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Trials and tribulations of conducting bio-behavioral surveys in prisons: implementation science and lessons from Ukraine

Lyuba Azbel,

The Ukrainian Institute on Public Health Policy, Kyiv, Ukraine and Department of Internal Medicine, Section of Infectious Diseases, AIDS Program, Yale University, New Haven, Connecticut, USA

Yevgeny Grishaev,

The Ukrainian Institute on Public Health Policy, Kyiv, Ukraine

Jeffrey A. Wickersham,

The Department of Internal Medicine, Section of Infectious Diseases, AIDS Program, Yale University, New Haven, Connecticut, USA

Olena Chernova,

The Ukrainian Institute on Public Health Policy, Kyiv, Ukraine and Department of Internal Medicine, Section of Infectious Diseases, AIDS Program, Yale University, New Haven, Connecticut, USA

Sergey Dvoryak,

The Ukrainian Institute on Public Health Policy, Kyiv, Ukraine

Maxim Polonsky, and

The Ukrainian Institute on Public Health Policy, Kyiv, Ukraine and Department of Internal Medicine, Section of Infectious Diseases, AIDS Program, Yale University, New Haven, Connecticut, USA

Frederick L. Altice

The Department of Internal Medicine, Section of Infectious Diseases, AIDS Program, Yale University, New Haven, Connecticut, USA and Division of Epidemiology of Microbial Diseases, School of Public Health, Yale University, New Haven, Connecticut, USA

Abstract

Purpose—Ukraine is home to Europe's worst HIV epidemic, overwhelmingly fueled by people who inject drugs who face harsh prison sentences. In Ukraine, HIV and other infectious diseases are concentrated in prisons, yet the magnitude of this problem had not been quantified. The purpose of this paper is to evaluate the systematic health survey of prisoners in the former Soviet Union (FSU).

Design/methodology/approach—Qualitative interviews were carried out with research and prison administrative staff to assess the barriers and facilitators to conducting a bio-behavioral survey in Ukrainian prisons.

Corresponding author: LyubaAzbel can be contacted at lyuba.azbel@yale.edu.

Findings—Crucial barriers at the institutional, staff, and participant level require addressing by: first, ensuring Prison Department involvement at every stage; second, tackling pre-conceived attitudes about drug addiction and treatment among staff; and third, guaranteeing confidentiality for participants.

Originality/value—The burden of many diseases is higher than expected and much higher than in the community. Notwithstanding the challenges, scientifically rigorous bio-behavioral surveys are attainable in criminal justice systems in the FSU with collaboration and careful consideration of this specific context.

Keywords

Prisoners; Substance use disorders; Ukraine; Ethics; Health status; Implementation science research; Infectious diseases; Former Soviet Union

1. Introduction

Prisons globally house a disproportionate number of people who use drugs (PWUD) (Stover and Michels, 2010) and are high-risk environments for the spread of HIV and other bloodborne infections (Izenberg *et al.*, 2014). With high-inmate turnover, this risk extends postrelease when drug overdose is the leading cause of death (Merrall *et al.*, 2010). Furthermore, this population transitions between the highly structured prison environment and the community, acting as bridges for the spread of the epidemic to the general population. Accordingly, the time during incarceration provides unique access to vulnerable populations that otherwise fall outside surveillance, prevention, and treatment services (Bridge *et al.*, 2010). Accurate data from prisons is sparse and often unrepresentative due to numerous logistical constraints (Dolan *et al.*, 2007; Vagenas *et al.*, 2013; Altice *et al.*, 2005; Azbel *et al.*, 2013).

Community-based treatment, rather than incarceration, is effective and cost-effective, but for those incarcerated, periods of detainment should be leveraged to diagnose, treat, and prevent the further spread of disease. This is especially pertinent to the countries of the former Soviet Union (FSU), home to the fastest growing HIV epidemic, particularly driven by PWUD (Joint United Nations Programme on HIV/AIDS, 2010). Ukraine is home to Europe's worst HIV epidemic (Kruglov *et al.*, 2008) with an estimated 360,000 HIV-infected persons (Ministry of Health of Ukraine, 2010a) and a similar number of people who inject drugs, nearly three-quarters of whom have been arrested (Jolley *et al.*, 2012). Where the syndemic between HIV, substance use, and criminal justice is salient, prison-based surveillance may reliably estimate the scope of the problem to inform treatment and prevention activities. This report provides guidance on how to effectively conduct ethically and scientifically sound biosurveillance studies in order to assist future efforts in the FSU region, where such studies are virtually non-existent. We examine barriers and lessons learned to conducting bio-behavioral prison studies in Ukraine to help guide prevention efforts regionally (Bridge *et al.*, 2010).

2. Methods

Setting

Ukraine, a lower middle-income country with a population of 45.2 million, has one of the highest worldwide incarceration rates with 321 per 100,000 population currently imprisoned (International Centre for Prison Studies King's College London, 2013). The State Penitentiary Service of Ukraine (SPSU), operated by the Ministry of Justice, oversees 145,189 prisoners (State Penitentiary Service of Ukraine, 2013). Voluntary HIV testing and antiretroviral therapy (ART) is statutorily required for prisoners, (United Nations Office on Drugs and Crime, 2012) but often falls short in practice (Ministry of Health of Ukraine, 2010b; Azbel*et al.*, 2014). Obtaining objective information to inform implementation of evidence-based interventions requires collection of reliable data.

Bio-behavioral survey

We conducted a nationally representative bio-behavioral health survey of prisoners within six months of release. The operating procedures are based on similar seroprevalence surveys in prisons (Weild et al., 2000) and were agreed upon in collaboration with the SPSU. The procedure is presented in greater detail elsewhere (Azbel et al., 2013). Before study initiation, research assistants from local NGOs underwent a three-day training on the implementation of the protocol. The study was conducted in four national regions (north, south, west, and east) and participants were recruited from three types of facilities within each region (men's prisons for first-time offenders, repeat offenders, and women's prison) and weighted according to the number of prisoners within six months of release at each facility. A random-selection algorithm selected study participants from a list provided by SPSU of all prisoners with six months until their release into the community. After consent, participants underwent phlebotomy and completed a self-administered bio-behavioral survey using touchpad tablet computers in order to avoid bias and maintain confidentiality while guards remained present to ensure protection of research staff. Although literacy in Ukraine is 99 percent, research assistants read the survey in a private room to the participants who had difficulty reading.

Assessment

To assess the barriers and facilitators to conducting the first ever representative biobehavioral survey of a prison population in the FSU, individual interviews were conducted with the research coordinators, research assistants, and prison administrators before the start of research, mid-way through the study, and upon its completion. Each involved party qualitatively evaluated barriers and facilitators to the conduct of the research, with a subsequent discussion of possible solutions.

3. Results

Bio-behavioral survey

Table I summarizes the results of the bio-behavioral survey including the prevalence of HIV, hepatitis B and C, and syphilis among the study sample, including whether the participants were previously informed of their positive status. The results present higher prevalence of

infectious diseases and SUDs than recorded elsewhere from official sources (Azbel *et al.,* 2013). Figure 1 illustrates the gap in official SPSU statistics by comparing them to the data obtained from this study.

Assessment

Barriers and facilitators to implementing this study in the Ukrainian context were identified. Table II provides a list of the respondent-, staff-, and institutional-level factors that were highlighted by the research staff, along with solutions. These factors are further elaborated here.

Respondent-level factors—Interviewing prisoners within prisons poses numerous unique challenges. In these restricted settings, all respondents must obey facility rules, which often include limited movement and continual supervision by authorities. Thus, obtaining transparent data must be balanced with maintaining a safe and secure environment. Confidentiality is central to this premise since researchers may be liable to report any "illegal" behaviors occurring within prison such as drug risk behaviors, obliging them to identify individual prisoners. To avoid this, study personnel and consent procedures remained independent from prison staff and all drug and sexual risk-behavior questions referred to the pre-incarceration period. Additionally, assigning an anonymous identifier linking blood specimens to individual surveys protected prisoners' confidentiality.

Ukraine, like many countries globally, administratively divides healthcare provision in prison from community healthcare structures. Thus, we chose to recruit participants about to re-enter the community because our research study could not guarantee that study participants would otherwise have full access to treatment in prison (despite assurances by the prison staff). Our rationale was that identifying new conditions in prisoners, as long as they were provided with the essential information about their condition and sites of referral, was possible just before their community release. Four participants, with CD4 counts under 100 cells/mL (far below the <350 cells/mL threshold for receiving ART), refused our referral for immediate prison-based medical care and ART, citing concerns about the perceived quality of prison-based healthcare and the fear of measures taken that would stigmatize them among other prisoners.

Only 24 (5.6 percent) of the 426 inmates randomly selected for consent declined participation, resulting in a high participation rate. At the end of the study, each participant received token compensation for their time (e.g. shaving supplies). After survey completion, most participants stated that compensation played no role in their participation, but that getting valid results and medical counseling and information external from prison staff about their health was a key motivating factor.

Staff-level factors—Oversight and training for research assistants and staff proved key to successfully completing the study. The research assistants underwent a three-day protocol and research ethics training supervised by coordinators. Because fieldwork lasted six months, however, it became clear that a single training at the start of the study was insufficient, so study coordinators provided continuous monitoring and ongoing training throughout the study, bringing to light important lessons learned along the way.

Despite having permission to operate the study from senior SPSU administrators, research assistants observed that staff attitudes in various geographical locations (especially in the east) interfered with study conduct. After completion of the study, all medical and nonmedical, administrative and non-administrative staff in the 12 study facilities were surveyed and confirmed markedly negative attitudes toward substance users. For example, over threequarters (68.5 percent) agreed that "modern society is too tolerant toward drug addicts" and similarly 71.3 percent agreed that "people who become addicted to opioids have only themselves to blame." Of note, nearly half (42.5 percent) of prisoner participants selfreported substance use in the month prior to incarceration, suggesting that prison staff harbor negative feelings to a contingent to whom they have significant exposure. These attitudes were reflected in the administration of the study protocol. As an example, when prison staff was presented with a list of randomly selected study participants to approach for participation, those familiar with the prisoners would often express their desire to select those who were "well-behaved" and "clean" for study participation. Training was important in order to explain study procedures such as the necessity of random selection of participants to ensure a representative study sample. To meet this need, we conducted training meetings with prison staff before and during the study in order to keep them involved in the protocol and abreast of procedures.

Institutional-level factors—In a vertical prison bureaucracy, characteristic of the prison structures in the FSU, administrative approval is instrumental to receiving access to prison facilities. During the planning stages of the study, we learned that prison guards were required to remain in the room during interviews to "protect" research assistants. In order to respect patient privacy and ensure data collection accuracy, we created self-administered, computer-assisted structured interviews (CASI) that allowed participants to keep their responses confidential. Because electronic devices are not permitted in prison facilities, however, we ultimately agreed to allow the SPSU to remove all communication functionalities, thereby guaranteeing that they would be used exclusively for research purposes. For lower literate populations, however, CASI could be problematic and may require audio capabilities.

A second institutional hindrance was the need to receive written permission from the head of the SPSU for entry into each facility. These passes could not be prepared ahead of time and it was not possible to enter the prison without them. Securing them in a timely fashion required regular communication with the deputy of medicine at the SPSU. The parties involved in conducting the research had to establish congenial connections with the top-level bureaucrats and be flexible with last minute changes to the study schedule, which happened frequently.

4. Discussion

The data presented as a result of this survey illustrates how scientifically rigorous assessments drastically differ from official statistics which should be interpreted cautiously. This study highlights the urgent need and feasibility of such assessments. As part of the implementation process, international stakeholders from other FSU countries (e.g. Azerbaijan and Kyrgyzstan) have since conducted parallel studies, which document similar

disparities in official vs actual statistics (data forthcoming). The experiences garnered from this health survey, with some modifications, are transferable to other countries in Eastern Europe and Central Asia which have HIV epidemics among PWUD, severe sentencing for drug-related crimes, and structurally similar prison systems. Currently, this study's protocol is being adapted for replication in the prisons of Central Asia.

These findings demonstrate that accurate data can in some instances result in significant changes in prison settings. The bio-behavioral study provided motivation to use best evidence to transition to routine HIV testing and evidence-based interventions such as opioid substitution therapy (OST). Despite evidence that OST with methadone and buprenorphine is effective in criminal justice settings (Haig, 2003; Smith-Rohrberg *et al.*, 2004; Stallwitz and Stover, 2007; Wickersham *et al.*, 2013) and its availability in the community for over ten years, it has not been implemented in Ukrainian prisons. After presenting key findings to local NGOs, international authorities, and government officials, however, the SPSU decided to introduce and pilot test evidence-based therapies as part of the implementation science framework. The first steps to introducing OST into the criminal justice setting were taken by passing into law in October 2012 legislation ensuring the continuity of OST for those enrolled in community programs who are arrested. The recent political destabilization stalled OST introduction in prisons, but this process has now been resurrected after the October 2015 parliamentary elections.

Receiving feedback from each of the parties involved and adjusting operating procedures throughout the course of the study helped tackle deterrents to its successful conduct. The hurdles to conducting ethical and scientifically rigorous research within prisons in the FSU can be overcome with dialogue and culturally sensitive planning. This requires a delicate balance between honoring the stringent rules of these institutions and upholding scientific ethics in an environment that breeds significant challenges to providing healthcare.

Ethics statement

This Institutional Review Boards at the Ukrainian Institute on Public Health Policy and the Yale University School of Medicine approved the study. Further safety assurances were provided by the Office for Human Research Protections (OHRP) in accordance with the 45 CFR 46.305(c) "Prisoner Research Certification" requirement. Participants provided their written informed consent to take part in the study.

Acknowledgments

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Figure 1. Infectious disease and substance use disorders in the Ukrainian prison population according to official vs study statistics

Notes: ^aAll prevalence data for 2011 among sentenced prisoners; ^bState Penitentiary Service of Ukraine, Department of Statistics; ^cThe study data are exclusively for Hepatits B and C whereas the official data are for all liver diseases. Ukrainian Institute of Sociological Research, "Potreby penitentsiarnoi systemy vdoskonalennia polityky z zapobihannia poshyrenniu VIL-infektsii" 2012

	Tabl	el
Bio-behavioral characteristics	of study	participants

Characteristic	No. (%) of participant
Sex	
Female	80 (20.1)
Ethnicity	
Russian	290 (72.7)
Ukrainian	91 (22.8)
Recidivists	196 (48.8)
Region	
North	104 (25.9)
South	98 (24.4)
West	97 (24.1)
East	102 (25.4)
Age in years, mean (SD)	31.9 (8.4)
Poverty level	
Below poverty line	242 (60.2)
Highest education level	
Elementary	6 (1.5)
Some secondary	82 (20.4)
Completed secondary	271 (67.4)
Completed higher education	34 (8.5)
Length of this incarceration, mean years (SD)	2.5 (23.0)
Months until release, mean (SD)	2.1 (1.7)
Number or lifetime arrests, mean (SD)	5.4 (7.0)
Major depressive disorder	129 (32.9)
Alcohol use disorder	224 (56.6)
Have injected drugs	
Yes	193 (48.0)
No	204 (51.4)
Infectious diseases	
HIV	78 (19.4)
Previously informed of HIV + status	37 (49.3)
Previously uninformed of HIV + status	38 (50.7)
Mean CD4 count, cells/mL (SD)	355 (251.8)
CD4 count under 250 cells/mL	44 (56.4)
Hepatitis C	241 (60.0)
Previously informed of Hepatitis C + status	26 (10.8)
Previously uninformed of Hepatitis C + status	215 (89.2)
Hepatitis B	21 (5 2)

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Characteristic	No. (%) of participants
Syphilis	41 (10.0)
Previously informed of syphilis+status	13 (31.7)
Previously uninformed of syphilis+status	28 (68.3)
Illicit substance use in 30 days before arrest	
Opioid use	264 (65.7)
Amphetamine use	85 (21.1)
Sedative use	330 (82.1)
Polysubstance use	127 (31.6)
Shared injection equipment	104 (25.9)
More than 30 injections	85 (21.1)

Note: n = 402

Problem	Situation		Bias	Solution
Respondent-level factors				
Previously diagnosed prisoners	Prisoners with known HIV status would testing	l refuse HIV	Underestimates disease prevalence	We provided additional testing for several other conditions as well as reflex CD4 testing with provision of results and recommendations about treatment
Disappearance for follow-up components of the study			Limited study to 2-3 days; insisted on follow-up irrespective of location within prison (isolation unit) or upon transfer	
Phlebotomy logistical constraints	Venous access; secondary testing of CD	4	PWID may have poor venous access and excluding them underestimates blood-borne virus disease prevalence	Oral point-of-care testing as a back-up option (more costly); additional vial of blood for CD4 testing that could be used if HIV test was positive
Confidentiality of participant data	Data collected included sensitive inform behaviors and infectious diseases	aation about risk	Concerns for potential breach of confidentiality which influence participation	Anonymous identifiers were assigned to link blood specimens to individual surveys
Staff-level factors				
Interview privacy	The prison staff insisted on being preser all interviews	nt in the room for	May under-estimate risk behaviors	Negotiated with the prison department to place a guard right outside of the room in order to facilitate a private interview environment
Bureaucratic restrictions surrounding testing and disease registration	Testing done for research cannot be used establishment to "confirm" a disease. Pa sometimes had to be retested through of mechanisms in order to qualify for disea in order to receive treatment	d the medical atients fficial ase registration		
Insistence on being informed of positive results from testing	Prisoners who do not want to be identifianty disease would refuse participation	ied officially for		All disease detection was promised not to be officially reported unless the prisoner signed a release-of-medical information to allow his/her status to be reported
Inquiring about sex and drug use behaviors	Prison officials wanted reports of any "i reported during the incarceration	illegal" behaviors	Underestimates prevalence of these stigmatizing behaviors	All data were collected anonymously using CASI and no "withinprison" risk behaviors were assessed
Institutional-level factors				
Selection of sites	The prisons department wanted to control which of their sites was surveyed	May over- or und- addiction or HIV the country (know	er-estimate findings based on the type (e.g. specialty prison), recidivists, gender, region of vn differences in HIV prevalence regionally)	We created a matrix of all the types of prisons that were operational and then stratified by factors that we anticipated would influence disease prevalence and randomly selected ones that met these criteria
Selection of prisoners	The prisons department wanted to identify which prisoners they thought were appropriate for our study and would indicate that some were not "goodcharacters" for research. They	May under-estim were allowed to p	ate disease prevalence if only "good" prisoners aarticipate	The prison created a comprehensive list of all prisoners who were within 6 months of release. Only after the full list was generated centrally did we assign each prisoner to a unique identifier and randomly selected from among

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Problems and solutions in avoiding bias introduction when surveying prisoners I

Table II

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Problem	Situation	Bias	Solution
	also wanted to exclude anyone they already knew to have a diagnosis		this group. When "bad" characters showed up for the study and the prison guards said they were not appropriate, we still interviewed them
Use of computers	Concerns about internet connection and cameras on the computer	Influences participation due to stigma; more stigmatized populations are likely to be more at risk	Computers were officially "approved" for entry, the cameras were disabled by research staff and confirmed by prison authorities and were also covered with tape
Mandatory reporting of participant data	Sex- and drug-related behaviors that occur within prison are considered illegal and must be reported to prison authorities	Potential underestimation of risk behaviors	Drug and sexual risk-behavior questions referred to the pre-incarceration period to avoid having to report any behaviors in order to avoid punishment
Note: CASI, computer-assisted survey ir	nstrument		

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