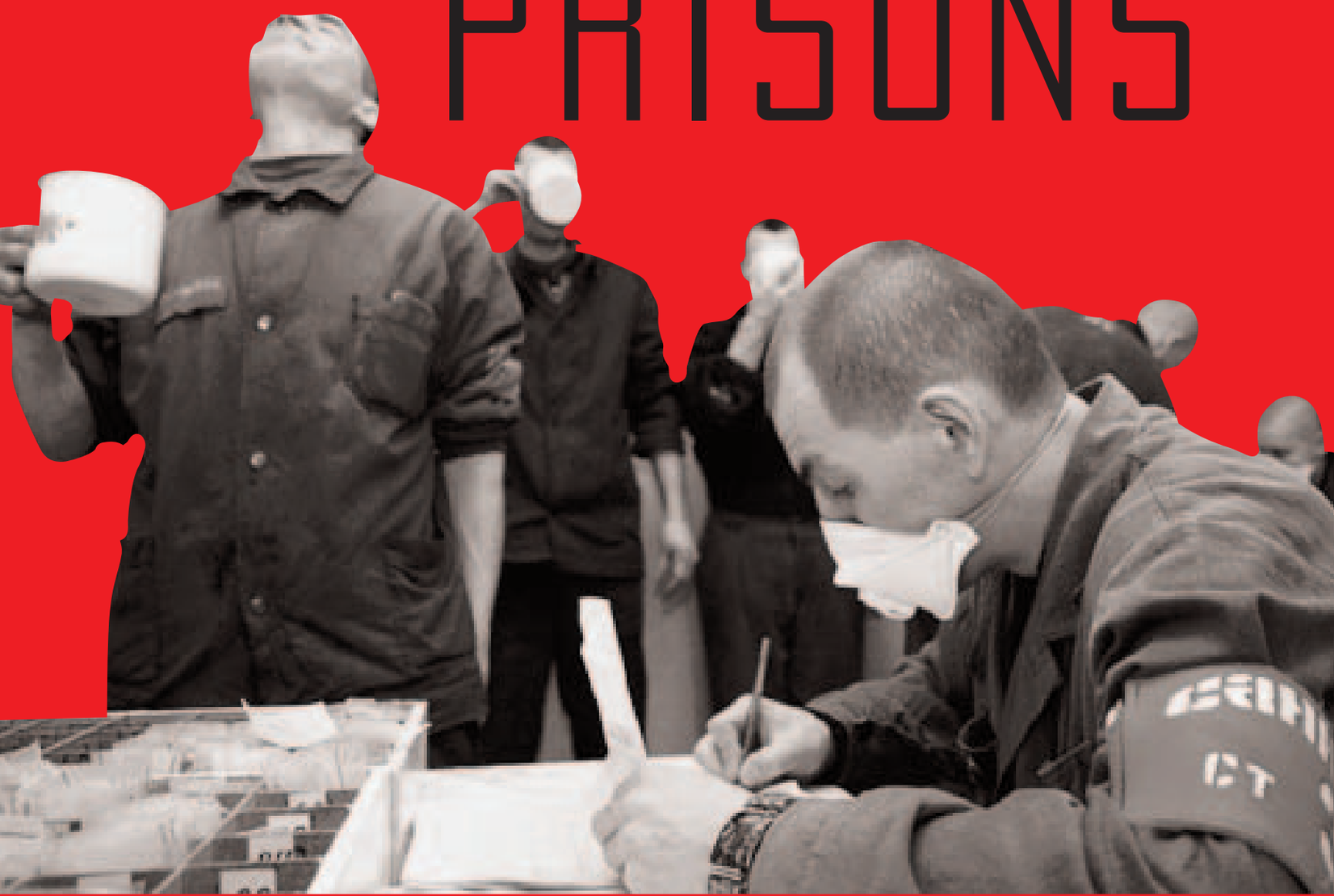
BREAKING THE BARRIERS TO TB MEDICATION ADHERENCE IN

RUSSIAN PRISONS



The russian prison system is a world in itself, defined by its own myths and traditions, social norms, and hierarchies. Dangers lurk behind every corner; real, imaginary, institutional and self-afflicted.

In the photos above Rebecca Fry is featured with physicians and nurses at the prison health care facility she visited in St. Petersburg in the summer of 2003.

Pleasures are scarce and heavily guarded. Inmates in Russian prisons take delight in even the most mundane diversions from routine; a cigarette inhaled hastily in the corner of the cell block, a glimpse of sky beyond the prison walls, a semi-candid conversation with someone from "outside the system." Inside each prison there are as many distinct tales of woe as there are inmates. These stories vary a great deal, yet there are some common threads. Drug addiction, poverty, mental illness, physical and psychological abuse are frequent. A large percentage of inmates are repeat offenders. By the time they are in their twenties and thirties, many will have spent as much or more time as inmates than as civilians. All prisoners' stories are tragic, and the majority of them will never be heard outside prison walls.

Russian prisons and labor camps house what has historically been one of the most isolated and underserved populations in the world. Crumbling infrastructure, overcrowding, lack of adequate health care, and human rights violations have plagued the prison system throughout the twentieth century. Years of institutional neglect have also bred a new set of acute threats, both to the prison population and to the world community. Among the gravest damages inflicted on society is the spread of tuberculosis (TB). In recent years, the incidence of TB in Russian prisons was 40–50 times higher than the civilian population. The Russian Federation Ministry of Justice estimates that close to 100,000 inmates, or 10% of Russian prisoners, have TB. Currently, TB is the main cause of death among all Russian prisoners.

"Even more alarming is the increase in the proportion of inmates infected with the virulent resistant forms of the disease, known collectively as multi-drug resistant tuberculosis (MDR-TB)," said Kaveh Khoshnood, an infectious disease epidemiologist and Assistant Professor at the Yale School of Epidemiology and Public Health.

Russian prisons are an ideal environment for the spread of TB due to poor sanitary conditions, overcrowding, food shortages and the lack of attention to and funding for infectious disease prevention. TB is curable with a 6 to 9 month long course of inexpensive antibiotics. But this is often not the case in the Russian prison system where MDR-TB has emerged through spontaneous genetic mutation. The reasons for MDR-TB in the Russian prison system are lengthy transfers between prison facilities, delays in the identification of TB in the early stages of a prison stay, and an un-standardized approach to TB treatment in Russia which relies more heavily on clinical symptoms and surgeries than laboratory results and standardized medication regimes. Once the prisoners are released into the civilian population, interrupted treatment is attributable to lack of social support networks, unemployment, poverty, drug and alcohol abuse, and absence of easily accessible information about available treatment services and facilities. "Upon their release, TB-infected inmates who interrupt their treatment pose a serious health threat to the civilian population," said Dr. Khoshnood.

Dr. Khoshnood is one of the investigators of the Yale/St. Petersburg TB Project. This three year project builds in-country research and public health capacity in transitional case management of cases of active TB infection in Russian prisoners at the time of their release. In the summer of 2003, a YSN student, Rebecca Fry, traveled to St. Petersburg as a Wilbur Downs International Fellow to assist Dr. Khoshnood with the project.

"Much like the rest of Russia, the St. Petersburg prison system is a main breeding ground of tuberculosis," said Rebecca. Not enough is known about what happens to prisoners with active TB who are released from prison into the civilian population in St. Petersburg. The Yale/St. Petersburg TB Project estimates that only 28% of 80 active TB patients released from prison in 2002 had a single post-release visit to the outpatient TB dispensaries. Even fewer ever completed treatment. "These facts, when combined with what we know about the social factors that beset former prisoners, demonstrate a need for a program in St. Petersburg to link

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"The sickest of the sick," according to Rebecca Fry, these men are being treated for TB and related conditions at the prison hospital ward in St. Petersburg where Rebecca conducted her research.

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former prisoners with TB treatment services for civilians," Rebecca said. Her research project, titled "Barriers to Completion of Tuberculosis Treatment Among Prisoners and Former Prisoners in St. Petersburg, Russia," examines characteristics of and barriers to medication adherence for prisoners and former prisoners with active TB in St. Petersburg to inform the development of an intervention to increase medication adherence among these vulnerable groups.

During the summer of 2003, Rebecca collaborated with the Department of the Russian Ministry of Justice in the St. Petersburg Region to administer surveys to 100 TB patients (60 within the prison system and 40 dispensary patients) to inquire about basic demographics, knowledge about TB, and life plans upon release. Most importantly, the surveys asked TB patients to identify barriers to taking TB medication and to identify potential solutions to cope with the problem outside prison. Preliminary results show that 90% of prisoners surveyed expressed the desire to continue with their TB treatment on the outside, with 91.5% of the sample stating that completion of their TB treatment was "very important." Despite the optimistic outlook, few participants had plans for a job or money for food and clothing after release. Of the imprisoned sample, 41.5% stated that they had experienced a disruption in their TB treatment. The most common reasons were transfer among correctional faculties, lack of adequate supply of medication at the facility and a reluctance to take medication because patients did not "feel sick." On the knowledge section of the survey, prisoners scored approximately 67% correctly, indicating a fair to moderate knowledge base on the disease's transmission and severity. In contrast, former prisoners scored approximately 58%, which was significantly lower than their counterparts in prison.

With respect to participation in a planned and funded future project to help complete TB treatment, a resounding 93.1% of imprisoned patients and 77.8% of former prisoners stated their interest. Of the types of incentives listed for prisoners, the top three were help finding a job, an offer of psychosocial help at the dispensary, and help with an internal passport. For former prisoners, a small offer of money, food, and help finding a job were the motivators of choice. When asked to elaborate on what barriers they may face to continuing TB treatment on the outside, prisoners remarked, "The Military Police!," "I am homeless and this is the greatest reason" and "I have no passport and this makes my life and my treatment very difficult."

"While unnerving, these statements, along with survey results, give us a glimpse into the lives of former prisoners in St. Petersburg," said Rebecca.

Because prisoners have great difficulty obtaining an internal passport upon their release, their readjustment to civilian life is made particularly harsh. The internal passport functions like a social security or a national identification card. Without it, a person released from prison cannot seek legitimate work, establish permanent residence, or obtain access to health care and other social services provided by the state. "Essentially, the lack of an internal passport makes the released prisoner a 'non person' as far as the state is concerned," explained Rebecca.

With thousands of prisoners released each year, drug-resistant strains of TB are spreading. According to Rebecca, they have been found among Russian émigré communities in Europe, Israel, and the United States. "The problem of TB in Russian prisons is not just a Russian problem any longer," she said. "Armed with a view of their world, we can design and pilot test an intervention that identifies soon-to-be released prisoners and markets an array of social incentives to attend a TB dispensary and to complete treatment in the hopes of decreasing TB among this very high risk group."

The work of designing and pilot testing an intervention is already under way. A manuscript of Dr. Khoshnood's study in which Rebecca participated is pending submission to the International Journal of Tuberculosis and Lung Diseases. Yale researchers, along with partners from Russia and Sweden, continue to design and implement a program for released prisoners at the main TB dispensary in St. Petersburg. "The work they are doing is of vital importance not only to Russia, but to the entire world," said Rebecca. "It has been a great privilege to be part of this effort."