U.S. had been released from a correctional facility during that year, thus in effect, returning their existing problems to their communities.

Given the staggering number of individuals living with or at risk for HIV/AIDS in the justice system, correctional settings have considerable potential for advancing science and improving healthcare through epidemiological, prevention, and treatment research (Gaiter & Doll, 1996; Grinstead et al., 2003; Macalino et al., 2004). However, limitations on the scope and extent of possible research activities in correctional settings exist in response to historical events that preceded the HIV/AIDS pandemic. That is, the history of research with prisoners has been characterized by activities that conflict with the basic ethical principles of autonomy, beneficence, and justice. Although the more egregious violations of prisoners' rights have been reported in other countries, violations have also occurred in the United States. Examples of these violations include testing drugs without proper consent and using inducements (e.g., food and medical care) that may be coercive for individuals in correctional settings (Dubler & Sidel, 1989; Hammett & Dubler, 1990; Lazzarini & Altice, 2000). Even unintentional abuses are possible considering that prisoners often have limited ability to provide informed consent; are more readily denied access to the benefits of research; and present with increased likelihood for impaired ability to understand risks, benefits, and harms of research participation.

To address the increased vulnerabilities of incarcerated people and to prevent possible recurrences of unethical treatment of prisoners participating in research, additional federal rules and regulations were implemented to provide extra safeguards for the protection of prisoners as research participants (Kalmbach & Lyons, 2003; Protection of Human Subjects, 2009). These safeguards include that research with prisoners be limited to studies that provide no more than minimal risk as defined by "the probability and magnitude of physical and psychological harm that is normally encountered in the daily lives, or in the routine medical, dental, or psychological examination of healthy persons" [45 CFR 46.303(d)], a definition that is more stringent than the definition of minimal risk for non-prisoner populations. Additionally, studies that include assignment to control groups that may not benefit from the research must be approved by the Secretary of the U.S. Department of Health and Human Services (HHS) after expert comment and publication in the Federal Register [45 CFR 46.306(a)(2)]. Unfortunately, an unintended consequence of such regulations has been the limiting of research and subsequent restriction of access to research benefits for individuals in correctional settings (Brewer-Smyth, 2008; Hammett & Dubler, 1990; Harris, 2001; Institute of Medicine [IOM], 2006; Kalmbach & Lyons, 2003).

In addition to barriers to research that may have been created unintentionally by federal guidelines, correctional settings pose unique ethical and environmental challenges to the conduct of HIV/AIDS research, including these settings' need to prioritize security and the

vulnerability of prisoners (Harris, 2001; Hogben & St. Lawrence, 2000; Lazzarini & Altice, 2000; Peternelj-Taylor, 2005; Seal, Eldridge, Zack, & Sosman, 2010). This need for security is exemplified by restrictions on prisoners' access to researchers; limitations on equipment that researchers may bring to the correctional setting and data that they may take away; and the need to monitor inmates in such a way that may reduce their confidentiality. Further, the closed nature of correctional settings presents unique challenges to maintaining privacy and confidentiality, particularly when the research focus is on a stigmatized disorder, such as HIV/AIDS. Due to these regulatory and environmental challenges, research efforts in correctional settings have been hampered, effectively negating an opportunity to provide research benefits to an underserved population. Further complicating the conduct of HIV/AIDS research in correctional settings is the fact that HIV/AIDS remains a stigmatized disease that more often occurs among already stigmatized individuals who have unequal access to services, such as substance users and their sex partners, members of minority groups, and men who have sex with men (Lazzarini & Altice, 2000).

The Institute of Medicine (2006) reopened the debate about prison research in general and provided an opportunity and framework for focusing on prison HIV/AIDS research in specific. This report identified the need for empirical data on the challenges of conducting correctional research and data-based recommendations that could help facilitate such research. Given the disproportionate rate of individuals with or at risk for HIV/AIDS in correctional settings and the added vulnerability of this population, there is a particular need for the development of empirically-based recommendations on the conduct of HIV/AIDS research in correctional settings. In response to the IOM report, Eldridge et al. (2012) conducted qualitative interviews of HIV/AIDS researchers, ethicists, IRB members and prisoner representatives, and prison administrators to identify the top ethical challenges of conducting HIV/AIDS research in correctional settings. Findings revealed that the most challenging ethical considerations were confidentiality and privacy; autonomy and informed consent; and justice and access. Contributing to these ethical challenges were characteristics of people who are incarcerated, nature of correctional institutions, and state and federal regulatory issues. The current study further expands this work through a quantitative investigation of HIV/AIDS researchers to understand the challenges of conducting HIV/ AIDS research in correctional settings. To accomplish this, we surveyed HIV/AIDS researchers in correctional settings and compared them to HIV/AIDS researchers in noncorrectional settings. The goal of this study was to identify the relative challenges of conducting HIV/AIDS research in correctional settings with the ultimate goal being the increase of HIV/AIDS research in correctional settings and subsequent improvements in HIV/AIDS treatment and prevention.

# Method

#### **Participants**

This study is part of a larger project funded by the National Institute on Drug Abuse to explore ethical and other challenges to conducting HIV/AIDS research in correctional settings. For the overall project, potential participants included researchers who conducted HIV/AIDS research in correctional or non-correctional settings; IRB chairs and members

who have reviewed HIV/AIDS correctional or non-correctional protocols; and IRB prisoner representatives. For purposes of the current study, we used only data collected from HIV/AIDS researchers. To identify researchers, we scoured electronic databases for recent research funding, publications, and convention presentations. We retained researchers who had relevant extramural funding and/or two or more HIV/AIDS-related publications after the year 2000. From these searches, a total of 3,692 authors were retained.

Of these authors, we identified 677 researchers who have conducted HIV/AIDS research in correctional settings. To complement this sample, we identified an additional unduplicated 37 researchers from a list obtained from the Office of Human Research Protections of prisoner certified studies, leaving a final total of 714 researchers who have conducted HIV/ AIDS research in correctional settings. To select non-correctional HIV/AIDS researchers who have conducted HIV/AIDS research in non-correctional settings, we took an initial sample of 750 from among the remaining 3,015 authors identified through our electronic searches. After eliminating deceased, retired, non-US researchers, and those for whom contact information was not available, we were left with a sample of 550 researchers. We then took another sample of 750 authors and from among those for whom we had contact information and were not retired, deceased, or non-US, we sampled an additional 57 researchers, for a total of 607. This sample of 607 was complemented with 94 referrals we obtained through snowball sampling, leaving a total of 701 non-correctional researchers that were eligible to be surveyed. After removing potential participants due to having undeliverable addresses, being deceased or retired, or having responded to the survey from the perspective of an IRB chair, member or prisoner representative, we were left with a final sample of 472 correctional HIV/AIDS researchers and 451 noncorrectional HIV/AIDS researchers. Of these 923 individuals, 341 participated by completing our survey, for an overall response rate of approximately 37%. Table 1 provides demographic information for these participants.

#### Instrumentation

Participants completed a comprehensive survey related to ethical challenges and barriers to conducting HIV/AIDS research in correctional settings. The 26-page survey was developed based on extensive qualitative work conducted over a 2-year period and included 11 sections: participant background; factors and participant characteristics with potential impacts on obtaining informed consent; positive outcomes to participants and non-participants; addressing potential harms and participant characteristics that may affect potential harm; ensuring justice and fairness; role of IRB and federal regulations; challenges in conducting HIV/AIDS research and their impact (researchers only); challenges in providing ethical oversight of HIV/AIDS research (IRB members, chairs, and prisoner representatives only); perceptions and opinions about HIV/AIDS research with correctional populations; knowledge of rules and regulations governing correctional research; and vignettes. For purposes of the current paper, the section asking participants about how often they had experienced common challenges in conducting HIV/AIDS research was analyzed. Only individuals who reported experience as an HIV/AIDS researcher completed this section. The 15 items (see Table 2) in this section were responded to using a 4-point scale

that ranged from 1 (*Almost never*) to 4 (*Almost always*). Participants were also given the option of responding to each item by indicating *No experience/Not applicable*.

#### **Procedures**

After receiving approval by the University of Alaska Anchorage Institutional Review Board, following the general recommendations of Dillman (2007), the survey process began with a pre-letter notifying potential participants that they would soon receive an email requesting their participation in an online survey. This letter was followed two weeks later by an email consisting of a cover letter and a link to an informed consent form, payment form, survey, and non-participation form. Relying on individualized code numbers for tracking purposes, up to four reminder emails were sent at approximately two-week intervals to individuals who had completed neither a survey nor a non-participation form. A letter was mailed approximately one week prior to the last email reminder. As our final contact, to address concerns that emails may have been mis-identified by email hosts as spam and not delivered properly, we mailed a paper version of the survey to all potential participants who had yet to respond by either completing the survey or a non-participation form. Respondents who completed the survey received \$60 compensation and had the option of entering a raffle for prizes.

## Statistical Analyses

Preliminary analysis compared correctional and non-correctional HIV/AIDS researchers on years of experience at each of 12 settings. A total score was calculated for each participant and, to account for participants indicating experience in multiple settings within the same timeframe, the maximum for total experience was set at 50 years. Across all participants, experience ranged from three to 50 years, with a mean of 23.33 (SD = 14.39). Correctional and non-correctional researchers differed in their total experience, with the average total experience for correctional researchers (M = 25.31, SD = 15.10) being significantly greater than that of noncorrectional researchers (M = 20.85, SD = 13.10), t[339] = 2.92, p < 0.01).

As participants were given the option of indicating *No experience/Not applicable* to each of the 15 research challenges, the number of participants who responded varied from item to item, precluding the use of multivariate statistics. Thus, separate analyses of covariance (ANCOVAs) were calculated with researcher group as independent variable, research experience as covariate, and each of the 15 research challenges as dependent variables.

# Results

As indicated in Table 2, correctional researchers had higher mean scores on all but two of the 15 research challenges. The two exceptions for which correctional researchers reported less frequent challenges, although not statistically significant, were related to recruiting and retaining participants, activities that are likely to be easier in closed environments such as correctional settings.

To investigate differences between HIV/AIDS researchers with and without corrections experience on each of the 15 research challenges, ANCOVAs were calculated. Results of the ANCOVAs revealed significant differences on eight of the research challenges. When

considering the eight challenges on which the two researcher groups differed significantly, five were related explicitly to the research setting. More specifically, correctional researchers more frequently faced challenges with gaining access to the research setting, F(1, 296) = 31.60, p < 0.001; obtaining research review and approval, F(1, 282) = 14.96, p < 0.001; navigating research settings' policies and procedures, F(1, 300) = 18.15, p < 0.001; dealing with interruptions and delays due to the research setting, F(1, 296) = 31.63, p < 0.001; and obtaining review and approval prior to dissemination, F(1, 257) = 5.45, p < 0.05.

In addition to challenges related to the research setting, researchers with correctional experience also reported significantly more frequent challenges with securing or maintaining informed consent, F(1, 293) = 5.35, p < 0.05; making compensation or incentives available to participants, F(1, 282) = 19.60, p < 0.001; and retaining participants in the follow-up stages of research, F(1, 265) = 3.57, p < 0.05.

Table 3 provides rankings of the 15 individual research challenges based on the average scores given to each item, presented separately by correctional and non-correctional researchers. As indicated and concordant with the ANCOVA findings, the relative ranking of items related to research setting was higher for correctional researchers than non-correctional researchers. Interestingly, the five items ranked the lowest were identical for the two groups.

# **Discussion**

In comparing challenges experienced by researchers in their work, the current study found that researchers conducting HIV/AIDS research in correctional settings reported significantly more frequent challenges than HIV/AIDS researchers in non-correctional settings. The dominant difference between these two groups of researchers was related to challenges experienced due to the research setting, including navigating policies and procedures, dealing with interruptions and delays, obtaining research review and approval, and gaining access.

That challenges related to gaining access and obtaining research review and approval, were experienced more frequently by corrections researchers is not surprising, given the additional safeguards in place for research with incarcerated participants and the additional security measures required in correctional settings. Correctional research often requires not only the approval of prison administration, but also the buy-in and cooperation of all stakeholders, including security and staff (Applebaum, 2008). Furthermore, the necessary presence of a prisoner representative for IRB review often lengthens the review process simply due to logistical considerations related to scheduling and attendance. Similarly, corrections researchers also indicated more frequent experiences with navigating institutional policies and procedures and dealing with interruptions and delays related to the research setting. Researchers working with incarcerated participants may be subject to unanticipated logistical delays related to issues such as institutional lockdowns and/or the inability to move freely unsupervised, lack of private interview areas, and the unavailability of participants due to court dates, mealtimes, counts, segregation, offsite work, etc.

(Applebaum, 2008; Day, Acock, Bahr, & Arditti, 2005; Wakai, Shelton, Trestman, & Kesten, 2009).

Correctional HIV/AIDS researchers reported more frequent challenges related to making compensation or incentives available to participants. This too is not surprising given the increased concern for autonomy and the absence of coercion when conducting research with incarcerated individuals, as well as the variability in rules and regulations regarding such compensation. For example, a recent study examined regulations related to the compensation of incarcerated research participants in 46 states, the District of Columbia, and the Federal Bureau of Prisons, and found that even within the 21 jurisdictions that allowed for compensation, policies varied widely with regard to amount, type, and approving authority, and were often approved on a study-by-study basis, with one state (Wyoming) requiring additional compensation to the Department of Corrections. The remaining 27 jurisdictions prohibited all forms of compensation, with the exception of food and beverage consumed by Federal prisoners while in the research setting (Smoyer, Blankenship, & Belt, 2009). In cases in which compensation is allowed, while identifying the proper balance between incentive and coercion is always an important consideration, this balance is even more delicate with incarcerated populations, given the increased value of every dollar in the prison economy. Further complicating the issue of compensation and incentives (or the lack thereof) is the ability for prisoners at some institutions to earn money for many of their daily activities or jobs, resulting in a disincentive to participate in research offering no incentives (O'Brien & Bates, 2003).

Closely related, findings indicated that the informed consent process within correctional settings presents additional challenges to researchers than those experienced in community settings. In addition to significantly lower levels of educational attainment and lower levels of literacy as compared with the population at large (Greenberg, Dunleavy, & Kutner, 2007), incarcerated individuals are susceptible to forms of coercion and may be driven by motivators which are unique to correctional settings, such as alleviating boredom, meeting new people, and appearing cooperative in hopes of better treatment (Moser et al., 2004). Furthermore, given the nature of the setting, a direct contradiction may exist between researchers and prison administration and staff with regard to the autonomy of incarcerated individuals and their ability to give true informed consent (O'Brien & Bates, 2003). Even more important for correctional settings than non-correctional settings is the ease of readability and comprehension of informed consent documents and adequate time and resources for decision-making for incarcerated participants. Similarly, close attention must be paid to possible forms of coercion, both overt and subtle, with one such possible benefit particularly salient to individuals with HIV/AIDS being access to adequate healthcare. Exemplifying this potential risk is a recent study that concluded that many inmates in federal, state, and local facilities fail to receive care for ongoing physical illnesses (Wilper et al., 2009). This lack of access or treatment may serve as a powerful incentive for research participation and researchers must carefully consider this possibility when designing their correctional projects and IRBs when reviewing the projects (IOM, 2006).

The final research challenge on which correctional and non-correctional researchers differed significantly was that of retention during follow-up phases of research. Similar to other

differences, this finding was not surprising given the reality of participants moving from a closed system back to their communities and the challenges they subsequently face related to housing, employment and reintegration in general. Studies with incarcerated participants that have included post-release follow-up visits report high levels of attrition despite post-release monetary incentives, as well as unsuccessful attempts to locate released participants due to incorrect contact information, recidivism, and lack of coordination with parole officers (Day et al., 2005; O'Brien & Bates, 2003).

These findings support those reported by others on the complex and challenging environment that correctional settings present to researchers (cf., Applebaum, 2008; Wakai et al., 2009). What is less clear is whether these increased challenges are unique to HIV/AIDS or whether they are experienced by researchers of other topics as well. The challenges may be unique to HIV/AIDS given the continued stigma experienced by individuals living with HIV/AIDS, which is further exacerbated in correctional settings (ACLU National Prison Project & Human Rights Watch, 2010; Derlega, Winstead, Gamble, Kelkar, and Khuanghlawn, 2010). Indeed, individuals living with HIV/AIDS in correctional settings have reported fearing or experiencing isolation, rejection, and discrimination by other prisoners, corrections security and other staff, resulting in some choosing to conceal their status (ACLU National Prison Project & Human Rights Watch, 2010; Derlega et al., 2010). On the other hand, it may be that correctional settings present unique challenges to most or all types of research. Future research could clarify this question by conducting the same or similar survey with other types of researchers examining topics that are less sensitive or stigmatized in nature.

The current study is not without limitations. Although response rates to surveys have been declining over the last 20 years (Tourangeau, 2004), only 37% of potential participants completed the survey. Given that the survey took an hour to complete, and that all potential participants were busy professionals, the response rate was adequate; however, it is important to note that more than half of those identified did not respond to our online and hard copy inquiries. In addition, the current study compared the frequency of challenges specific to conducting HIV/AIDS research in correctional settings and non-correctional settings. It may well be that the differences identified in the experiences of researchers in these settings may be further pronounced by the added complexities of working with HIV/AIDS populations, associated stigma, and challenges associated with health care, privacy and confidentiality in correctional institutions. Finally, while researchers working with individuals with HIV/AIDS both in community and correctional settings have an invaluable perspective given their experience, no individuals incarcerated in correctional settings were included.

Despite these limitations, the current study supports the assertion that HIV/AIDS researchers in correctional settings experience considerably more challenges, particularly those related to the correctional setting itself, than HIV/AIDS researchers in non-correctional settings. Our research contributes empirical data to the national dialogue initiated by the IOM (2006) report on how to increase valuable research in correctional settings and confirms and expands on the qualitative findings reported by Eldridge et al. (2012). Clearly, further research is needed to understand the situation before developing recommendations.

However, the current findings highlight numerous aspects of research that are particularly challenging for correctional HIV/AIDS researchers and represent a building block that will contribute to increased awareness of the issues as well as concrete recommendations for addressing the issues. Future research examining the challenges faced by correctional researchers on other topics, gaining the voices of correctional staff, and listening to the voices of individuals incarcerated are important next steps in this national dialogue.

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 $\label{eq:Table 1} \textbf{Table 1}$  Demographic Characteristics of Survey Participants (n = 341)

Demographic Variable	Number	Percent
Professional Group		
Correctional Researchers	190	55.7%
Non-Correctional Researchers	151	44.3%
Gender		
Males	135	39.6%
Females	206	60.4%
Race/Ethnicity		
African American	29	8.5%
Asian/Pacific Islander	17	5.0%
Caucasian	240	70.4%
Hispanic	12	3.5%
Alaska Native/Native American	1	0.3%
Other	11	3.2%
Missing	31	9.1%
Highest Level of Education		
Less than Master's degree	14	4.1%
Master's degree	58	17%
Doctoral or professional degree (including JD, PhD, MD)	197	57.8%
Missing	72	21.1%
	Mean	SD
Age		
Years	47.36	9.72

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Table 2

Means and Standard Deviations for 15 Research Challenges by HIV/AIDS Researcher Group and Gender

		Researcher Group	
		Correctional (n=190)	Non-Correctional (n=151)
Obtaining and maintaining IRB approval	М	2.09	1.98
	SD	0.95	0.90
Obtaining permission from or access to the research setting	M	2.24	1.72***
	SD	0.78	0.74
Obtaining research review and approval by the research setting	М	2.07	1.67***
	SD	0.85	0.73
Obtaining certificates of confidentiality	М	1.63	1.46
	SD	0.85	0.71
	M	1.83	1.71
	SD	0.86	0.82
Navigating policies and procedures required by the research setting	M	2.32	1.89***
	SD	0.89	0.73
Recruiting participants	М	2.00	2.24
	SD	0.82	0.72
Securing and maintaining informed consent  A	M	1.62	1.38*
	SD	0.91	0.70
Making compensation or incentives accessible to participants	М	1.99	1.50***
	SD	1.00	0.75
Dealing with interruptions and delays in progress arising from the research setting	М	2.51	1.95***
	SD	0.87	0.80
Experiencing harm to participants because of their involvement in the research	М	1.12	1.10
	SD	0.42	0.36
Experiencing harm to staff or others because of the research protocol	M	1.10	1.09
	SD	0.33	0.34
Retaining participants during the active phase of research	M	1.83	1.86
	SD	0.77	0.80
Retaining participants during follow-up phases of research	M	2.48	2.26*
	SD	0.88	0.86
Gaining review and approval by research setting prior to disseminating results	М	1.53	1.31*
	SD	0.73	0.66

<sup>\*\*</sup>p<.01

<sup>\*</sup>p<.05

p<.001

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 Table 3

 Rank Order of Items by Correctional and Non-Correctional HIV/AIDS Researchers

Item	Correctional Researchers	Non-Correctional Researchers
Dealing with interruptions or delays in research progress arising from the research setting	1	4
Retaining participants during follow-up phases of research	2	1
Navigating policies and procedures required by the research setting	3	5
Obtaining permission from or access to the research setting	4	7
Obtaining and maintaining IRB approval	5	3
Obtaining research review and approval by the research setting	6	9
Recruiting participants	7	2
Making compensation or incentives accessible to participants	8	10
Retaining participants during the active phase of research	9	6
Conducting preparatory work prior to starting the research	10	8
Obtaining certificates of confidentiality	11	11
Securing and maintaining informed consent	12	12
Gaining review and approval by the research setting prior to disseminating results	13	13
Experiencing harm to participants because of their involvement in the research	14	14
Experiencing harm to research staff or others in the research setting because of the research protocol	15	15