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Doctors, NGOs, and the HIV Epidemic in Russia

1. Introduction

Several decades after the initial rise of HIV, Russia is witnessing an epidemiological crisis. Most industrialized countries that experienced outbreaks in the 1980s and 1990s have implemented methods to slow the spread of HIV. Russia, however, is still struggling to curb this deadly disease. The country not only has the highest HIV-incidence rate in Europe but also currently faces one of the fastest-growing epidemics in the world.¹ As of 2017, reports show that roughly 1.16 million Russians are living with HIV.² These alarming statistics raise the question of why the virus has been able to spread so easily in Russia. The key to this answer lies in the stigma and denial surrounding HIV there. Misconceptions about the disease are widespread among the general public and even affect the medical community. This has led to a lack of understanding about HIV and has negatively influenced the way physicians treat HIV-positive individuals. While this is a major public health concern, there is potential for a healthier society. If medical professionals work alongside HIV nongovernmental organizations (NGOs), they can help reverse the crisis by fighting the stigma and denial surrounding HIV in Russia.

The Russian government has exerted tremendous influence on the medical community’s response to HIV. For many years, state officials tried to ignore the disease. This longstanding policy of denial and censorship unsurprisingly failed to address the needs of high-risk groups, such as injecting drug users and sex workers. Secrecy and lack of information intensified the negative response to HIV among the Russian public. Due to anti-European sentiment, many citizens saw the disease as foreign, an invention of the West. Others believed that the virus could

¹ See Rechel et al., 1148–49.
² See Beyrer et al.
only be contracted by homosexuals and addicts. A lack of initiative at the federal level, coupled with the widespread stigma surrounding HIV, has thus created an environment conducive to its spread in Russia.

The censorship and stigma surrounding HIV has affected the medical community. While Russian healthcare professionals do not work directly for the government, they are still tied to the state in many ways. Salaries, medical institutions, and hospital infrastructure, for example, are all federally funded; therefore, any training or education doctors and nurses receive must align with official policy. Since the subject of HIV continues to be censored heavily in the news and medical school curricula, those in the healthcare field possess limited knowledge about the disease. Misconceptions and lack of information about HIV have caused medical professionals to develop a misplaced sense of duty when treating patients. Some doctors, for example, refuse to treat patients with HIV; depending on the individual, this hesitation comes from a place of fear, ignorance, or moral belief. Other doctors are unwilling to offer their services to HIV-positive drug addicts until they quit using. Still others breach confidentiality and openly discuss the medical records of patients. These actions create multiple obstacles for individuals with HIV and pose a threat to the general public, who consequently face a higher risk of contracting the disease. Many are afraid to seek treatment because they fear their HIV status will be exposed. Individuals brave or sick enough to pursue medical care are then denied by medical professionals who lack basic information about HIV. This leaves them without the medication or knowledge to contain the disease; thus, despite their education and oath to care for the sick, the medical community has contributed to the country’s HIV crisis.

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3 See Pape, 60.
4 See King et al., 2599.
5 See Rhodes and Sarang, 1831.
While the rising rate of HIV contraction in Russia is cause for alarm, hope to combat the disease and decrease the risk of infection lies in the potential for cooperation between healthcare professionals and HIV activists. NGOs are not directly controlled by the state and have access to resources and funds from international companies. These organizations have more freedom to operate than the medical community. Despite resistance from the government hundreds of HIV NGOs exist in Russia. Their goals and success rates vary, but many do not address one of the main roots of the problem: the ignorance or bias of Russian doctors. Communication between activists and medical professionals is necessary if people are to receive proper treatment without fear of judgment or rejection. Certain organizations in Russia, such as the Tomsk AntiAIDS NGO, the Andrey Rylkov Foundation for Health and Social Justice (ARF) in Moscow, and the Siberian Alternative Center for Health and Social Support (SIBALT) in Omsk, have begun to recognize the benefits of forming connections with medical staff. Members of the Tomsk AntiAIDS NGO, for instance, work with doctors in the Tomsk region to establish trusted, properly educated professionals who serve the needs of the local HIV community.\(^6\) Volunteers at the ARF, meanwhile, work alongside social workers and psychologists to ensure that drug addicts living with HIV in Moscow have their rights protected and receive proper medical care.\(^7\)

Lastly, members of SIBALT focus on HIV prevention within the LGBT community in Omsk by recruiting medical, family planning, and contraceptive specialists.\(^8\) Although these three organizations target different populations, they are united in their commitment to working with medical professionals to fight HIV. This cooperative method, if adopted by other NGOs and healthcare personnel on a larger scale, could begin to reverse the effects of censorship and help

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\(^{6}\) See Pape, 151.


\(^{8}\) See Omsk Regional Public Organization, “About SIBALT.”
doctors address the stigma and denial that have contributed to the alarming spread of HIV in Russia.

2. Censorship and Denial: The Beginnings of HIV in Russia

To understand how the medical community has contributed to Russia’s growing HIV crisis, it is necessary to examine the origins of the disease in the country. Due in part to the Soviet Union’s isolation from the rest of the world, HIV arrived relatively late, with the first official case diagnosed in Moscow in 1987. Several outbreaks occurred throughout the USSR the following year, all resulting from the use of contaminated needles in hospitals. Most of the patients who contracted the disease during these outbreaks were part of vulnerable groups, such as mothers and infants. The government, accordingly, was quick to respond, ordering the mass production of HIV tests and promoting the development of one-use syringes. In 1989, the Central Committee of the Communist Party addressed this emerging health issue by establishing a special commission on AIDS.

Although the government initially offered a committed response to combating HIV, policy quickly began to change. In 1989, information about the disease was removed from Soviet medical and academic journals. Soviet doctors lost access to the education and training they needed to effectively treat patients with HIV as a result of this increased censorship. The crisis only escalated after the fall of the Soviet Union. The economic turmoil that defined the 1990s for Russia led to a significant rise in drug use and prostitution, which allowed the HIV virus to dramatically spread. The former “innocent” mothers and children with HIV were now being replaced with “guilty” addicts and sex workers.

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9 See Medvedev, 933.
10 See ibid., 934.
11 Pape, 93.
the hands of unsanitary hospital practices, the latter garnered less sympathy because of their associations with deviant behavior. Lack of information about HIV allowed stigma to grow among the general public and eventually spread to parts of the medical community. In 1997, for example, several Russian medical school graduates released a statement declaring, “We [...] categorically are opposed to combating the ‘new disease’ AIDS! We intend [...] to impede the search [...] to combat this noble [blagorodnyi] epidemic. We are certain that [...] AIDS will destroy all drug addicts, homosexuals, and prostitutes.... Long live AIDS!”12 While this statement does not reflect the attitude of the entire Russian medical community, it underscores an alarming shift in the understanding and characterization of HIV in Russia during this time.

3. Narcology: How Abstinence Contributed to the HIV Epidemic

Stigma and insufficient education about HIV drove Soviet and Russian doctors to address the spread of the disease via controversial medical practices such as narcology. A relatively new science developed in the Soviet Union, narcology is the study and treatment of diseases caused by substance abuse. Originally created as a response to the country’s rampant alcohol problem, it was later modified to tackle the growing rate of drug addiction. The main preventative measure promoted by narcologists is abstinence. While this approach may seem effective on paper, it is in fact highly unrealistic and does not consider the consequences for drug addicts with HIV. One of the major arguments against abstinence-only treatment acknowledges the tendency of most patients to relapse within six months.13 If and when HIV-positive individuals begin using again, they enter an unstable mental state that makes them less likely to take their antiviral

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12 Powell, 118.
13 See Elovich and Drucker.
medication.\textsuperscript{14} This leads to higher rates of sickness and death among those with HIV as well as more opportunities for the virus to spread.

One alternative to abstinence is substitution treatment, which involves clean needle initiatives and the use of less potent, clinically prescribed opiates such as methadone. Despite the benefits of substitution therapy reported worldwide by organizations such as the World Health Organization and the United Nations, methadone continues to be prohibited in Russia. This ban is especially devastating for drug users in Crimea, because they formerly had access to methadone while the territory was part of Ukraine. One patient, referred to as D-, was a musician who used heroin for thirteen years. He eventually sought substitution treatment in Crimea and was finally able to hold down a job and start a family. After Crimea was annexed by the Russian Federation in 2014, however, the treatment was banned and D- relapsed. Many of his friends who also wanted to get clean were forced by doctors to significantly lower their drug dosages before allowing them to enter a detoxification program. One man he knew, Anton, escaped the clinic after the medical staff refused to help him; he died from a heroin overdose soon after.\textsuperscript{15}

Anton’s death, like those of many other drug users, could have been prevented if doctors had offered more treatment options. The narcologists who run clinics in Russia force addicts to stop using completely without giving them the emotional and physical support necessary to fight withdrawal symptoms. They are so resolute in their beliefs that they “seem to assume no special obligation to save lives.”\textsuperscript{16} Most addicts thus relapse and return to their previous unhealthy lifestyles, in which the threat of HIV continues to loom. Clean needle initiatives, unlike methadone, are legal in Russia and are intended to lower the rate of HIV transmission in these

\textsuperscript{14} See Zhilin.
\textsuperscript{15} See ibid.
\textsuperscript{16} Elovich and Drucker.
high-risk situations. Unfortunately, these exchange programs face political obstacles and are so scarce that they cannot produce effective change.

Russian doctors and nurses have confidence in narcological practice because it is the chief methodology with which they are familiar. Because the government has censored information regarding HIV and drug use, the healthcare community lacks access to promising medical research conducted in other countries. Medical professionals, however, cannot allow their idealistic hope of curing addiction through abstinence to interfere with proven methods of treating injecting drug users. As intellectual servants of the community, Russian doctors are expected to provide the best possible care for their patients. They must, therefore, look beyond Russian medical literature and consider substitution measures posed by credible international organizations. Even traditionally conservative countries, such as China and Iran, have taken the advice of the WHO and the UN and have adopted methadone maintenance programs. Because of this initiative, it is believed that at least thirteen thousand HIV drug infections have been prevented in China alone.\(^ {17}\) Russian healthcare professionals must use statistics like these to stress the benefits of methadone. If they exert their moral authority as experts in their field, then government officials may be more inclined to respond and modify current drug policy.

4. The Medical Community and the Current HIV Situation

Even as new research about HIV continues to be published each year, Russian medical professionals’ misconceptions about the disease persist. A 2015 study, for example, reported that one in four nursing students in their last year of training thought that all homosexuals have AIDS.\(^ {18}\) From an international standpoint, this statistic is frightening. It highlights the extent to which stigma and censorship have contributed to the lack of education among Russian healthcare

\(^ {17}\) See Hoskins.
\(^ {18}\) See Kalinich.
professionals. Another study conducted in Ekaterinburg in 2012 captures the devastating effect of this ignorance upon HIV-positive patients. One person interviewed, Nadya, was told by her doctor that she “deserve[d] to be beaten” for using drugs and was denied a prescription for antiviral medication. She then watched her husband Oleg die from AIDS because his physician would not treat him until he cured his drug addiction. According to Nadya, Oleg sought help for his addiction numerous times but could not progress through the country’s narcology-influenced abstinence-only methods of treatment. He suffered because of his doctors’ obstinacy.

Nadya’s and Oleg’s interactions with their physicians, while extreme, are not uncommon in Russia. Even HIV-positive individuals who receive treatment from better-educated medical personnel report negative experiences. In these instances, the main issue is breach of confidentiality. Patients are afraid to seek treatment because their loved ones or employers could learn of their HIV status as a result. In a study conducted in Saint Petersburg in 2016, for instance, one female participant explained her apprehension about receiving treatment: “I cannot be hospitalized because they may report me to my work. I work in the police.” She was not alone in her sentiment. In the same study, 55 percent of participants expressed fear that their HIV status would become known if they spoke to a doctor or entered a healthcare facility. Afraid of risking their jobs and personal relationships, many ignore their symptoms until it is too late. This leads to the additional problem of underreported HIV cases in Russia. If fewer people are known to have the disease, then less funding is provided for HIV services. The misguided practices of certain doctors therefore prevent their colleagues from receiving the equipment and medication necessary to help patients.

19 Sarang et al., 685.
20 See ibid.
21 See Kuznetsova et al., 2436.
While the actions of certain members of the healthcare community have contributed to the spread of HIV in Russia, doctors and nurses are hardly the sole cause of the country’s HIV epidemic. Because of the uniquely intertwined relationship between medical professionals and the government, the state has the power to influence the thinking of doctors and nurses. After the fall of the Soviet Union, the Hippocratic Oath taken by all Russian physicians was intentionally updated in order to separate doctors from the government. In the new version of the oath, physicians swear to continue their “study of the art of doctoring [...] and to promote its advancement” regardless of the interests of the state.\(^{22}\) This pursuit of independence and knowledge has proven difficult, however, because the medical community still relies on the state for resources and has been hindered by censorship and stigma. If the current relationship between healthcare professionals and the government does not change, HIV-positive individuals will continue to avoid proper treatment, and the HIV crisis in Russia will worsen.

5. HIV NGOs—Hope for the Future

Russia’s response to the HIV epidemic, fueled in part by cultural conservatism and the medical community’s inadequate education, paints a bleak picture of the country. Fortunately, there is still a way to combat the disease. Russia’s hope for a healthier society lies in the cooperation of doctors and NGOs. Although recent legislation branding NGOs as foreign agents has created obstacles for these organizations, they remain committed to their fight against HIV. Many activists operate locally and offer prevention and treatment services to small communities. Others collaborate with legislators to influence federal policy. HIV activists could make an even larger impact on the lives of those living with the disease if medical professionals were to join

\(^{22}\) Edelstein, 23–24.
their cause. Using NGO resources to educate physicians about the virus could lead to significant progress in the treatment of patients and could combat stigma and denial at the societal level.

Upon recognizing the potential benefits of forming alliances with other groups, three HIV NGOs have changed the way activists and medical personnel interact in Russia. The first, Tomsk AntiAIDS, founded in 2000, works closely with local medical staff to provide HIV prevention and treatment services to high-risk individuals in the Tomsk region. Initially supported by the government-funded Regional AIDS Center, Tomsk AntiAIDS is now an autonomous organization with unique ties to both international agencies and the state. The second, the Andrey Rylkov Foundation for Health and Social Justice (ARF), is a grassroots organization founded in 2009 that collaborates with medical professionals to protect the rights of drug addicts living with HIV in Moscow. The third, the Siberian Alternative Center for Health and Social Support (SIBALT), established in 1996, educates and collaborates with medical specialists to reduce stigma and prevent HIV transmission within the LGBT community in Omsk. Because these three organizations have created positive relationships with their local healthcare communities, they are slowly but confidently eliminating four major obstacles fueling the HIV epidemic: government censorship of the disease, the refusal of some doctors to treat HIV-positive patients, the unwillingness of other doctors to treat marginalized groups with HIV, and the fear of having one’s HIV status exposed.

Government censorship lies at the root of HIV ignorance in Russia. Part of the mission of Tomsk AntiAIDS is to fight this stigma by providing “complete and up-to-date information on the disease” to both the general and medical communities. This goal actively undermines the government’s official policy of silence surrounding HIV. Another issue stemming from the

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23 Pape, 151.
state’s denial, underreporting, leads to insufficient funding for HIV programs. Members of the Tomsk NGO work around this barrier by utilizing their connections with international agencies. They use grants from foreign donors like the GLOBUS project to fund prevention services such as condom and clean needle distribution.24 The ARF, meanwhile, combats censorship through the dissemination of its newspaper, Shlyapa i Bayan. First published in 2014, it contains material written by drug addicts about HIV and drug prevention as well as information about opioid substitution therapies.25 Copies of each issue are handed out on the streets of Moscow, serving as an important tool in educating local drug users and healthcare professionals. Lastly, SIBALT utilizes a variety of means to fight censorship in Omsk. Its members provide telephone counseling, create and distribute educational pamphlets, and lead seminars for the local LGBT community. SIBALT has also reached a wider audience by offering online consultations and establishing an electronic library of special literature on HIV.26 This provides medical professionals access to scientific literature about HIV that the government has concealed. The various tactics of these three NGOs all serve to educate general and healthcare communities in Russia and foster a more optimistic perception of HIV.

Tomsk AntiAIDS counters the environment of fear and ignorance among the country’s medical professionals by providing health seminars for local medical staff. Activists present accurate research about HIV and safe medical practices so that health professionals are properly informed about the virus.27 The activists thus create a highly educated network of doctors and nurses whom the NGO can trust. Conversely, those who do not respond positively to the training are blacklisted, and the NGO will steer clients away from them. In Moscow, members of the

24 See ibid., 152.
27 See Pape, 160.
ARF provide educational services to social workers in addition to local physicians and nurses. With the financial backing of international organizations like the Global Fund to Fight AIDS, the ARF has been able to offer seminars on HIV and drug addiction as well as short-term internships to social workers from all over Russia. The ARF’s focus on educating social workers is a unique but promising approach, for social workers can serve as liaisons between HIV-positive drug users and their doctors. Upon completion of their training, they can draw upon their newfound knowledge when informing physicians about HIV and harm reduction. Finally, members of SIBALT are combating doctors’ refusals to treat HIV-positive patients in Omsk by creating their own alliances with local medical and contraceptive specialists. They also offer workshops to HIV-positive members of the LGBT community, in which they discuss their rights as patients and refer them to outside clinics willing to treat them.

Additionally, these three NGOs have conceived of ways to protect the rights of specific marginalized groups with HIV. Tomsk AntiAIDS, for example, has created services to keep patients away from narcology-oriented physicians who deny them antiviral treatment until they quit using drugs. Tomsk AntiAIDS boasts strong ties not only to general practitioners but also to psychologists and addiction specialists. When an HIV-positive client seeks help for their drug problem, members can refer them to experts who will treat them using harm reduction instead of abstinence methods. These patients are simultaneously treated for HIV; they do not have to wait to be drug-free. Because these rehabilitation programs are not narcology-based, relapse rates

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28 See Andrey Rylkov Foundation, “Kak sotsrabortniki iz Kaliningrada na stazhirovoq v FAR priezzhalo.”
29 See Omsk Regional Public Organization, “About SIBALT.”
30 See amfAR, 26.
31 See Pape, 151.
are lower than at traditional clinics, and patients are more likely to continue their HIV treatments after completing them.

Members of the ARF have enacted similar initiatives to help drug users living with HIV in Moscow. They employ case managers who accompany patients to clinics, making sure they receive proper treatment and documenting any signs of human rights abuse. The ARF is also the only organization in Moscow that offers drug users clean needles and syringes. Members even hand out naloxone and teach users and their loved ones how to administer the life-saving medication. In 2017 alone, ARF volunteers handed out 301,286 syringes, provided 214 HIV tests, and prevented 423 deaths by overdose with the help of naloxone.

SIBALT works with a different marginalized group—men who have sex with men (MSM). Fearing discrimination from healthcare professionals, many MSM do not disclose their sexual orientation when receiving medical care. As a result, they are hesitant to be tested for HIV and fail to receive counseling on safe sex practices. This contributes to the spread of the disease. In 2012, SIBALT confronted this issue by launching an initiative called PULSAR. The mission of the program was to reduce stigma and increase knowledge about HIV within Omsk’s MSM community. One major component of PULSAR focused on educating local healthcare workers about HIV and safe sex practices. This training proved successful in restoring trust between MSM and their physicians; SIBALT reported an 11 percent increase in HIV testing among MSM as well as a 9 percent increase in the number of clients willing to disclose their sexual orientation at their health clinic. For members of Tomsk AntiAIDS, the ARF, and SIBALT, working

33 See ibid., 2, 5.
34 See amfAR, 25.
directly with medical professionals has proven to be an effective way to protect the rights of marginalized groups who have HIV or are at risk of infection.

Finally, these three NGOs have tackled the growing concern over confidentiality. Activists and medical professionals understand that high-risk individuals, such as injecting drug users and sex workers, are less likely to seek help if they feel uncomfortable or believe their HIV status will be made public. For those who are afraid of being recognized at an HIV clinic, Tomsk AntiAIDS provides a service that sends team members directly to patients.\(^{35}\) Members of the ARF, meanwhile, perform outreach on the streets of Moscow five days a week, with counselors and surgeons sometimes accompanying them to assess patients and offer medical advice.\(^{36}\) Lastly, SIBALT activists recognize that certain people may not be comfortable going to their community center, so they provide services at discreet LGBT nightclubs throughout Omsk.\(^{37}\) This type of outreach work highlights the importance of respect and empathy when working with HIV-positive patients.

**Conclusion**

While the HIV crisis only seems to be worsening, partnerships between healthcare professionals and HIV NGOs offer a glimmer of hope for a healthier Russia. Three HIV NGOS—Tomsk AntiAIDS, the Andrey Rylkov Foundation for Health and Social Justice in Moscow, and the Siberian Alternative Center for Health and Social Support in Omsk—are effectively combating the virus through this model of cooperation. By arranging medical workshops and distributing up-to-date information about HIV, members of these NGOs have created an intricate network of educated general practitioners, psychologists, social workers, and

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\(^{35}\) See Pape, 153.


\(^{37}\) See amfAR, 26.
volunteers who are committed to fighting the disease. These initiatives are helping diminish the stigma surrounding the disease and restore trust between medical professionals and HIV-positive individuals at the local level.

The alliances established between these NGOs and their local healthcare communities are so valuable to the fight against Russia’s HIV epidemic because both groups have unique skills and resources to contribute. NGOs provide outside funding and uncensored knowledge about the disease. Doctors and nurses, meanwhile, have the authority as medical experts to educate the public and change societal views about HIV. In this way, cooperation between NGOs and healthcare professionals could create a supportive, judgment-free environment in which HIV-positive individuals are more willing to seek treatment.

The HIV crisis in Russia has proven to be more than just a healthcare issue; rather, it is symptomatic of larger societal problems tied to stigma and cultural conservatism. Ideally, the government, the public, the medical community, and the NGO sector would unite to make Russia healthier. Decades of censorship and denial, however, have altered each group’s views of HIV, making cooperation difficult. Nevertheless, Tomsk AntiAIDS, the ARF, and SIBALT have each found ways to form positive relationships with both medical personnel and their local communities, and these successful collaborations can serve as models for cooperation in other areas of political and social activism in Russia.
Works Cited


