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Alexandra Endaltseva

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**Chapter 12: Communication and health knowledge production in contemporary Russia:
from institutional structures to intuitive ecosystems**

by

Alexandra Endaltseva

(L'École des hautes études en sciences sociales (EHESS)\ Higher School of Economics,
Department of integrated communications)

Introduction

This chapter describes the shades and composites of health communication in the Russian Federation, which could be called a procedural block of health knowledge production, because the term “health communication,” which was invented in the Western parts of the globe, is barely compatible with Russian realities. In Russia (as in any organized human structure, from a tribe to a sophisticated nation-state), Carol Hanisch’s (2000) “the personal is the political” did not spare such an intimate and emotional topic as health. Both in its biological and social meanings, health, despite arduous attempts to assign it individual properties, is comprised of state regulations, international economic structures, business strategies, ontological norms, social and cultural institutions, popular myths, and communication,. Therefore, the manner in which we communicate health reveals quite a bit about our histories, realities, discourses, and ways of knowing. This chapter portrays how health is produced and communicated in contemporary Russia, by questioning its relation to the dominant health communication discourse; by tracing the transformations of health economics models; and, finally, by presenting an infrastructure of what could be characterized as down-to-top “health communication” in Russia.

When it comes to health, who is the communicator?

Health has gone global. And so have health communication objectives, scholarship, and practice—although “global” here means an attempt to translate models that were created in the developed Western countries into the contexts in which health communication is not recognized by the financial support-giving bodies. The search for epistemological status and disciplinary identities of health communication (Hannawa et al., 2015) questions the nature of research objects and interdisciplinary links. Health communication can be characterized as a system of human interactions, both face-to-face and mediated, within a health-related context. The practices of health communication have been linked to the emergence and reinforcement of social structures and to the production and reproduction of the social meanings of health, illness, and disease. These practices expose and articulate the relationship among biomedical objectives, sociocultural contexts, material and symbolic productions, and internal subjective sense-making in health-related contexts (Banks & Riley, 1993; Sharf & Vanderford, 2003). However, health communication has been primarily explored on the basis of those nation-states that have the financial and institutional support for its research and industry implementation (Parrish-Sprowl, 2009). Russia is not present in this list (the reasons will be discussed in this chapter). Therefore, following Craig’s (1999) argument that communication constitutes a practical theory or, in other words, a discursive theoretical field evoking from praxis and contributing back to the practical discourse, I propose that the situation in Russia is an opening window for critically interrogating the field of health communication per se.

In addition, the dominant reading of health communication does not include non-human entities, for example, medicaments, assistive technology, diagnostic equipment, city infrastructures, that disregard the contexts that have a shortage of these non-human media and actors. In the early 2000s, Ratzan (2001) observed that, “today people, governments and the state

interact in ways that affect health.... Health can be fully recognized as an essential component of global civil society” (p. 208), which translates health communication as a science-and-art partnership among the public, policy makers, and business sector. Nine years later, Ratzan clarified that this partnership should also be governed by “ethical employment of persuasive means for health decision making” in “public relations, advocacy, negotiation, and social marketing” (Ratzan, 2010, p.3). This clarification is becoming relevant in contemporary Russia, which has begun to recover from its post-Soviet transition (at least, in the developed urban areas) and to expand professional communication attention toward dialogues with “power”, patient-provider relations, and public health communication programs, thus forming unique intuitive health communication structures and infrastructures.

Assuming that an understanding of health communication approaches is particularly important in the attempts of global health agents to address the challenges of global mobilization and collective response to health crises (Obregon and Waisbord, 2012), this chapter invites readers to ponder the questions: who is the communicator in health communication theories and practice; whose interest health communication should serve; and what is the benefit of the visibility and invisibility of communicators and their interests in the region in which health communication is not institutionalized?

Foundations of Russian health communication: reforms, the reformers, and the reformed

The Russian Federation has overcome many systemic reforms in the healthcare sector since the collapse of the Soviet Union and its centralized Soviet Semashko public healthcare model. All of these reforms have been directed at the shift toward the mixed insurance-based healthcare provision that maintains the constitutional right to free healthcare and is driven by the socio-economic and political crises in the region. This shift has been performed in the ambiance

of the continuous decline of life expectancy in Eastern Europe in the late 20th century, an unprecedented case in the history of global health in which highly industrialized nations during this peacetime have experienced rapid health deterioration despite the “health for all” motto of socialist regimes (Cockerham, 2002). In other words, the implementation of this new system was accompanied in this region by a major socio-economic crisis, the socio-cultural trauma of “lost generation”, the increase in crime levels, and the shock economic policies. The new state has inherited a broad infrastructure of institutions and staff that committed to universal access to care; however, this heritage has appeared to be (and remains) a burden rather than an asset. Additionally, in accordance with the uncertainty reduction theory (Berger & Calabrese, 1975) and other behavioral studies, the lack of information about how the healthcare system functions has resulted in a more cautious behavior within this system and more questions about the reasonability of the system, which can count for the socio-cultural reason of public distrust in Russian reforms.

During the crisis of the 1990s, hospitals tended to use manipulating debts and barter to overcome lack of funding (Gordeev, Pavlova & Groot, 2011; Twigg, 1999). According to Shishkin and Vlasov (2009), the lack of governmental guarantees and poor health throughout the population, accompanied by low salaries in the state hospitals and insufficient use of the available governmental resources, are the main issues in the current state of healthcare in the Russian Federation. Gordeev, Pavlova & Groot (2011) also note poor management, the impossibility of competition due to a vertical political system, and the resistance to changes from the physicians and medical personnel. All of the above-mentioned premises indicate the absence of explanatory, let alone persuasive, communication of the reforms in the healthcare sector. Thus, health knowledge production in contemporary Russia is based on the sense of lost

paradise, of betrayed hope for a free democratic society, on the uncertainties, and on the necessity to pioneer innovative ways to achieve one's purposes.

In 1993, a new law implemented a system of compulsory social health insurance (OMS) for all citizens who wished to use public healthcare services (ambulance, out- and in-patient care, and research facilities) throughout all of Russia's regions (Gordeev, Pavlova & Groot, 2011; Twigg, 1999). This initiative was in line with the overall transition toward the free-market system, the deregulation of the state economy, and a decrease of governmental presence in the lives of Russian citizens. During the transition to insurance-based public healthcare, the governmental body in charge of managing OMS, which was named the Federal Compulsory Health Insurance Fund (FFOMS) with 87 (which later was reduced to 83) Territorial Compulsory Health Insurance Funds (TFOMS), collected contributions per region and redistributed these funds to the independent insurance companies that contracted care providers. The revenues for TFOMS and FFOMS derived from the United Social Tax and health premiums for non-working population from the municipalities. As the independent insurance providers entered the market later, TFOMS acted as the insurers and were able to contract any provider, public or private, as long as this was in the interest of the insured patients (Gordeev, Pavlova, & Groot, 2011). This was typical for economies in transition in which former social institutions were replaced by new ones without a strategic plan and material and human resources to manage them. Even with the growing number of private and public insurers, the system did not produce the expected competition and simply redistributed the funds from OMS to the providers. Considering the socio-economic and political instabilities in the region as well as the lack of professional training for the new administrators, high levels of corruption, and passive to negative attitudes among the public, the ineffectiveness of the reforms was quite expected.

All of these factors have affected the results of implemented reforms, which, for example, turned into a decrease in birth rates, high mortality, and a decrease in life expectancy at birth (Cook, 2015); consequently, the poor state of health has led to further reformation of the system up until today. Finally, the perpetual distrust in these social reforms among the population that were carried out as a legacy of transition times co-existed with the absence of competencies in, recognition of, and the budget for health communication on all the levels, from organizational to public relations. This created a gap between the intended objectives of the reforms and the interactions between these reform and the population in need of healthcare.

Apart from the socio-bureaucratic challenges, the new financial forms of health institutions and the growing sector of private healthcare required a change in communication strategies between doctors and patients and healthcare establishments and those who require healthcare. In a state that has been thrown into reforms in every sector of economic, political, and everyday structures, there was no space for the professionalization of communication practices of healthcare professionals or for organizational communication campaigns. The focus of attention has been, not on the standardization of communication practices, but on the articulation of such to overcome the inconsistencies of the new system. Zvonareva et al. (2016) have presented an account of these articulation practices in their article on the international commercial clinical trials in the Russian Federation. Zvonareva et al. (2016) said the health system after the collapse of the Soviet Union was characterized by insecurities, delays in salaries, lack of medical supplies, and the constant search for support from officials and international research grants to keep healthcare afloat. The illiteracy of the post-Soviet population has added to the allure of international clinical trials to Russia, which, despite ethical troublesomeness, gave a larger portion of the population access to healthcare.

Since the 2000s, Russia was no longer a recipient of aid, but had become an aid-donor in the international health arena (Twigg, 2010). After 2007, in the global health arena, Russia has been acquiring, at least on paper, the knowledge and skills of the United Nations Development Program, World Bank, and G-20 (Twigg, 2010); and, on the national scale with a more-or-less stabilized economic strategies under Putin's administration and as a response to a continuous health crisis, a new single TFOMS finance model was introduced that offered a free choice of insurance companies. However, researchers question the effectiveness of this system, especially when the choice of the insurer was mostly made by the employer and the tradition of quasi-formal out-of-pocket and under-the-table payments continued to be prevalent (Gordeev, Pavlova & Groot, 2011; Shishkin & Vlasov, 2009). A part of such systemic failures has been—and continues to be—the lack of communication with the public; inefficient and insufficient funding; low quality of care or care technology; and overall distrust in governmental decision-making.

According to the most recent health reform plan, the amount of federal expenses on health is expected to be as high as 5.2% by 2020; however, according to Shishkin and Vlasov (2009), this initiative may only produce positive results when accompanied by health lifestyle promotion, specific boundaries between paid and unpaid healthcare, and clear standards. I would add to this list by taking seriously the practices of health communication that have reaped positive results in the region; scaling them up; and implementing local evidence-based health communication campaigns in Russian healthcare institutions. Additionally, due to the significant income inequality in Russia, resulting in inequality in access to, costs of, and quality of healthcare between metropolitan cities and regions, we can hardly speak of the possibility of health communication standardization and professionalization.

In the long-term socioeconomic development plan, modernization of the public healthcare system is put on the priority agenda since 2008 (Shishkin & Vlasov, 2009), and, in this modernization process, “patient-oriented medicine” has been the buzzword starting only in 2016. Therefore, the question of what comprises a “patient-oriented medicine”, including the role of professionalization of communication practices and the development of public engagement, is still to be determined. It becomes specifically relevant now, after telemedicine was officially recognized in the legislative documentation at the end of 2017, and the gaps in bioethical standards reappear as a public concern.

Public discontent with the quality of healthcare and the inefficiency of healthcare reforms, together with strong political influences of the Putin administration, economic insecurity, the geopolitical crisis, and budget cuts have resulted in healthy lifestyle promotion by the government to turn the population to self-care (Pautov & Pautova, 2014). This promotion, nevertheless, is not sufficiently accompanied by careful and elaborated communication campaigns, mostly being represented by mass media and in the forms of grants for NGOs and social organizations, including universities and charity funds. However, the maximum size of a presidential grant is 500,000 rubles (about \$8,700 US), which makes public organizations compete for these small allocations to satisfy their visions and needs, rather than to collaborate in joint health communication programs. In contrast, pharmaceutical companies and transnational brands are successfully using this neoliberal trend for their commercial purposes, recruiting public organizations in return for financial support. As a result, the role of a lead communicator in the chain of health knowledge production in Russia is being gradually acquired by patient organizations, a grassroots advocacy movement, which had emerged in the 1990s as a watchdog

on patients' rights and are now mutating as a mediator among the government, healthcare professionals, and the Russian population.

The absence of institutional structures or infrastructures that feed into health communication development in Russia has contributed to the appearance of a peculiar intuitive system of communication in health-related context, in which “grassroots” communication and “grassroots” communication exist in parallel realities, but in search for mediation spaces. The challenge of these emergent mediation entities, therefore, is to reconcile the gap between authoritative initiatives and public decoding of such with abundant pharmaceutical marketing campaigns; elaborate patients' communities (online and offline); municipal festivals promoting public health; growing in popularity of a “healthy lifestyle” movement; shortage of resources in the regional health institutions; tensions between patients and doctors; and never-ending budget optimization reforms that are not sufficiently communicated to the concerned parties.

The plethora of communicating actors, each representing a commitment toward their social worlds with little to no alignment with the strategies of other actors, can be articulated thus:

- Governmental institutions and officials, which exercise the strategies dictated by state policies from budgets allocated to the healthcare field to promote import substitution due to the current geopolitical crisis;
- Patients groups and associations, which aim for a mediator role among the healthcare professionals, the population in need of healthcare, and governmental institutions, with a commitment to patients' rights protection;

- Pharmaceutical industries, which are driven by profit-gaining strategies and which aim for a dialogue with patient communities to secure their client base and research resources;
- Private health institutions or private sectors of public health institutions, which convey a message of easier access to and better quality of care;
- Marketing and public relations firms that are outsourced by the industries, which promote professionalization of health communication practice and aim for the role of mediators between business sectors and the publics;
- NGOs and funds, which provide relief, promote self-care, and act on the discursive grounds of intersection of disability and health;
- Ministry of labor and associated formations, which communicate the intersections of health, work, and disabilities from the governmental decision-makers to the publics;
- Insurance companies, which take advantage of neoliberal trends for profit-seeking strategies;
- Other commercial entities, for example, web platforms, equipment producers, and alternative practices, which promote professionalization of health communication, Western approaches to patient-oriented medicine, and self-care;
- Traditional and alternative medicine, which communicates the link between the uncertainties of the healthcare system, low quality of biomedical care, and self-care as a response;
- Education and research sector, which uses the current situation to communicate the topicality of medical professions, the expansion of the resource base, and adjustment to curricula (teaching how to communicate with patients).

“I am a professional patient, like many of you here....” (co-chair, All-Russian Patients Union, public speech at All-Russian Patient Congress, 2017)

While, in developed Western countries, a movement of patients began to gain power during the beginning of the 20th century, it was not until the end of 1990s in Russia in which several legally registered patient organizations appeared in healthcare. European and American social scientists (Epstein, 1996; 2007; Rabeharisoa et al., 2014; Moreira et al., 2014; Akrich, 2016) discuss the acknowledgement of patients’ organizations in knowledge production in health and chronic illnesses. However, these works do not explicitly discuss communication infrastructure as a building block of knowledge production in the context of continuous reforms, uncertainties, and the lack of consistent information. Moreover, patients’ organizations are among the least-researched areas of Russian society, due to their work’s non-political character and the lack of consolidation within the movement (Krashennikova, 2009). In the making of health communication in contemporary Russia, patient organizations are the most motivated communicators. They commit a vast amount of their work to overcoming or navigating uncertainties in the health economic models; to mediating cross-sectional dialogue among patients, business, and power; and to providing access to trustworthy information in the domain of health. Furthermore, patients’ organizations serve as a buffer that smoothens public and health professionals’ discontent with never-ending neoliberal reforms in the health sector, preventing this discontent from coming onto the streets and expanding into the civil crisis.

Patient organizations began to appear in Russia in the 1990s; since that time, they have evolved in their complexity and in their influence on governmental policies, although they are still under-consolidated (Shirokova, 2012). Today, over 40 public patient organizations are in Russia, 14 (including 80 regional chapters) of which are official members of the All-Russian

Patients' Union, representing the interests of more than 5 million Russian citizens who have chronic illnesses. These numbers do not include pseudo-patient communities, which are arranged and sponsored by pharmaceutical companies around certain types of medicaments—a trend that has jumped on the bandwagon of the rapidly strengthening movement of Russian patients. According to Shirokova (2012), despite the abundance of patients' organizations today, just a few are genuinely in touch with patients and their families and do not simply represent the interests of pharmaceutical companies. To demonstrate that the work of patients' organizations is still at its institutional inception, Shirokova (2012) cited the president (when the article was published) of the All-Russian Association of People with Multiple Sclerosis, Yan Vlasov, who also has served as a co-chair of the All-Russian Patients' Union. Vlasov said the assessment tools for Russian healthcare are still based on economical determinants, rather than on the quality of patients' rights, which challenges the commitments of the patients' movement, especially since it lacks strong leaders and professionals (as cited in Shirokova, 2012).

Russia has two major forms of legal representation of patients' organizations: public organization and public organization of invalids (in which 80 % of the organization should be comprised of invalids and their legal representatives) (Krashennikova, 2009). Today, public patient organizations can be divided into three groups (Shirokova, 2012):

- Associations committed to the legal rights protection (such as The League of Patients' Protectors),
- Patient communities based on membership and uniting people in the same nosology (type of illness)—a mixed-goal formation that deals both with rights protection and rights explanation,
- Charity funds and NGOs dealing with explanation of patients' rights.

Having begun with almost invisible activities, which had been powered by the charisma of a few patients, lawyers, and doctors in Samara and Moscow, Russian grassroots health communication today is centralized in Moscow. Thus, it shadows the centralized governance of the state healthcare system ... and the concentration of the “receivers” of health messages, aka governmental officials and key players in the health industry as well as entities in charge of health finance. Shirokova (2012) quoted Yuri Zshulyov, president of the Russian Hemophilia Society and now also a co-chair of All-Russian Patients’ Union saying that resistance to dialogue among governmental officials and the absence of transparency have traditionally challenged the work of patients’ organizations in Russia. In the search to overcome these communication barriers, several communicative platforms were created, and now these platforms have begun to reap functional results These platforms include:

- Public Councils for patients’ rights protection for the Federal Bureau for Supervision in the Sphere of Healthcare and Social Development in the Russian Federation and in their regional chapters
- Public Organizations’ council for patients’ rights protection for the Ministry of Healthcare and Social Development
- Coordination councils for the civil rights provision and protection in the system of compulsory health insurance for the regional and territorial OMS funds
- Congresses and conferences with governmental officials organized by the patient organizations.

While public councils serve as a platform for decision-based communication, the conferences and congresses that unite the medical personnel, patients, and healthcare officials are the tools for establishing rapport, networking within patients’ movement as well as cross-

sectionally, and demonstrating intentions. All-Russian Patients' Congress, launched in Samara in 2010, is a good example of such communicative space: right now, it is one of the most prominent platforms for the dialogue between the patients' community and the "power", including legislative and executive power branches. In 2017, this congress was held in a luxurious congress hall in Moscow City Business Center. As Zshulyov had mentioned in his address to the congress participants, the reason for choosing such location was that the movement was growing in numbers and influence, attracting more patients' groups, and, with them, attracting representatives from the Ministry of Healthcare, government bureaus dealing with disability issues, and business.

The outlook on the Russian "grassroots" health communication infrastructure today shows an intuitive ecosystem with All-Russian Patients' Union as a central communicator, which was formed in 2010 as a bona fide group of the strongest leaders and best practices of the Russian patients' movement. The union is ruled mostly on the charisma of the leaders and the accumulated social and technological capital of the strongest Russian patients' organizations. The All-Russian Patients' Union gathers under its umbrella several federal and regional patients' organizations, including the most prominent, which include the Russian Hemophilia Society; All-Russian Association of People with Multiple Sclerosis; All-Russian public organization of invalids from psychic disorders and their families, "New Opportunities"; the Cross-regional Public Organization of Nephrologic Patients, "Nephro-Liga"; the All-Russian Society of Oncohematology "Assistance". The central communicative hubs of this infrastructure are Public Councils to the Ministry of Health and Social Development and their regional chapters, All-Russian Patients' Congress, and the recently formed Public Councils to the Bureau of Medico-Social Expertise and their regional chapters. These hubs, which also serve as outputs of

grassroots health knowledge production, are interconnected and are powered by individuals who were at the foundation of the patients' movement in Russia in the 1990s and by their social and legal knowledge capital. The knowledge communicated to these hubs is formed primarily within the patients' organizations that represent the interests of people who have chronic diseases and disabilities who receive governmental aid for treatment from the "7 nosologies" federal program. The communicative means in this passage are mixed offline and online, interpersonal and impersonal interactions, resulting in written communiques, public survey results, and allocation of expert patients for participation in events and meetings. The deeper layer of this communicative ecosystem is the subsystems within each organization: central leadership, regional leadership, and technological and financial resources. Finally, the base layer is comprised of individual patients or those who are affected by illness who volunteer as regional program managers on the ground, communicating with patients and their families, answering hot lines on their cellphones, and performing the everyday tasks of organizational life.

Mikhail Churakov, head of the Social Mechanics agency and one of the active participants of patients' movement in Russia since its formation, said the major challenge to patients' organizations now is transforming organizational communication strategies (personal communication, November, 2017). Krashennikova, (2009) notes the major commitment to activism among Russian patient organizations traditionally has rested in the sphere of medicaments' provision. However, after reaching the goal by 2012 and securing generous governmental aid for expensive treatments for serious chronic illnesses, patients' movement lost a considerable number of activists. Therefore, although major problems exist with rehabilitation and crisis prevention in Russia, no strong patient base exists to tackle this problem with the same methods and instruments as the medical treatment provision was tackled. Now, according to

Churakov, Russian patients' movement is entering a new epoch, in which inner communicational structures must be reassessed, including more extensive employment of social media to attract younger activists. As well, leaders in grassroots health communication must develop a system of retention within the movement (personal communication, November 2017).

In conclusion, Russian health communication is in the making, but remains in constant flux since the fall of the Soviet Union, presenting a unique intuitive ecosystem for health communication research and practice. An ecosystem does not mean a perfect composition of best practices—rather, it represents an alignment of strategies of different actors grounded in historical and cultural implications that works despite its drawbacks. Based on uncertainties, inconsistencies, and the lack of trustworthy information, this ecosystem of health communication is now being solidified within the Russian patients' movement that aims towards a mediator position among the governmental, business, and public sectors of health production. However, to achieve this mediator position, Russian patients' organization must redirect attention from purely government relations to the development of organizational communication practices and strategies.

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Biography

Alexandra Endaltseva is a research fellow within the European framework PHOENIX Joint Doctoral Program on Dynamics of Health and Welfare based in EHESS, France, and Linköping University, Sweden. Her research interests are science and technology studies (STS, disability studies, knowledge infrastructures, patient movements, and care and repair. She has a master of arts degree in communication and social movements from Purdue University, USA. As a faculty member of the Department of Integrated Communication at the Higher School of Economics in Moscow, she has been working on the international dialogue on communication in Russia,

including organization of international conference-receiver of National Communication Association, “Advancing the discipline” grant.

Contact: aendalts@gmail.com

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