In Control?: Ukrainian Opiate Substitution Treatment Patients Strive for a Voice in Their Treatment

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This article explores the burgeoning advocacy movement for methadone and buprenorphine treatment by patients, parents, and doctors in Ukraine, and their efforts to remake a system that infantilizes and controls patients into one where patients have a voice in their treatment. Through a review of gray literature and in-depth interviews with 28 patient-advocates and doctors in five Ukrainian cities between October 2009 and July 2010, this piece chronicles the emergence of opiate substitution treatment in Ukraine, describes successes toward patient-friendly treatment, and explores the institutionalized barriers that have pushed the patients to become advocates for their own treatment.

Keywords opiate substitution treatment, Ukraine, patient advocacy, police, drug use

INTRODUCTION

Opiate substitution treatment (OST) began in Ukraine in 2004 with buprenorphine; methadone followed in 2008. Though the programs themselves are still small in scale—as of August 2010, 5942 people were on treatment—the voice of patients is increasingly loud. Born out of the legacy of Soviet narcology, a subspecialty of psychiatry distinguished by control of social deviance by provision of treatment, methadone and buprenorphine programs in Ukraine are hampered by regulatory barriers and harassment by law enforcement of both patients and doctors. Despite, or perhaps because of this challenging situation, groups of patients and allied parents and doctors have become advocates and agents for change—learning laws and regulations and building alliances with policymakers to find creative ways to remove barriers to treatment.

This article describes the emergence of OST in Ukraine and the efforts of coalitions of patients and allies to shape treatment to fit their needs. We first examine the history of drug user treatment and the impact of Soviet narcology on today’s treatment practices; we next provide a short overview of the epidemiological situation of HIV and opiate use in the country; and we then look at the introduction of OST as a public health response to the HIV epidemic. Finally, we examine some of the most difficult obstacles facing patients—namely, police raids on clinics, lack of prescriptions or take-home doses for medications widely prescribed in other countries, and treatment interruptions. For each of these institutionalized obstacles, we describe the response by patient-advocates and their allies and their successes to date.

METHODS

Between September 2009 and September 2010, the authors culled peer-reviewed and published literature in English and Russian from the period of 2002 to 2010 for accounts of substitution treatment and HIV in Ukraine. The authors also examined gray literature by international agencies, local nongovernmental organizations (NGOs), and relevant Internet sources, including blogs of patient-advocates. This literature review was supplemented by interviews and correspondence with eight physicians and 20 patient-advocates in Simferopol, Kiev, Dnepropetrovsk, Ivano-Frankovsk, and Sumy. Interview notes are on file with the authors. Some interviewees offered their insights through off-the-record conversations or through email.
Drug User Treatment and the Legacy of Soviet Narcology

It is no exaggeration to compare the lives of active users with the lives of spies living behind enemy lines: everyone around is alien and life and freedom are at stake. And it could go either way. Every time we left our homes, many of us thought: Will I come home today? Wind up in prison? Or the morgue? We were solitary fighters for survival, perishing in the unequal battle with a state machine that essentially sought to destroy drug-dependent people. (OST patient, female, 36)

In contrast to Western countries, where buprenorphine is prescribed to patients for weeks at a time and where stable methadone patients are also allowed take-home doses, OST in Ukraine is doctor controlled, clinic based, and requires daily visits by patients. While adopted following recommendations by international agencies and public health authorities to address growing rates of HIV infection, OST in Ukraine remains a new modality poured into an old mold, that of Soviet narcology.

The system of narcology was developed to deal with addiction and is a hybrid model that combines medicine, social manipulation, and control. It was designed and implemented to restore those who were seen as being unproductive members of society to productivity and to stop drug users, viewed as being out of control and unaware of the dangers that they cause, from bringing harm to others (Mendelevich, as cited in Elovich & Drucker, 2008). An offshoot of Soviet psychiatry, narcology inherited its paternalism and strict administrative regulations in systems of care.

Despite the name, interventions were geared primarily not for users of narcotics, but for alcoholics. Coding, a treatment modality commonly used in Soviet narcology, was a form of psychotherapy based on hypnosis that manipulated the patient into thinking that his drinking during a prescribed treatment period would cause death (Elovich & Drucker, 2008).

There was official denial that drug use could and did happen in the Soviet Union. In cases where drug addiction was encountered, it was addressed using methods for treating severe psychosis associated with end-stage alcoholism—blood purification and prescribing strong anti-psychotic drugs with significant side effects, including painful sulfozinum injections that raised body temperature, which was thought to accelerate the process of detoxification, as well as insulin and atropine shock interventions, which were believed to lessen the cravings and effects of withdrawal by affecting the brain receptors (Babayyan & Ganapol’skii, 1981). At times, forced labor was also used (Gilinskiy & Zobnev; Rouse & Unnithan, as cited in Wolfe, 2007). These methods were employed partially to control patient behavior and punish “unruly” patients while they underwent inpatient treatment, which was strictly regulated and lasted from 60 to 90 days, as mandated by the drug user treatment protocols enforced at the time (Order No. 388, 1978; Order No. 704, Ministry of Health of USSR, 1988).

While most patients returned to substance use immediately after their release, if not during treatment itself, these methods became inscribed as tools of narcological treatment discussed in Soviet medical journals, such as *Narkologie*. Additionally, many Soviet countries limited the ability of non-narcologists to treat drug dependence, further consolidating the power of the discipline (Wolfe, 2007).

With the exponential growth of registered opiate addicts in the 1990s, narcology’s methods remained largely unchanged. While compulsory treatment/labor centers were too expensive for post-Soviet governments under economic duress, various mechanisms to compel drug users seeking treatment to register themselves and be the object of state surveillance remained in Ukraine. (Shields, 2009; Tolopilo & Vlasenko, 2008). Narcologists in Ukraine have historically been placed in what analysts have called a “dual loyalty” position (International Dual Loyalty Working Group, 2002), given that, on the one hand, they are supposed to help patients and respond to their needs and requests, while on the other hand, they have been mandated to protect the “interests of the state,” as understood by the government. Doctors treating patients were viewed as being responsible for the patient’s behavior during treatment and sometimes even afterward. To ensure obedient behavior among patients, most doctors strictly adhered to the prescribed detoxification and control regimen.

After the fall of the Soviet Union, Ukraine did not follow Russia’s course with more stringent drug user treatment regulations, and therefore, had a greater degree of freedom in choosing its treatment methods. Because doctors’ salaries were quite low, this provided them with a financial incentive to improve their practice and attract patients with better treatment, as well as to develop and expand their arsenal of therapeutic methods. The use of injection buprenorphine for detoxification, which began in 2001, was the first use of specific medications targeted for opiate addicts and the harbinger of substitution treatment in Ukraine. While it was supposed to be administered for 10 days, in some instances, injectable buprenorphine was provided for up to six months, resulting in short-term maintenance treatment (Human Rights Watch, 2006). Although some administrators of narcological hospitals, wishing to avoid increased inspections, refused to carry the medication in their pharmacies, the use of buprenorphine became an established clinical practice.

Just as it was limited in its ability to address problems of opiate addiction, narcology as a discipline was also not prepared to deal with the burgeoning HIV epidemic among drug users in the 1990s. Narcologists were authorized to treat drug dependence; for HIV treatment, their role was limited to issuing referrals to AIDS centers for testing. But the growing AIDS epidemic and the introduction of large-scale antiretroviral therapy (ART) prompted the introduction of OST as a way to effectively limit HIV risk and increase adherence to HIV treatment regimens.
**HIV and Drug Use in Ukraine**

The second largest country in Europe, with a population of about 46 million, Ukraine’s HIV epidemic has been called the most severe in Europe (Kruglov et al., 2008). Primarily concentrated among the “most-at-risk populations” of injecting drug users (IDUs), sex workers, and men who have sex with men, the estimated number of adults aged 15–49 in the country living with HIV is 395,000, or a national prevalence of 1.63%, the highest in Europe. An approximate 163,688 IDUs in Ukraine are living with HIV, with estimates of overall prevalence ranging between 38.5% and 50.3% (Kruglov et al., 2008), and regional prevalence estimated to range from 8.7% to 58.3% (Vinnitsya Regional Epidemiology and Sanitation Station; Ukrainian Institute for Social Research; Booth et al., as cited in Dumchev et al., 2009). Of those living with HIV, IDUs make up the largest group, or 41.4% (Kruglov et al., 2008). Heterosexual transmission, which accounts for an increasing share of new infections, is primarily linked to sexual contact with IDUs (Thorne, Semenenko, Pilipenko, & Malyuta, 2009). The number of HIV cases that progressed to AIDS was high at 4419 in 2009 (HIV/AIDS Alliance, 2009), and AIDS mortality has increased over time (Kruglov et al., 2008). Hepatitis C is a pressing issue for people who use drugs as well, with prevalence among IDUs in Ukraine ranging from 62% to 88% depending on the region (Dumchev et al., 2009).

Opiate users in Ukraine do not primarily inject heroin, but rather homemade preparations made with locally grown poppy, such as shirka, an acetylated opium solution (Dumchev et al., 2009). At the same time, homemade methamphetamine, including ephedrine-based vint and boltushka, are also widely injected, especially among younger drug users.

It has been documented that OST can prevent new HIV infections by reducing injecting (Gowing, Farrell, Bornemann, Sullivan, & Ali, 2008) and can prevent progression to AIDS for those who are HIV-positive by increasing adherence to ART and improving virological success (Roux et al., 2009). To that end, the World Health Organization (WHO), United Nations Office on Drugs and Crime (UNODC), and United Nations Program on HIV/AIDS (UNAIDS) (2009) have jointly recommended that substitution maintenance treatment, including methadone and buprenorphine, be incorporated into the national HIV/AIDS programs, both as an HIV/AIDS prevention measure and to support adherence to ART for opiate-dependent drug users. A recent study has shown buprenorphine and methadone treatment to have positive effects in reduction of HIV risk in Ukraine (this study looked specifically at OST outcomes for users of homemade opiates). It found that illegal activities, including illegal drug use, and HIV transmission rates were reduced, while psychiatric problems and employment improved among OST patients compared with baseline (Schaub, Chtenguelov, Subata, Weller, & Uchtenhagen, 2010).

**The Introduction of Substitution Treatment in Ukraine**

In the mid-90s, Ukraine’s National AIDS Committee made the first attempts to introduce methadone treatment, as part of the effort to combat the onset of the HIV epidemic. Due largely to media hype that portrayed methadone as a dangerous drug, this early attempt failed.

A second attempt was made in 2002 when NGOs and UN agencies began conducting activities to lay the groundwork for the introduction of treatment. A review of the laws found that there were no legal barriers to OST introduction. Fact-finding missions to countries such as Lithuania and Poland educated Ukrainian doctors about methadone. Substitution treatment activists from Vilnius, Lithuania, participated in roundtables in the Ukrainian cities of Odessa and Dnepropetrovsk, where they shared their treatment experience with methadone. These roundtables brought together members of the medical community, law enforcement representatives, and drug users, who at the time were mainly involved in harm reduction services. These discussions had an effect on the local level, with the local authorities in Dnepropetrovsk making the decision to include methadone programs as an integral component of the region’s HIV/AIDS program in 2003.

In 2003, methadone was registered in the country and preparations were made for pilot methadone trials. Due to opposition from the Ministry of the Interior, however, these pilots were delayed. In the meantime, two buprenophine substitution treatment pilot programs funded by the United Nations Development Program began in the cities of Kherson (May 2004) and Kiev (November 2004) with a total of 70 patients (Bruce, Dvoryak, Sylla, & Altice, 2007). The fact that buprenorphine was already registered in the country, and was frequently administered as a detoxification medication, made the medication easier to introduce than methadone. Unlike in France, where general physicians prescribe the medication, or the United States, where buprenorphine patients can take home as much as a month’s worth of medication at a time, buprenorphine in Ukraine was delivered using a daily, directly observed therapy approach, necessitating the daily involvement of narcologists.

Even with this constrained model of service delivery, buprenorphine pilots were a success, having been evaluated as part of a larger WHO study “Substitution treatment for drug-dependent people and HIV/AIDS.” According to the findings of the study, outcomes of the first two pilot projects at six months showed a 70% client retention rate, fourfold decrease in illegal opiate use and high-risk behavior, as well as 0% crime rate among the projects’ participants (Dvoryak & Skala, 2008, p. 5).

Introduction of buprenorphine also saw the development of nascent patient advocacy. In 2005, several buprenorphine patients in Kherson had founded an NGO Awakening, which sought to advocate for expansion of substitution treatment both at the city and at the country level. The members of the group became peer educators to potential substitution treatment patients and took...
part in numerous press conferences, roundtables, and public hearings across the country. Their active stance vis-à-vis their treatment experience helped to promote a positive image of the program, dispelling the many myths that accompanied initiation of buprenorphine programs in Ukraine.

In 2005, the Kherson buprenorphine program experienced a crisis, when the United Nations Development Program, which funded the program, announced that no medication would be provided as of that September. The future of the program was in jeopardy as patients faced the prospect of returning to street drug use. At this time, Awakening launched a campaign to save the buprenorphine program in Kherson by appealing to local and international HIV/AIDS and harm reduction organizations. The campaign was successful in ensuring that the Kherson program became one of the seven sites to be supported by the Global Fund to Fight AIDS, Tuberculosis and Malaria, thus helping to avoid interruption in treatment for the patients (Human Rights Watch, 2006). It also set a precedent for the patient advocacy groups that would be formed later as substitution treatment scaled up. Following the positive results of the pilot projects and recommendations put forth by a joint mission of UNAIDS, UNODC, and WHO, in September 2005, with support from the Global Fund, Ukraine began to implement a pilot substitution treatment program with sublingual buprenorphine in seven cities: Dnepropetrovsk, Donetsk, Kherson, Kiev, Odessa, Nikolaev, and Simferopol (Human Rights Watch, 2006).

Despite the ongoing scale-up of buprenorphine programs, the prohibitive costs of the medication ($170 per month) made it immediately clear that widespread provision of OST would not be possible. The opposition to methadone treatment remained strong both within the Ministry of Health and the Ministry of Interior. Despite the fact that this medicine was cheaper by a factor of almost 10 and that the opiate substitute was at least as effective as buprenorphine (Mattick, Kimber, Breen, & Davoli, 2008), in 2005, the Cabinet of Ministers attempted to reclassify methadone as a List 1 drug, which would effectively ban its use for substitution treatment. This move prompted an outcry from the leading national organizations working in the field of HIV/AIDS and harm reduction, such as the International HIV/AIDS Alliance in Ukraine, the Ukrainian Harm Reduction Association, the Coalition of HIV/AIDS Service Organizations, and the All-Ukrainian Network of People Living with HIV. What the Ministry of Interior sought to block, on the one hand, was on the other wave forward by the Ministry of Health, which that same year had signed an agreement with the Clinton Foundation HIV/AIDS Initiative to “pilot and then scale up methadone-based drug substitution therapy” (Human Rights Watch, 2006). Following pressure from the Global Fund to make good on pledges to scale up substitution treatment, sustained advocacy by civil society groups taking primary responsibility for implementing that grant, a protracted battle with the Ministry of Interior, and a decree signed by President Victor Yuschenko, the Ministry of Health Committee on Drug Control at last issued a certificate to allow the import of methadone to Ukraine in December 2007. After a prolonged procedure of acquiring the necessary permits from the International Narcotics Control Board to import the medication into the country, methadone finally entered Ukraine in April 2008.

Responding to an Unresponsive System: The OST Patient Advocacy Movement and Challenges to OST Delivery in Ukraine

The key to sustainability of substitution treatment programs is in empowering the patients to advocate on their own behalf. When the funding ends, the donors and experts will move on to a different issue. But the patients whose life and well-being depends on these programs will remain and continue to advocate for integration of substitution treatment into the state health care system. (OST patient, male, 50)

As of 15 August 2010, 5942 patients in all 27 regions of Ukraine have been enrolled in OST programs, supported through the Global Fund to Fight AIDS, Tuberculosis and Malaria and United Stated Agency for International Development (Ukrainian Institute on Public Health Policy, 2010). Despite the steady expansion of the programs and the documented reduction in drug use and criminal activity, as well as the overall improvement of health among program participants (Uchtenhagen & Shaub, 2010) that has accompanied the scale-up process in Ukraine, a host of systemic and structural barriers continue to hinder access to substitution treatment for people who use drugs.

Limited capacity of the clinics and burdensome reporting requirements stall expansion of the program and create long waiting lines. Inability to receive the medication by prescription at a pharmacy or as take-home doses interferes with finding or maintaining legal employment and traveling. The absence of a uniformly enforced mechanism for continuing substitution treatment in inpatient facilities, such as tuberculosis hospitals or maternity homes, forces patients to forgo critical health care:

Substitution treatment today, yes, it’s awkward, yes, it still carries Soviet undertones. But it is our achievement, so let’s think about what we can do to make this program what we once imagined it would be like—low threshold, accessible, of good quality and with good prospects for expansion. We have invested so much effort and so much of our own lives to bring the program here. And yet, we still have to contend with hawk-like presence of the police at our sites, aggressive religious zealots, “members of society in defense of morality . . .” It is up to us, the patients, to continue to prove, not with our words, but with our health, with our patience that substitution treatment for us is the right course of action. (OST patient, male, 50)

Further complicating the treatment experience is the overtly hostile attitude of law enforcement toward substitution treatment programs in Ukraine. It is not uncommon for the police to enter the clinics demanding to see (and make copies of) the patients’ medical records, including their personal information. Similarly, patients often fall prey to the police (who wait near clinics to make arrest quotas and extort bribes) when entering or leaving
the premises of the OST clinic—and as a result, are taken to the police station to be fingerprinted, questioned and sometimes held in detention for extended periods of time in the state of opiate withdrawal.

Evidently, introduction of substitution treatment in Ukraine has not been without its challenges. Yet, paradoxically, these very challenges have also compelled patients to move beyond the role they have traditionally been assigned—that of docile recipients of services—to become outspoken activists, seeking not only to adapt to the changing environment but to confront the unyielding system and its laws and regulations to secure their right to evidence-based treatment.

Patients struggle to respond to the excessively rigid and controlling policies and practices regulating substitution treatment provision in Ukraine, from a patient-run substitution treatment hotline to the formation of an Association of Substitution Treatment Advocates of Ukraine. These experiences—of participation and activism—appear to have brought an improved sense of empowerment and autonomy to many methadone and buprenorphine patients.

Advocacy begins with education. From the outset, doctors and drug users alike had misconceptions and fears about substitution treatment. The former, whether opposed to it ideologically or concerned about the impact of this new treatment modality on traditional approaches to drug user treatment, attempted to distance themselves from the program. The latter needed proof that substitution treatment presented a safe and viable alternative to the lifestyle to which they were accustomed. Yet for many families of drug users, substitution treatment presented a welcome opportunity for a new beginning for their loved ones. Therefore, some of the first and most relentless advocates for expansion and sustainability of substitution treatment programs in Ukraine were parents of drug users in treatment. In the summer of 2007 in the city of Simferopol, Crimea, parents and patients inundated the local health authorities with faxes and telephone calls when the protracted process of renewing a clinic’s license threatened to jeopardize continuity of treatment for the patients receiving buprenorphine in the program. It should also be noted that to avoid interruption in treatment while the clinic’s license was being renewed, the buprenorphine program in Simferopol became the first in Ukraine to pioneer administration of buprenorphine by prescription. Though this measure was temporary, it was nevertheless a bold and risky move at the time, one that would set an important precedent for advocacy for prescription buprenorphine in the future.

Meanwhile, in Kiev, a group of parents, led by a particularly outspoken and passionate activist and mother of an OST patient, Irina Sukhoparova, registered an NGO called Nadiya, meaning “hope” in Ukrainian. The hope was that the parents’ voice would prove to be a powerful one in galvanizing support for substitution treatment and countering the arguments of its opponents. Sukhoparova became an important part of the national debate on substitution treatment, participating in roundtables and press conferences, drawing on her family’s experience with substitution treatment and advocating for its expansion throughout Ukraine.

As methadone and buprenorphine programs scaled up across Ukraine, Nadiya transformed itself into a parent-and patient-run hotline on substitution treatment. The toll-free hotline, which receives an average of 60 phone calls a month, serves as a source of information about the program for prospective clients and their families, but also has the capacity to respond to critical situations, such as treatment interruptions, inadequate dosing, and police harassment. With its location in the capital, Kiev, Nadiya has the advantage of being close to key stakeholders, such as the Ukrainian Institute of Public Health Policy and the International HIV/AIDS Alliance in Ukraine, which allows the hotline to take action and inform experts of problems at the clinics as they arise. On a number of occasions when the police had raided clinics and confiscated the medication or harassed patients and doctors, the hotline operators were the first to find out and to alert the relevant institutions in Kiev.

Alongside the parents, patients have mobilized to establish an Association of Substitution Treatment Advocates of Ukraine—the first association of its kind in the post-Soviet region. What started as a meeting of nine substitution treatment patient activists in January 2009 has gradually expanded into a registered entity with 113 members in at least 13 regions. While still in its nascent stages, the Association seeks to establish its place among the non-governmental partners working to improve policies and practices guiding substitution treatment in Ukraine. At the national level, representatives of the Association are part of the Partners’ Working Group on Substitution Treatment, which oversees the day-to-day implementation of substitution treatment programs in Ukraine. The Association is also a part of the Working Group on Substitution Treatment within the Ministry of Health, which is tasked with drafting and reviewing the normative documents regulating substitution treatment in the country. Being part of these groups allows the Association to voice the patients’ perspective and participate in the decision-making that ultimately affects more than 5000 patients in substitution treatment programs across Ukraine.

The Story of the Association of Substitution Treatment Advocates of Ukraine as Told by Co-founder Olga Belyaeva

It is easy to express your opinion when you live a law-abiding life. Can you name a forum where active drug users can express their opinion? Prior to the beginning of opiate substitution treatment in Ukraine, there was none for two reasons: the only voices heard were of those who no longer used drugs, and active users themselves were not prepared to speak out for fear of being reprimanded.

We understood that silence was death, and we could not bear to keep silent any longer. The so-called “war on drugs” being waged was not a war against drug use but against drug users. It was time for us to stand up for our right to live, our right to access to evidence-based medical treatment and social services. Our life was in need of serious change, and this called for unity and participation.
In January 2009, nine activists came together in the city of Dnipropetrovsk to start an association that could unite patients receiving methadone and buprenorphine and could represent their interests at the local and national levels. Substitution treatment has given us an opportunity to legalize our life. The Association was born out of our desire to actively participate in shaping our own future. It became a point of entry to the public discours that had previously been unavailable to people who use drugs. Every day, members of the Association maintain communication between the regions and the center through an email listserv, helping each other deal with the many issues that arise from being a substitution treatment patient in Ukraine. We are growing every day and hope to engage new members from every province of the country. We need our voices to be heard at the local and national level, and we need to be included in the decision-making process. Currently, we are part of every major working group that deals with implementation of substitution treatment in Ukraine. We participate in discussions about the new laws to be passed and in the decision-making process regarding procurement of methadone and buprenorphine. We are not token representatives of the “target population.” We make ourselves heard.

Every day we are reminded that the Association is a timely and much-needed intervention. People call us from various cities—sometimes to ask a question, sometimes to seek help in situations that they are not able to resolve alone. For example, there was a situation in the city of Donetsk, where the municipal authorities banned the substitution treatment program at a local drug treatment clinic. The Board of the Association came to Donetsk to investigate and speak with the local authorities. While working on this, one of us saw a woman in tears who was sitting at the steps of the hospital. This woman was a substitution treatment client who had been refused treatment. Our doctors still frequently withheld treatment as a form of punishment. As a result of our active effort—calls to the national OST hotline, to the chief narcologist of Ukraine, to partner NGOs on the national level—we got things done: the woman was given medicine that day and remained in the program. And people were drawn to us, having understood and seen the real power of patient advocacy through the work of the Association.

Although we are only a year old, we feel that we have already accomplished quite a bit. Over the course of the year we developed a strategy that will guide our advocacy efforts in the coming years; we’ve sat as voting members on the decision-making committees regarding implementation of opiate substitution treatment in Ukraine. We have submitted an inquiry to the International HIV/AIDS Alliance in Ukraine, the primary recipient of the Global Fund grant, about the planned number of methadone and buprenorphine slots up until the end of the grant in 2012. At a recent meeting of the Association we distributed this information to our regional members in 16 regions of the country, which they then circulated at their sites. By doing this we sought to ease the anxiety many patients feel about the future and sustainability of OST programs in Ukraine.

Our plans for the next year include strengthening the Association and developing the capacity of its members. Our goal is an Association with thousands of members, access to treatment, care, and support for everyone who needs it, sustainability of OST programs, and freedom to travel to visit friends and family in different cities and countries. Sustainability of opiate substitution treatment in Ukraine depends on our active engagement and participation.

The disruptive actions of law enforcement officials threaten to jeopardize the expansion and improvement of substitution treatment programs in Ukraine, while the highly rigid healthcare system continues to lag behind in responding to the needs of patients. In the midst of this are the patients who are learning to reconcile their personal struggle of being a patient in the current substitution treatment dispensing system with being part of the advocacy movement that seeks to institutionalize substitution treatment in Ukraine. While the tension between the two roles is palpable, the everyday experience of being a substitution treatment patient in Ukraine is such that participation and activism appear to have become an indispensable coping strategy for many patients receiving treatment.

**Falling Down Only to Get Up Again: OST Patients in Ivano-Frankovsk Look to Themselves for Solutions**

After we became OST patients, we faced a question: What’s next? Everyone had their own problems that needed to be addressed sooner or later. But no one is going to solve our problems for us. How do we live after ten, 15, 20 years of being in a daze . . . ?

How do we re-enter this world, this sober world with its own laws and challenges? How do we adapt, how do we start over? Where do we begin? Some of us are in our thirties and forties, with no experience, no skills, no social networks; some—homeless, without any documents. In searching for answers to these questions, an idea was born—to create an entity, an organization, whose goal would be to help with these issues.

But where do we start, with no money and no experience? In this kind of a situation somebody had to take the initiative. Sasha Grin was that person. He is now the Head of our nonprofit organization Zahid Shans. At the core of the organization are people committed to the idea to help, to struggle, to break out of inertia. Our chief doctor, V. Skopych, helped us by giving us a place to use as an office. We also met great people: Olya Belayaeva, Pasha Kutsie, Lesha Zagrebelyny. Others supported us, gave us useful advice, for which we are grateful.

Over the course of time, our organization has achieved quite a bit. We help in restoring documents and finding employment, we provide psychosocial support for OST. We are advocates; we are invited to speak on the radio and TV . . . We were also one of the first to start administering buprenorphine by prescription. Yes, it’s still done sporadically, on an individual basis, but it’s a start! All of this is thanks to a great relationship between our doctors and the organization. The doctors trust us, which is important for our work; and we trust them. That is important to us.

**Illegal Enforcement: Police Raids on Substitution Treatment Clinics**

The clinic is closed until further notice due to confiscation of the medication. Please remain calm. (A sign on the door of an OST clinic in Pershotravensk, Ukraine. April 2010)

OST in Ukraine seems to ebb and flow, with the Ministry of Interior or local law enforcement particularly active in undermining what the Ministry of Health or nongovernmental partners promote. Beginning with the introduction of methadone in 2008, for example, treatment moved beyond the threshold of 1000 patients, where it had remained for years, expanding more than fourfold. By Fall of 2009, however, the police were pushing back: In September 2009, 10 OST clients in the city of Sumy were detained by police as they were coming in to receive
their daily dose of medication, in what the police claimed was a routine operation. They were held in the police station for four hours, with no explanation given for their detention. After numerous calls and inquiries by the relevant authorities in Kiev, the patients were finally released. Yet two weeks later, a number of patients from the same clinic were once again arrested. This time, the police sought out those with driver’s licenses. OST clients with driver’s licenses appear to be particularly vulnerable, as those with a history of drug use are supposed to be denied licenses in Ukraine. OST patients who drive are thus targets for extortion (despite the fact that the urine screens may yield no traces of illicit substances).

The boundaries between the public health and the law enforcement aspects of substitution treatment in Ukraine have been blurred since the inception of the program, so it is no surprise that the police have always been directly or indirectly involved in “helping” the doctors decide who should or should not receive the medication, setting their own criteria for what the treatment process should look like. An example of this was a recent development in Sumy, where the OBNON (anti-drug police) began testing OST clients for traces of opioids, cannabinoids, stimulants, barbiturates, and other illicit substances. For those whose urine screens came back positive, the OBNON put pressure on the doctors to dismiss the clients from the program, going as far as setting up quotas for the number of patients to be dismissed. While in this instance, the local NGO managed to resist the pressure, it is obvious that the overarching presence of the police acts as a significant destabilizing power in the treatment process, cultivating suspicion and mistrust between patients and doctors and discouraging potential new clients from entering OST programs.

### Alexiy Zagrebelniy of the NGO Club Chance in Sumy Tells the Story of How They Resisted Police Pressure to Dismiss Patients from the Local OST Program

Since the opiate substitution treatment program began in our region, I’ve often resorted to using military terms to describe the program and the processes around it: there were attacks, reconnaissance missions, counterintelligence, prisoners of war, truces, non-aggression pacts . . .

To us this is a struggle for survival, the struggle to just be. To the OBNON this is a way to expand its sphere of influence to substitution treatment—through threats, intimidation, blackmailing. Just consider OBNON’s suggestion to include their representative as part of a multidisciplinary team [that makes decisions on admission and dismissal of OST patients]—a “social worker” from OBNON!

In these instances the medical providers sometimes put up a fight and sometimes remain neutral observers. When the OBNON tried to pressure us to dismiss 12 patients from the program, they almost succeeded. The doctors wanted to find a compromise: “Maybe we can dismiss five patients instead of 12?” Some could consider that a successful compromise: “We saved the other seven!”

The thing is . . . we’re not just an NGO that provides services to OST patients. Four of our last names were on that list of people to be dismissed from the program. Over the course of two days we wrote and sent petitions to the Ministry of Interior and the Ministry of Health, collected signatures, called the press. A few days later all five of the patients were re-admitted into the program. We didn’t back down. We couldn’t. This is our program, and we had to fight for what was ours.

Further complicating matters is the legal uncertainty created by conflicting regulations about the process of OST delivery, which makes doctors almost as vulnerable to police action as their patients. An example of this is the conflict between the regulation for adding a person to a clinical drug user registry and that which governs protocols for enrolling the patient into a substitution treatment program. A joint Decree No.306/680/21/66/5 of the Ministry of Health, the Ministry of Internal Affairs, and the Prosecutor’s Office requires that a medical committee diagnose a patient with drug addiction and add him to a clinical drug user registry. At the same time, according to the still-active Decree No.704 of the Ministry of Health of the USSR as well as the Decree No. 645 of the Ukrainian Ministry of Health, which outlines the guidelines for substitution treatment provision, a doctor may diagnose a patient with drug addiction without the medical committee, and the patient may only be placed on the drug user registry with his permission. The confusion created by these two conflicting mandates is one that can be pursued at the discretion of law enforcement, who may choose to identify failure to register a patient and work without the committee as diversion of resources and illegal distribution of medication.

Two recent cases highlight the gray areas of the law, within which the doctors are often forced to operate. In one instance, Yaroslav Olendr, a doctor involved in substitution treatment provision in the city of Ternopol, was detained for prescribing and administering methadone to a patient without consulting the medical commission. At the time this article was submitted, Dr. Olendr was under house arrest for allegedly violating an article of the Criminal Code of Ukraine on “Circulation of Narcotic Substances.”

The second case took place in March of 2010 in Odessa, when the police arrested a doctor and two nurses dispensing OST, as well as a social worker, confiscating the patients’ medical records and the clinic’s supplies of methadone and buprenorphine. The raid left 200 OST patients without treatment, as the police action halted the course of the program. Mass protests ensued, with patients and their parents demonstrating in front of the local department of health, demanding that the program be resumed and the medical staff released. The patients joined the advocacy campaign launched by the International HIV/AIDS Alliance, the Ukrainian Institute for Public Health Policy, and a number of other NGOs in addressing petitions to the local authorities, the Ministry of Health, and the Prosecutor’s Office. The incident was widely covered by the national media. The public outcry had an effect, with the clinic resuming its work some 48 hours later. The nurses were released, but the doctor, 62-year-old Ilya Podolyan, although briefly released on
bail, was indicted and re-arrested on May 28, 2010. At the time this article was submitted, he remained in pre-trial detention on drug trafficking charges—42 counts of illegally distributing buprenorphine and failure to inform the relevant authorities of the address change of the clinic (Cohen, 2010).

The arrest of Dr. Podolyan on essentially trumped-up charges and his detention despite the mobilized legal aid efforts and appeals to the Prime Minister have shaken the medical community involved in OST provision. This has also caused the medical staff to exercise extreme caution, shifting the already-troubled process of OST delivery even further away from patients’ needs, in order to guard against police persecution.

Surveillance cameras have been installed in some clinics throughout Ukraine. Police pressure to avoid diversion is also cited as the main factor in the move to crush sublingual buprenorphine tablets, which are meant to be absorbed under the tongue. Despite the ongoing complaints by patients that taking the medication in this altered state reduces its effectiveness and exacerbates gastroenterological conditions, such as ulcers and gastritis, the doctors and nurses consider this to be a necessary step to minimize the risk of diversion. As the debate about these responses being necessary or excessive continues, there is no question that safety concerns have taken priority over the patients’ needs:

What do I think about the crushing of the pills? I try to be understanding. But I have to say, I think the practice of crushing the pills is reducing the effect of the medication. I tried buprenorphine with the pill intact and it made a difference to me. But our doctors think differently. What’s changed since the police raids [across the country] became more frequent? Not much. Just that the doctors began to pay more attention to the process of putting the powdered medication in our mouths. Not everyone obviously likes this kind of attention—not because it may interfere with trying to get the medication out, but because it’s invasive! Who wants to have their mouth inspected by a stranger? You feel like half a person. This process of inspection is degrading, you know?

It’s clear that any effort by the police to try and “control” the situation with OST in their “gracious” ways makes everyone nervous—the doctors, the nurses, the patients. Non-disturbance—it’s a requirement for an OST program to function well. (OST patient, male, 42)

Lack of OST Prescription or Take-Home Allowances

You think a diverted pill is horrible? That’s alarming? No! Because it’s not just a pill. It’s a day of my life that I just gained. What about when it’s two or three pills? We’re not being greedy, no! For us it’s an opportunity to go see our mother, our family in a different town, go to a funeral, go meet somebody. What am I saying? It’s a taste of that freedom, that different life that we dream of, because we ourselves have become different! Yes, people try to divert pills, yes, they break the rules . . . But what other choice do we have? (OST patient, male, 50)

An unpublished evaluation done in 2009 assessed the process of OST scale-up in Ukraine and provided a set of recommendations on reaching the Global Fund target of 11,300 patients on substitution treatment by June 2012. To reach this target, it estimated, eight patients would have to be started on methadone every day, seven days a week for the next three years. Yet the current regulatory requirements (such as filling out four copies of a medication log for every tablet formulation dispensed to a patient and requiring a consensus by a medical committee to change a dose) significantly limit the capacity of the clinics to accommodate the growing number of patients.

The evaluation concluded that the simplest way to achieve the targets set by the Global Fund would be to provide patients with take-home doses of the medication or with prescriptions that would allow them to obtain methadone or buprenorphine at a licensed pharmacy. According to the evaluators, this would rapidly expand the number of patients without a significant increase in administrative and clinical time.

Yet in the existing paradigm, where fear of police and regulatory stagnation define the treatment process and patients’ individual needs are forced to take a back seat, the opportunity to receive OST by prescription at a pharmacy or as a take-home allowance remains out of reach for most OST clients in Ukraine. The emphasis on directly observed treatment, which contradicts the experience of best practice programs in other countries, hinders the expansion of the program by creating long waiting lists and inhibits the process of reintegration of OST clients in society by preventing them from traveling, finding legal employment, and joining new social networks.

Presently, limited hours of operation at the clinic, inability to receive the medication before work, and long waiting lines all interfere with patients’ efforts to find and maintain stable employment. Some clinics throughout Ukraine have sought solutions. In Nikolaev, for example, the doctors and patients have worked out an arrangement whereby the clinic produces a certificate for the employer, which states that the patient is undergoing long-term treatment (of unspecified nature) and needs be seen by the doctor on a daily basis. Other clinics have introduced special early hours for working patients, allowing them to receive the medication as early as 7 am. While this partially addresses the issue of employment, it does little to tackle another issue, which similarly arises from the need to come to the clinic on a daily basis—the ability to travel. In the absence of a centralized database that allows doctors to track and admit patients from other regions, the de facto practice is for the doctors to make arrangements with the host clinic by phone. While this seems to work in most cases, the absence of a systematic process of referral ultimately places the decision regarding a patient’s ability to travel in the hands of the medical provider, who may or may not be willing to accommodate the patient’s request. Furthermore, the patient’s ability to travel is limited to the cities where the medication is available. This is less of an issue for methadone, which is currently available in all 27 regions of Ukraine, but remains a greater problem for patients receiving buprenorphine (currently available in 21 regions, but only in one clinic per region).
In 2008, a group of OST patient activists began to explore opportunities for administering buprenorphine by prescription. Olga Belyaeva, the Head of the Board of the Association of Substitution Treatment Advocates of Ukraine, tells the story: “We saw prescriptions as an important step to improve the quality of life for many patients—to allow us to travel, apply for better jobs or keep existing ones . . . . Order No. 360 made it possible to receive buprenorphine by prescription. We wanted to pilot this model on a smaller scale at first and, in March 2009, six people in the city of Dnepropetrovsk began to receive buprenorphine by prescription. The process to replicate the model is currently underway in other cities of Ukraine.”

Belyaeva is one of the handful of people in Ukraine currently receiving buprenorphine by prescription. As part of the Working Group on OST, members of the Association have joined key national stakeholders in reviewing proposed amendments, which, if adopted, would make it possible to obtain methadone by prescription and extend buprenorphine prescriptions for up to 10 days.

**Interrupted Access to Substitution Treatment at Inpatient Facilities**

To be an OST patient means you have no right to get sick. You can’t afford to be sick, unable to be in two hospitals at the same time, and every day—with no weekends or holidays, in the heat and in the cold, on your two feet (and sometimes, just one) drag yourself across town, with its endless traffic jams. Drag yourself across town with tubes sticking from your lungs, with a catheter, on diuretics. Hunched over in fatigue on the bus in the summer heat and the bitter cold, coughing as only a person with TB would . . . . And how did you picture a “drug addict”? As healthy guys with a Hollywood smile and strong hands with blisters from a hard day’s work? (OST patient, male, 50)

The inability to receive OST by prescription or as a take-home particularly affects patients who require hospitalization for their medical conditions. With OST programs limited for the most part to drug user treatment clinics and AIDS treatment centers, no provisions have been made to ensure continuity of OST treatment in other inpatient facilities, such as maternity clinics, tuberculosis (TB) clinics, or general hospitals, through reallocation of the medication within the region and from clinic to clinic. The consequences of the lack of a clearly defined policy on continuity of treatment are often dire, with OST patients refusing to be hospitalized even when this refusal will almost certainly result in the patient’s death. The lack of OST in TB dispensaries means that patients with an active form of TB must often choose between receiving treatment for TB or continuing to receive substitution treatment in a different clinic. With most choosing the latter option, the public health implications of this choice are clear. In the absence of a standard practice to make methadone and buprenorphine available in maternity hospitals, some patients report having to leave the maternity ward shortly after receiving a caesarian section in order to receive their methadone or buprenorphine at the OST clinic or having to continue to come to the OST clinic despite being on bed-rest in the hospital during a complicated pregnancy. Others tell stories of going to great lengths to conceal their health problems from medical providers to avoid being referred to a hospital where OST medication would not be available.

A recent Ministry of Health order now requires regional governments to ensure continuity of OST treatment, yet it does not spell out a mechanism by which this provision must be implemented. As a result, the status of implementation of this order varies from region to region, with the mechanism functioning in a number of regions with proactive doctors, NGOs, and patient groups, while in the rest, delivery of OST to hospitalized patients is *ad hoc* or absent. Once again, the control of the situation rests with the medical providers who may or may not be responsive to the client’s health needs and concerns.

Nevertheless, NGOs as well as *ad-hoc* patient groups throughout Ukraine are working with doctors and local health officials to remedy the situation and create favorable conditions for the patients to seek inpatient treatment. Recently, a number of patient groups joined forces with a national stakeholder to advocate for development of such a decree in Kiev—a city that until now did not have a formal procedure for delivering the medication to its OST patients in inpatient facilities despite having one of the largest OST programs in the country. Through a series of meetings with the clinics’ administration and petitions to the city’s health department signed by patients, parents, and local NGOs, a decree was drafted in February 2010. At the time of writing, the decree is being reviewed for signature, yet delivery of medication to inpatient facilities has begun. A bittersweet victory for the patients, it has also meant that the clinic responsible for delivering the medication to the patients has had to reduce its hours of operation in order to fulfill its new set of obligations. This, in turn, has contributed to longer waiting lines—a reminder of the fragility of the advocacy wins in this ever-changing environment.

**CONCLUSION**

Ukrainian methadone- and buprenorphine-treated patients and their allies are finding inroads to change the environment in which they receive their treatment. Much of the success has been through relationship-building at the local and regional level, and these nascent groups should be supported to share experiences across Ukrainian regions and to expand their advocacy on the national level.

The shift from complacency to action is a gradual process. Patients are experiencing and finding empowerment in joining forces with like-minded people resolved to: (1) change the status quo, (2) understand the laws and regulations governing provision of substitution treatment, and (3) use this knowledge to impact overly rigid policies and practices. Yet even in their role as agents of change, they remain patients, as well as members of a stigmatized group, whose lives in large part depend on their ability to access substitution treatment. Public expressions of
discontent out patients as drug users in an environment where disclosing that identity risks law enforcement attention. This inherent vulnerability cannot be overlooked, for it limits the extent to which patients are able to express their grievances and seek greater flexibility in their treatment process. Though some public demonstrations have been possible, much action has been restricted to expert meetings and professional gatherings, where the environment is more supportive. But even in pushing the boundaries with the medical providers, patient-advocates ultimately run the risk of biting the hand that feeds them.

Six years into the process, substitution treatment in Ukraine remains complicated. The issues raised in this article are significant but the list is by no means exhaustive. Hard-won gains are constantly threatened by interference from law enforcement, which deters patients from accessing treatment and makes doctors reluctant to stray from the most conservative interpretations of the law. Sustained advocacy with police, both by patient-advocates and by broader coalitions, is needed in order to create the space for further reforms and to allay the fears of clinicians, who might otherwise be more supportive of patient autonomy in the form of take-home doses or prescriptions. However, more importantly, the government of Ukraine must send a clear message of support for substitution treatment; a message that must be heard not only by the patients and medical providers but also by the law enforcement community. Without the government’s full commitment, the patients and their allies—doctors, parents, activists—face a lonely struggle against a perverse choice between personal safety and health.

Declaration of Interest
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GLOSSARY

Buprenorphine: A semisynthetic partial opioid agonist used to treat drug dependence and pain.
Methadone: A long-acting synthetic opioid agonist used to treat drug dependence and pain.
Narcology: A medical discipline developed by the Soviet Union to address addiction.
Patient-advocate: Used here to refer to a person receiving substitution treatment who is also engaged in activism to improve the provision of that treatment.

REFERENCES


