



HEALTH CARE CRISIS AND GRASSROOTS SOCIAL INITIATIVE IN POST-SOVIET RUSSIA

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Abstract

This article analyzes the development of civil society in Russia in response to the fledging post-Soviet health care crisis. In recent years, Russian civil society has become significantly stronger and more actively engaged in public debates on social as well as political issues. This trend suggests that the process of social capital accumulation in Russia is well underway, thus instilling some hope for Russia's future. To illustrate this recent trend, I will analyze the development of two grassroots movements in St. Petersburg, which help families of children diagnosed with cancer to overcome the everyday psychological, legal and financial difficulties associated with treatment, and to lobby the government to go forward with health care reform. This paper is based on the author's personal experience as a participant in one of the grassroots initiatives, published materials in Russian journals and newspapers and a series of interviews with volunteers. With this article, I hope to shed new light on developments in the Russian health care sector, and deepen our understanding of contemporary Russian civil society.

Introduction

The collapse of communism generated much interest in the concept of civil society, defined by the Center for Civil Society at the London School of Economics as “the arena of un-coerced collective action around shared interests, purposes and values” (quot. in Jenei and Kuti 2008, 9). Civil society was regarded as an important alternative force that limited the overarching power of the state and thus prevented the state from drifting toward authoritarianism. It was argued that during democratisation civil society not only helped restrain the government, but also educated the state authorities about democracy and the rule of law (Weigle 2002; Taylor 2006).

The interest in civil society development was accompanied by increased attention being paid to the development of Russia’s non-governmental and voluntary organisations (known as the third sector), and their role in promoting and strengthening democratic civil society in the post-Soviet states (Mercer 2002). The third sector organisations are rightly viewed as the essential building blocks in the process of civil society development and social capital accumulation. They play an important intermediary role between the state, the market and the people, serving as vehicles for participation and social integration.ⁱ Not only do they deliver various public services, especially in the welfare and educational domains, but they also serve as “bedrocks of social milieus and societal communities and therefore as transmitters of values and norms” (Jenei and Kuti 2008, 13). In other words, the third sector organisations perform various social, political, educational and integrative functions in democratising societies, offering citizens an opportunity to participate in public life, to monitor and influence the authorities, to advocate on behalf of disadvantaged groups, and to educate the people and the authorities about democracy and the rule of law (Jenei and Kuti 2008, 10; see also Taylor 2006).

Given the importance attributed to civil society and the non-governmental sector during democratisation, it was thus natural for political scientists to focus their attention on the development of Russian civil society in the aftermath of communism’s disintegration. Two major arguments were made. Some scholars emphasized the weakness and underdevelopment of Russia’s civil society as a result of the Soviet legacy and attitudes held over from the Communist period (Howard 2002). According to this view, a tiny, but growing civil society, which existed in Russia before the revolution, was wiped out when the Bolsheviks came to power. With the arrival of the Soviet regime, the development of an independent civil society in the country became virtually impossible. Mass organisations were established; however, their functions and operations were determined by the ruling state ideology and controlled by the state. Even though small pockets of opposition to the regime existed, their influence on Soviet society as a whole was rather minimal. In the end, these Soviet legacies and the negative memories of the Russian people about enforced mass participation during the Communist regime, as well as growing disappointment with post-Soviet realities during the early and mid-1990s, contributed to the fact that civil society in post-Soviet Russia remained weak and underdeveloped (Howard 2002; Cook and Vinogradova 2006).

Other scholars, however, held a more optimistic view, stressing the progress made in the development of civil society in Russia, yet also acknowledging the presence of several problems faced by Russian NGOs (Weigle 2002; Taylor 2006). According to this view, with the arrival of Mikhail Gorbachev and the subsequent collapse of the Soviet Union, a new period in civil society development began. Starting in the late 80s and early 90s numerous independent political, environmental, educational, religious and social groups and movements were set up. As time passed and the initial democratic euphoria faded, these loose informal groups were replaced with formal non-governmental organisations, whose number has steadily increased. According to the International Center for Not-for-profit law (ICNL), in 2009 there were more than 240,000 NGOs operating in Russia (‘Non-governmental organisations and civil society’). Many of these NGOs promoted human rights and civil liberties, advocated on behalf of minorities and disadvantaged groups, or provided services to the most vulnerable population groups, including the disabled, chronically-ill, migrants, street children, and others (Cook and Vinogradova 2006).

However, the biggest problem, which complicated the work of these NGOs, was associated with their reliance on foreign funding (Crotty 2003; Cook and Vinogradova 2006). As Crotty points out, many

Russian NGOs relied on Western aid, which offered them an opportunity to become important political actors (2003). At the same time, foreign aid contributed to the growing detachment of Western-funded NGOs operating in Russia from local constituencies (Crotty 2003). This undermined public support for the third sector, thus slowing the process of civil society development.ⁱⁱ Many Russians started viewing these Western-funded NGOs with great skepticism, accusing them of ignorance and corruption.

This trend played into the hands of Russian President Vladimir Putin, who used it as an opportunity to weaken and gain control of Russia's civil society sector. Since the passage of the 2006 Law on NGOs, the development of Russian civil society has faced significant challenges, especially Western-funded international and Russian NGOs. The majority of outside observers and civil society activists agreed that the new law drastically limited the ability of NGOs to function as independent organisations. In light of these developments, scholars and civil society activists began to speak of a hostile environment for NGOs in Russia and a significant regression in democratisation (Bigg 2005; Marinova 2008; Human Rights Watch 2009). However, Sharon Tennisonⁱⁱⁱ defended the law, arguing that "Russia's not-for-profit sector is in serious need of regulation. It still hasn't developed legal underpinnings to assure transparency of expenditures, operations or founder information - all of which are crucial for societal trust and civil society development" (Fisher 2006). In her view, there were still many opportunities for independent civic activism (Fisher 2006).

Taking this debate and the recent developments in the civil society sector as the starting points for my argument, I assert that, in the last decade, Russia's civil society has grown significantly stronger and more vocal, demonstrating a great potential for social and political mobilisation in the future. Dissatisfied with state policies, Russian citizens started organising within genuine grassroots movements to address various social issues. The majority of participants in these movements were critical of government actions, but did not regard the state as an enemy. Many of these social movements originated online, uniting people of various backgrounds and interests. They have since grown popular and influential, addressing not only social issues but also issues related to the lack of adequate political and social reforms, weak state capacity and corruption in state bureaucracy.

I will illustrate this broad trend by analyzing the origins and development of two volunteer movements, the NGO *Advita* and a volunteer movement formed on the website of a local parents' forum in Saint-Petersburg. The initial goal of these movements was to help the families of children diagnosed with cancer to overcome the everyday psychological, legal and financial difficulties associated with treatment. However, as these movements grew, they could no longer remain apolitical, and began promoting various issues related to health care, calling on people to get involved and demanding health care reform and the passage of effective drug and health care policies.

This recent trend is important, as until recently, the role of civil society in the evolution of the Russian health care system has been largely insignificant. As Diane M. Duffy correctly noted, in the 1990s the Russian health care system lacked any home-grown voluntary organisations beyond those with international connections, such as the Red Cross, the Cancer Society and the Heart Association (41). According to her observations, voluntary contributions were limited to donations from government-owned enterprises (Duffy 1999, 41-2). This meant that the policy agenda was established at the center, with little involvement of civil society and few feedback mechanisms to accommodate people's needs and concerns. In this framework, citizens passively accepted the conditions, or used their own personal resources to obtain what they needed. As Duffy stated in 1999: "A successful health program needs a civil society that sees health care as valuable, a health system responsive to the public's needs, and a political system with adequate leadership skills and motivation to develop and implement a realistic national health plan that will achieve the health outcome goals for the nation. As things currently stand in Russia, all are underdeveloped" (42). In light of this, the recent mobilisation of Russia's civil society in response to the ongoing health care crisis is a socially and politically important development. It indicates that the process of social capital accumulation in Russia is underway, thus instilling some hope for Russia's future.

This article proceeds as follows. In the next section I will explain the overall state of the Russian health care system with particular emphasis on cancer care. I will then discuss the origins and

development of the civil society organisations working in the field of paediatric oncology in Saint-Petersburg and elsewhere in Russia.

Soviet and Post-Soviet Health Care System in Russia: A Brief Overview

To understand the state of health care in contemporary Russia, a brief examination of the Soviet past is required. The Soviet health care system was centralised, hierarchically organised and financed from general government revenues. The Soviet government claimed to provide health services free of charge to the whole population, irrespective of social and economic status. In practice, however, payment for health care services and medicines was common. Some citizens, including patients with communicable and chronic diseases such as tuberculosis, dysentery, diabetes, cancer, schizophrenia etc., and children under one year of age, were exempt from payment for medicine. Others, such as WWII invalids and persons receiving a personal pension, were offered reductions in the cost of prescribed medicines; however, all other patients were expected to pay for medicine (Winkelmann et al. 1998, 16).

The organisation of the Soviet health care system was developed and monitored by the Ministry of Health, which was responsible for the planning and control of all public health activities including assessing the state of health of the people, setting national health standards, determining population's need of medical care, medical equipment and pharmaceuticals, and conducting medical research and training (Winkelmann et al. 1998, 16).

In the Soviet Union, the first contact for a person with symptoms was the general practitioner in a local polyclinic. If cancer was suspected, the patient was referred to the district hospital for diagnosis, where the district oncologist performed clinical diagnosis of malignant and non-malignant neoplasms, and, if needed, referred the patient to the regional oncological dispensary for specialised diagnosis and treatment (Winkelmann et al. 1998, 22). The oncological dispensary was responsible for exact diagnosis and treatment of cancer. Each oblast and republic had at least one oncological dispensary, which consisted of an outpatient department and an inpatient facility of some 200-300 beds (Winkelmann et al. 1998, 22-3). Specialised departments included radiology, chemotherapy, surgery, X-ray, and others. For diagnosis and treatment of difficult tumours, such as a tumour of an eye, patients were referred to specialised institutions at the federal level such as the Institute of Oncology or to clinics attached to research institutes (Winkelmann et al. 1998, 22-3). After treatment, follow-up was provided by the local district hospital outpatient department.

In principle, the Soviet cancer care system looked quite comprehensive: the vertical system was meant to ensure that everyone, even in remote parts of the Soviet Union, had access to an oncologist. This, together with a great supply of hospital beds and free medicine provided to cancer patients at the state's expense, was meant to illustrate the comprehensiveness of the Soviet health care system, and cancer care system specifically.

In practice, however, the picture looked gloomier. Low salaries and absence of incentives, as well as the low quality of free medical services, contributed to the rise of corruption and bribery (Ryan 1989, 19-35; Winkelmann et al. 1998, 15). In addition, the low quality of pharmaceuticals, insufficient medical equipment and poor maintenance of health care facilities significantly undermined the quality of cancer care in the Soviet Union. The official cancer statistics were imprecise and never publicly revealed; however, rough estimates showed that in the Soviet Union the survival rate for children with leukemia or lymphomas did not exceed five to ten percent (Artemenko 2006; Molchanova and Maschan).

With the collapse of the Soviet Union, a period of radical economic and political reforms began. The liberalisation process saw sweeping reforms in the social security, education and health care sectors. Health care reform began as early as 1991, when the Yeltsin government initiated mandatory and voluntary health insurance programs and introduced a special tax to fund the mandatory component. The compulsory medical insurance covered the essential minimum medical services, while the voluntary portion covered all other expenses (Tishchenko and Yudin 2008). The government decentralised the health care sector and shifted a large portion of state expenditures to the regional level, including those for paramedics, medication, primary health clinics, hospitals and diagnostic centers (Duffy 1999, 28). All

other functions such as control of salaries and the responsibility for health promotion and oversight were left within the jurisdiction of the Federal Ministry of Health and Social Protection. These changes resulted in significant decentralisation of the Russian health care system with responsibilities shared between several regional and federal institutions.

The reassignment of the financing of health care programs to the regional level contributed to a dramatic decline in their quality. Poor regions lacked sufficient financial resources, and were unable to provide an adequate level of health care to its residents. Fiscal transfers from the federal government helped little due to their small size and irregularity. As a result, shortages of every kind of resource were dramatic. Bed sheets, bandages, food, soap, medicine, and even medical equipment often had to be purchased and delivered to the hospital by the patient or his/her relatives. Fundamentally, it meant that the quality of public health care and access to the public health care system were becoming increasingly unequal.

The crisis also affected medical personnel. Strikes and demonstrations by hungry health care providers were widespread through all of the 1990s (Tishchenko and Yudin 2008). Those who could leave, left the state-run health care sector to set up private medical clinics. Dental, gynaecological, eye, beauty and other private clinics sprang up across Russia, offering those Russian citizens who were in a position to pay for health care services some choice when choosing a health care provider. At the same time, the commercialisation of the Russian health care sector contributed to greater stratification of Russian society and, inadvertently, lowered standards of medical care in state-run polyclinics and hospitals, as many doctors left for better paid positions in the private sector. In short, the health care reform launched in the context of a deep economic crisis contributed to the worsening of the situation in the state-run health care sector and furthered the commercialisation of health care provision. All these changes had a profound impact on the Russian cancer care system.

Cancer Care in Russia: Institutional Structure, Trends and Problems

The collapse of communism, the economic crisis and the subsequent health care reform left a controversial imprint on Russia's cancer care system. On the positive side, closer collaboration with the West allowed Russian oncologists to learn from their Western colleagues. By following the more effective Western chemotherapeutic protocols, Russian oncologists were able to improve cancer treatment and hence raise the survival rate for cancer patients to roughly 50 per cent (Molchanova and Maschan). While better than under communism, these figures nonetheless did not match the effectiveness of cancer treatment for children in the West, where the survival rate usually exceeds 80 per cent (Molchanova and Maschan).

By all other indicators, the situation in fact turned out for the worse. The health care reform launched in 1991 did not alter the old Soviet system of cancer care, but added additional problems. Already plagued by Soviet legacies such as poorly paid medical personnel and low quality pharmaceuticals and health care services, the Russian cancer care system was faced with a number of new challenges such as inadequate financing and rapidly deteriorating provision of cancer care. Insufficient funding and fiscal decentralisation resulted in shortages of medicine in hospitals, outdated medical equipment, poor maintenance of health care facilities and poor sanitary conditions. Regional governments found it extremely difficult to finance and maintain their hospitals and medical facilities, update their medical equipment, and provide hospitals and their populations with free medicines. Even hospitals and research institutes funded from the federal budget were in need of renovation and experienced shortages of medicine and medical equipment. Finally, the poor organisation of cancer care provision has significantly complicated access to treatment and essential cancer care services for ordinary Russians.

Officially, cancer treatment was included in the compulsory insurance program, which meant that all costs of cancer treatment were to be borne by the state. The reality, however, was different. Upon admission to a hospital, a patient and his/her parents usually faced a number of problems, including the catastrophic shortages of state-funded medicines. Many chemotherapy medications were simply unavailable in hospitals, thus leaving the Russian cancer patients – and in our case, parents of sick

children – no choice but to seek money elsewhere. Virtually no oncology center in Russia was spared. Regional cancer centers as well as such top oncology centers as the Russian Children’s Clinical Hospital (RDKB) in Moscow, the Oncological Research Institute and the Raisa Gorbacheva Institute for Paediatric Haematology and Transplantology in Saint-Petersburg faced shortages of required medicines (‘Leading Russian Oncology Center Faces Shortage of Medicine’ 2008). As a result, parents and relatives of children were forced to seek funds and buy the required medicines themselves. The situation was so dramatic that in some instances, shortages of medicine or delivery delays forced doctors to appeal to the general public in search of urgent help and financial assistance (‘Help Us Save the Children’ 2005).

The quality of cancer care was further compromised by the fact that the government did not cover the costs of several additional vitally important drugs such as the drugs required in the pre- and post-chemotherapy periods, including the anti-fungal drugs Ampholip, Cancidas, and Vifend (‘Important information about the financing of paediatric medicine in Russia’). These medications helped the patients cope with severe infectious complications, which often occurred as a result of low immunity of children after chemotherapy, poor sanitary conditions in many Russian cancer centers, or both. Of note, most of these hospital infections are fatal if not treated in time, and many of them resist treatment with ordinary drugs, which is why doctors often prescribe children advanced, last-generation antibacterial, antiviral, and especially anti-fungal medicines. These medications are very expensive, and the entire course of treatment with these drugs usually lasts several weeks or even months, forcing families of cancer stricken children to spend many thousands of dollars on these medications.^{iv}

The children, whose parents cannot buy these expensive drugs, have to be satisfied with cheaper medicines, officially supplied by the state. The problem is not only that these drugs are extremely toxic and considerably less efficient in fighting complications, but that their supply is also interrupted (‘Important information about the financing of paediatric medicine in Russia’). In such cases, the parents must pay for these drugs themselves, and it often turns out that they cannot raise even these smaller sums.

The situation is further complicated by the fact that the government does not cover the costs of some important diagnostic and auxiliary procedures such as magnetic resonance imaging (MRI) and computerised axial tomography (CT) scans, some laboratory tests, etc. necessary for the successful treatment of the disease (‘Important information about the financing of paediatric medicine in Russia’). The costs of these procedures are usually borne by the families. Finally, due to a chronic shortage of blood in Russian hospitals, relatives of patients are forced to buy blood in other hospitals and/or seek blood donors, often offering them additional payment on top of that paid by the state. In some cases, the medical staff have no alternative but to give their own blood to patients (Arkus 2005).

The situation of families whose children are referred to national cancer care centers in Moscow or Saint-Petersburg because of the complexity and aggressiveness of their disease is even more alarming. In such families, mothers usually leave their jobs and relocate with their children. As for the fathers, many cannot bear the difficulties and break down, often leaving their families. Even those who make a concerted effort to secure the necessary funds seldom succeed if the family comes from a poor region. Quite often these families sell their apartments or houses to cover the costs of expensive drugs or treatments such as bone marrow transplantation. During the months-long stay at the hospital, these families exhaust their means to such an extent that even buying food and clothes becomes a real problem. With shortages of medicines common even in top cancer centers, these families usually require financial assistance.

For many children with complex and aggressive forms of leukemia, lymphoma, etc., the only hope for survival is bone marrow transplantation (BMT). Exact data on the number of patients, children in particular, requiring bone marrow transplants in Russia on an annual basis are hard to obtain. Estimates vary, with *Advita* Fund USA suggesting that there are about 7,500 patients in Russia who need bone marrow transplantations every year (‘Why do bone marrow transplant patients need your help?’). According to the Russian news channel “Russia Today,” each year there are at least 1500 Russian children who need bone marrow transplants (‘Russia’s cancer children struggle for much-needed treatment’). What these numbers indicate is that, even in the most optimistic scenario, each year there are up to two thousand Russian children requiring bone marrow transplants. These numbers do not include

patients from post-Soviet republics, who, due to the lack of qualified doctors and medical equipment in their home countries, are forced to seek help abroad, primarily in Russia.

There are, however, only four major bone marrow transplantation centers located in Moscow and Saint-Petersburg which accept patients from all of Russia and abroad. Together, these four centers have the capacity to perform up to 400 transplantations per year ('Why do bone marrow transplant patients need your help?'). Other haematological centers exist in Novosibirsk and Yekaterinburg, but they offer only autologous transplantations.^v Lengthy waiting lists mean that it often takes months before transplantation to one or another patient can be made, but BMT must often be performed quickly and without delay if the disease is especially aggressive and there is a danger of relapse. There have been several tragic cases of Russian children dying while waiting for the transplantation, even though a donor had already been found and funds, with the help of private sponsors, had been raised ('Important information about the financing of paediatric medicine in Russia').

The approximate total cost of each transplantation conducted in Russia is \$60,000-80,000, with the Russian government covering only part of the sum. Among the costs not covered by the Russian state are for example the search and delivery of bone marrow donations to Russia. Problematic is that only about 20 percent of children with cancer in Russia have suitable donors of bone marrow among parents or siblings, meaning that the majority of children must have transplantations from unrelated donors, usually found in a marrow donor registry according to immunological compatibility of tissues (Arkus 2005). But Russia has no marrow donor bank of its own, which means that the search for an unrelated donor must be performed in foreign registries, such as that of Stefan Morsch Stiftung in Germany. The cost of a donor search in such a registry is about 15,000-17,000 euro (Arkus 2005). As mentioned, this money is not granted by the state and must be donated by private sponsors.

The issue has been red-flagged by civil society organisations in Moscow and Saint-Petersburg, which have set up a number of autonomous bone marrow registries in Russia (Arkus 2005). However, as Professor Fregatova states:

All these databases are not connected to each other. And thus, we cannot speak about having a viable organisation. A bone marrow register is, in the first place, an organisation operating according to specific legal rules and procedures. In Russia, none of the problems associated with such transplantations has been addressed so far. Donors don't have a legal opportunity to insure their lives or be paid for their service. Transportation of transplant material across the Russian border is equally a grey and legally unregulated area (Arkus 2005).

In contrast to other countries, where all aspects of bone marrow transplantation are regulated and financed by the state, in Russia the role of the state in solving these problems is minimal.

Some Russian patients with cancer need treatment abroad, due mainly either to unique treatment procedures that are already used in foreign hospitals but not yet available in Russia, or simply the shortage of hospital beds in Russian cancer centers. In such situations, the only way to better a child's chance for survival is to send him or her abroad for the transplantation, which obviously raises the cost of treatment. A bone marrow transplantation in Israel, which is one of the most affordable options, costs over \$100,000 for each patient ('Important information about the financing of paediatric medicine in Russia'). The Russian Ministry of Public Health usually provides two-thirds of the required sum if the child falls within the so-called quota for life-saving treatment abroad, but one-third must be raised by the patient's family. In other cases, the child's family must raise the whole sum. Without private sponsorship, it is usually impossible.

In short, the provision of effective cancer treatment in Russia is complicated due to several problems that have, for decades, affected the existing cancer care system. First, there is a pressing shortage of hospital beds in Russia's cancer centers, especially for transplants. As well, the majority of the existing cancer centers are in need of regular maintenance and new medical equipment. Second, the legal base of the existing cancer care system does not accommodate the needs of cancer patients. In particular, there is an urgent need to update the existing list of state-funded medicines with new, vital

medications, without which the successful treatment of cancer is virtually impossible. Further, the government should increase the number of state quotas issued for treatment of cancer patients and simplify the application process for receiving a state quota. It should also raise the nominal value of such quotas to cover the expenses associated with cancer treatment, including bone marrow transplantations. Likewise, the Russian government should invest in creating a national register of bone marrow donors and formulate a clear legal base, which would regulate the search and transport of bone marrow transplants as well as address and protect the interests of donors and recipients.

Finally, there is the issue of terminally ill patients. Russian law does not contain any reference to providing adequate palliative care to such patients, and the Russian health care system is lacking in medical personnel qualified to treat such patients: currently, Russia has no stationary paediatric hospices for cancer patients. While mobile paediatric hospices exist, the range of their medical services is limited as their personnel often lacks professional training in palliative care and are unauthorised to prescribe narcotic painkillers to such patients. As a result, parents of terminally ill children are often forced to buy narcotics from illicit sources.

To address these problems, many Russian citizens have joined grassroots movements. In the beginning, the majority of these civic movements did not have any political influence or access to any regular funding, relying instead on individual donations from ordinary citizens. However, as these movements grew, their financial situation improved. Moreover, their growing popularity has allowed them to address the problem at the national level, thus spreading public awareness and pressuring the government to respond. Arguably, with the growth of the internet and other communication technologies, the popularity of such movements will only increase. In my opinion, the development of such grassroots movements is one of the key preconditions for the emergence of a strong civil society and further democratisation and liberalisation in Russia. I will illustrate this trend by discussing two volunteer movements in Saint-Petersburg, and proceed to situate this trend within the broader Russian context.

Accumulation of Social Capital and the Birth of Genuine Civil Society in Russia

Among the first movements supporting families of children with cancer in Saint-Petersburg was a local movement *Advita*, started by a software engineer who lost a friend to cancer, and a group of Russian oncologists from Saint-Petersburg. *Advita* was registered as a charity in 2002. *Advita* sees its mission as assisting families affected by cancer to bear the costs of treatment, to raise funds for the procurement of medicines and medical equipment, and to provide families and patients with legal, psychological and social help during pre- and post-operative periods. *Advita's* ultimate goal is to reduce the mortality rate among Russian citizens suffering from various types of cancer and blood disorders, to draw public attention to the necessity of developing a Russian Bone Marrow Registry, and to enhance the qualifications and practical experience of Russian haematologists, oncologists and transplantologists (*Advita*, http://advita.org/en/f_ustav.php).

Advita's staff consists of only five permanent employees, who are responsible for running the 24/7 blood donor call center and for some basic administrative work. The majority of *Advita* members are unpaid volunteers. Currently, *Advita* has between 100 and 150 permanent volunteers (Tikhomirova 2010; Elena Gracheva, pers. comm.). The volunteers come from a wide variety of social backgrounds and an extensive age range. They include men and women, young and old, rich and poor, and people from different professions and of different nationalities (Elena Gracheva, pers. comm.).

Some of these volunteers are responsible for maintaining and updating the *Advita* website, posting updates on internet-based social networks, communicating with the media, advocating for blood donations, and organising various social events aimed at raising funds and public awareness of the problems faced by cancer patients. Other volunteers are assisting the families of sick children by playing with children, helping families purchase food and clothes, searching for required medications, and assisting in dealing with the bureaucracy of various health care departments. These are the people who assist families in overcoming their everyday social, bureaucratic, psychological and financial problems (Tikhomirova 2010; Elena Gracheva, pers. comm.).

One should also mention the thousands of donors who donate money and blood, viewing it as their civic duty. According to Elena Gracheva, an active *Advita* volunteer and coordinator, the majority of donors are from poor and low middle income families – students, pensioners, women and disabled people regularly donate between 100 and 500 rubles (Elena Gracheva, pers. comm.). It is they who allow *Advita* to buy medicine, food and rent housing for the patients and their families. However, Gracheva also notes that during the last few years, more people from other societal groups have become interested in volunteer work and in giving donations. Engineers, lawyers, journalists and businessmen contact Gracheva and tell her that they want to participate (Elena Gracheva, pers. comm.).

A particularly interesting group of people actively participating in *Advita*'s work are Russian-speaking volunteers living abroad.^{vi} These people are usually responsible for translating Russian texts into English, German, and French, and maintaining the foreign versions of the main website. These volunteers assist patients and their families when they arrive for treatment in Germany, Israel, the US and other countries. It is these volunteers who buy medicine at lower prices abroad, arrange for its transportation to Russia and donate thousands of dollars annually.

As the number of volunteers grew, *Advita*'s popularity increased. This new popularity also led to a growth in their database of sick children. As more families from all over Russia began contacting *Advita* with their concerns, desperation among volunteers grew. A realisation was growing that only fundamental changes to the overall system of cancer care provision could alleviate this health care crisis. In response to their growing popularity, some *Advita* volunteers switched from aid provision to advocacy-related activity. In cooperation with other volunteer movements, *Advita* made an attempt to highlight various issues related to cancer care in newspapers, on television and in their conversations with regional and federal authorities, pushing for changes to current legislation regulating cancer care and drug policies. The work of *Advita* and several other NGOs working in this field was noticed by the government. This resulted in a series of meetings and roundtables with state authorities on issues related to cancer care in Russia.

In February 2009, *Advita*, *Podari Zhizn'* (Grant Life) and several other NGOs met to discuss the most urgent problems and possible solutions in the field of cancer care in Russia ('V Moskve obsudiat'; 'Osnovnye problemy detskoi onkologii'). Also in attendance were representatives from the Ministry of Health and Social Protection of the Russian Federation. Three main topics were addressed at the meeting. First, civil society activists discussed the existing quota system regulating the provision of cancer care in the top oncology centers. The volunteers emphasised the ineffectiveness of this system, which offered the regional health departments and the Republican Ministries of Health relative freedom in determining and requesting the required number of quotas from the Ministry of Health and Social Protection. The result of this system was that children from dozens of regions could not receive chemotherapy and bone marrow transplantation in time, because their regions did not apply for (or receive) a sufficient number of quotas. Waiting lists for receiving quotas (and hence, treatment) were frighteningly long, leaving parents no choice but to look for alternative places for treatment, usually abroad. In light of this situation, the Russian Ministry of Health and Social Protection was asked to review and improve the existing system of quotas and to better equip the regional cancer centers, so as to minimise the number of patients having to travel to Saint-Petersburg or Moscow ('Osnovnye problemy detskoi onkologii').

The second issue discussed at the meeting was the problem of what are known as orphan drugs.^{vii} As mentioned earlier, there are a number of vitally important drugs that are prescribed by oncologists, even though the drugs are not registered in Russia. In the majority of cases, such drugs are taken into the country illegally with the help of volunteers, friends and relatives living abroad. Abandoned by the state, people collect money, seek opportunities to buy drugs at cheaper prices, and look for people willing to smuggle these drugs into the country. NGOs called on the Ministry of Health and Social Protection to pass changes to the current legislation, introducing the concept of orphan drugs and formally regulating their transportation and distribution in the Russian Federation ('Osnovnye problemy detskoi onkologii').

The third problem discussed at the meeting was related to the issue of palliative care. Russia does not have a system of paediatric palliative care to assist children who are in the terminal stages of cancer. Such children are most often discharged from cancer centers and sent home, where their parents face the

horrible reality of not being able to provide adequate palliative care ('Osnovnye problemy detskoi onkologii'). The Russian volunteers called on the Russian authorities to address this issue and to change current legislation.

The dialogue between the third sector and the government looked quite promising; however, solving these problems turned out to be an extremely complicated and exhausting process. Many civil society organisations are jointly lobbying the regional and federal authorities to change the legislation regulating palliative care and circulation of narcotic-containing drugs in Russia.^{viii} The difficulty in modifying the existing system of palliative care stems from an overlap in Russian legislation regulating the circulation of narcotic drugs. Whereas the Ministry of Health and Social Protection allows the prescribing of narcotic-containing drugs in palliative care, a federal law regulating their use in the Russian Federation grants the authority to issue such prescriptions only to those hospitals and clinics which meet the prescribed security requirements (i.e. walls should be of particular thickness, windows should be grilled, etc.). In an effort to resolve this problem, the NGOs proposed selecting a number of polyclinics that satisfy the prescribed security requirements imposed by the government. These polyclinics could receive the authorisation to issue prescriptions for narcotic-containing drugs to all patients from a particular region. These polyclinics would also have their own emergency ambulances ('Saint-Petersburg. Kruglyi stol'). A concrete example of such a polyclinic is the ongoing construction of the first children's hospice in Saint-Petersburg, with *Advita* volunteers overseeing the process and reporting on it to the broader community ('Detskii khospis. Dolzhen byt').

With regards to orphan drugs, little progress has been made. However, civic groups continue to lobby the government in the hope that changes to the recently passed legislation will be made. During preparation of the pharmaceutical market bill in 2009, several Russian NGOs including *Advita* appealed to the government to make provisions for orphan drugs in terms of introducing a financing, licensing, and procurement mechanism (Sesay 2010). Thousands signed the petition ("Pod obrachsheniem za legalizatsiiu"). Nonetheless, the bill, passed on 31 March 2010, did not contain any mention of orphan drugs, even though some minor changes were made. For example, the new bill simplified the import of drugs not licensed in Russia. Russian patients and their relatives no longer need to secure special permission to import the drugs into Russia. Instead, the buyer will receive an electronic document containing a digital signature, allowing him/her to import the drug. Finally, all drugs imported to Russia for personal use will be cleared within five days. However, the bill failed to address major issues such as financing. Civil society groups reacted by organising and drafting another petition, this time addressed to the President of the Russian Federation Dmitrii Medvedev, requesting the legalisation of orphan drugs and simplification of their registration and transportation. More than 50 NGOs and grassroots movements called on the President to amend the bill ('Obrachshenie k Prezidentu'; Telegina and Rudnitskaia 2010).

It is no exaggeration to state that these activities would not be possible without the help of the internet. The role of the internet in the development of Russian civil society is indisputable in that it offered people the chance to find and participate in communities of interest, thus empowering the masses and strengthening the bonds of the civic community. This is evident in my next example discussing the origins and evolution of one local internet forum in Saint-Petersburg.

The website *littleone.ru* was developed by one young mother from Saint-Petersburg in 2000. Interested in communicating with other young parents, she created a website where she could meet other mothers and discuss issues related to children and family. Being the first such family-oriented website in Saint-Petersburg, *littleone.ru* quickly became popular ('Vtoroi rebenok'). Here the first local help forum was created, where people could volunteer and join various grassroots initiatives. As the number of topics grew, volunteers organised into groups that addressed various themes, including orphaned children, abandoned elderly citizens, oncology patients, etc. Often, citizens participated in several groups, spending time with orphans in orphanages or pensioners in retirement homes. Some topics on the forum list were temporary and appeared in response to some tragic events and situations, such as the 2004 Beslan tragedy, after which many Saint-Petersburg residents invited children and their parents from North Ossetia to visit Saint-Petersburg. Other topics such as "Cancer center of the 31st City Hospital" became permanent, with

thousands of people contributing their time, money and energy to assist children and their families during a difficult period in their lives ('Detskoe otdelenie 31-oi GB').

In short, having started as two small grassroots movements, *Advita* and *littleone.ru* have developed into powerful voices, capable of raising social issues at the regional and federal levels. They are not alone in their work. Several other NGOs and voluntary movements are working in the same field and collaborating with each other on various issues related to cancer care. For example, in Saint-Petersburg, the oldest NGO assisting cancer patients is the regional non-governmental organisation *Children and Parents Against Cancer*, which was created in 1998 (*Children and Parents Against Cancer*, http://www.capac.ru/index_e.htm). Since its inception, the organisation has evolved into one of the most influential voices for the rights of sick children in Russia. Likewise, in Moscow, volunteer movements including *Donors For Kids*, *Happy World*, *Nastenka Fund*, *They Believe*, *Podari Zhizn'* and many others have emerged over the past ten years.^{ix}

To raise public awareness of the problem, many NGOs and voluntary movements draw on support of Russian celebrities. An example is the case of respected actress, Chulpan Khamatova (Krasnopolska 2009). Khamatova became involved in charity work several years ago when the deputy director of the top oncology center in Moscow appealed to her for help, which is how *Podari Zhizn'*, a foundation to help children with cancer and other life-threatening illnesses, came into being. Today *Podari Zhizn'* is one of Russia's most successful fundraising organisations, raising nearly 7 million dollars annually, the bulk of which comes from individuals (Krasnopolska 2009).

Soon after, a wave of civic activism swept across Russian cities, from which hundreds of civic initiative groups emerged.^x The majority of these grassroots initiatives were aimed at solving various social problems that the country faced, including the plight of Russia's disabled and chronically-ill people, the elderly, homeless, and orphaned and/or abandoned children. Some grassroots initiatives grew into national civic movements, with multiple branches in several Russian regions. One of these grassroots movements, which quickly became popular throughout Russia, was the movement *Starost' v Radost'* [The Joy of Aging], founded by one young student from Moscow (*Starost' v Radost'*). Having started as a tiny civic initiative to help the elderly in Russia's seniors' homes, the movement quickly attracted many volunteers throughout Russia. It now patronises more than 50 seniors' homes in eleven Russian regions (*Starost' v Radost'*). Another notable example includes the all-Russian charity fund known as *Spravedlivaia Pomochsh* [Just Help] set up by a Russian doctor Elizaveta Glinka or the national movement *Otkazniki* [The Abandoned], which helps Russia's orphans ('Elizaveta Glinka. Biograficheskaia Spravka'; *Otkazniki.ru*). With time, cooperation among NGOs and volunteer movements increased. Websites emerged which collected and organised information about volunteer movements and NGOs working on specific issues across Russia and other post-Soviet republics.^{xi}

The outlook is quite promising: the work of the volunteers has inspired many ordinary people; Russians continue to join volunteer movements in growing numbers. Among the most recent events, which drew thousands of volunteers throughout the country, were the summer fires in Central Russia. Most of the volunteers were young urban dwellers driven by a genuine desire to help (Smirnov 2010; Faustova 2010; Baskakova 2010). Arguably, this trend illustrates the progress in the process of civil society development and social capital accumulation in Russia, which are indispensable components for successful re-democratisation and democratic consolidation.

Concluding Remarks on the Prospects of Civil Society Development in Russia

The importance of civic engagement and volunteerism in a democracy has been acknowledged by a number of authors (Almond and Verba 1989; Putnam 1993). Putnam, for example, argued that successful democratic government was only possible in societies marked by the active participation of its citizens in public affairs (Putnam 1993, 87). In such societies, a civic equilibrium was attainable in which "social trust, norms of reciprocity, networks of civic engagement, and successful cooperation [were] mutually reinforcing", thus raising the quality of democratic performance altogether (Putnam 1993, 180). In other words, Putnam suggested that the quality of democratic performance was positively related to the quantity

of social capital accumulated by members of a civic community over a substantial number of years (Putnam 1993).

Agreeing with Putnam on the importance of civic engagement and voluntarism in a democracy, this article demonstrated that even though Russia started its post-Soviet history as a country with relatively weak civil society, it is currently showing some signs of civic revival. What is interesting is that this burst of civic activism occurred in a political environment unfavourable to the development of an independent civil society. Critical of government actions, the Russian people started organising in various volunteer movements to address Russia's social and health care problems. This rapidly spreading mass grassroots activity suggests that the process of social capital accumulation and civil society development in Russia is underway, thus instilling some hope in Russia's future.

Even though the current level of civic engagement in Russia is still small-scale compared to the Western world, the recent trend suggests that civic activism and volunteer work are becoming more and more popular in Russia, even in remote parts of Russia such as the Altai region. The work of these volunteers inspires others. It motivates people to join or start various grassroots initiatives in their communities. Moreover, it forces the government to react to societal pressure, and collaborate with various grassroots movements in an attempt to solve Russia's urgent social problems. As of now, there are no signs that the process of civic mobilisation in Russia will slow down, thus allowing me to speak positively about Russia's future.

NOTES

ⁱ Claire Mercer (2002) provides a succinct overview of the literature on NGOs, civil society and democratisation.

ⁱⁱ This situation is not uniquely post-Soviet. According to Mercer (2002), the difficulties faced by the NGOs in Latin American, Asian or African countries were the consequence of their reliance on foreign funding and, as a result, their growing detachment from local communities.

ⁱⁱⁱ Sharon Tennison is the head of a Moscow-based NGO, *the Centre for Citizen Initiatives*.

^{iv} For example, an average price of one pack containing 14 capsules of Vifend, a vital anti-fungal drug, is over \$1000 per pack; a vial of Ampholip costs more than \$200; and a cost of one vial of Cancidas amounts to \$600. Refer to The Donors-for-Kids Group, 'Important information about the financing of pediatric medicine in Russia'.

^v In an autologous stem cell transplant, stem cells from the patient's own marrow are "harvested", stored and then returned to the body (engrafted) after the patient receives high doses of chemotherapy and/or radiotherapy conditioning therapy. Lymphomation.Org, <http://www.lymphomation.org/bmt-auto.htm>

^{vi} Read, for example, the stories of the volunteers at Advita Fund USA, 'Who we are', http://www.advitausa.org/?page_id=345, (last access: 13 January 2011).

^{vii} An orphan drug is a drug that is used to treat a rare disease that affects only a limited number of people. To date, the orphan drug legislation has been successfully developed in many developed countries, with Russia lagging behind.

^{viii} Review, for example, 'Fond Advita napravila predlozheniia glavnomu onkologu', 'Detskii khospis. Dolzhen byt'', 'Neizlechimo bol'nye deti zhdut otkrytiia khospisa i pomochshi metsenatov', 'Saint-Petersburg. Kruglyi stol 'Khospisy Peterburga'.'

^{ix} There are several organisations active in the field of children oncology. To name a few, review the websites of the following organisations: *Donors-for-Kids Group*, *Happy World*, *They Believe*, *Podari Zhizn'*, *Nastenka Fund*.

^x A list of selected volunteer movements and NGOs can be found at *Vsem Mirom*, <http://www.vsem-mirom.narod.ru/together/orgki2.htm>.

^{xi} See, for example, the websites of the volunteer movements *Blago* and *Vse Vmeste*.

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