

BIOETHICS AND JOURNALISM

Pavel Tishchenko & Boris Yudin

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The authors of this book uncover the role of the mass media in the emergence and evolution of bioethics. The book addresses the responsibility borne by journalists in reporting stories related to suffering – both physical and spiritual. Not only are journalists responsible for simply telling the stories of human suffering, they are also responsible for supplying the population with an appropriate linguistic context for processing, understanding and relating to that suffering. The book provides an in-depth bioethical analysis of the case of Snezhana Mitina v. journalist Alexander Nikonov – a case that was heard by a special ad hoc committee of the Public Board for Media Appeal of the Russian Federation’s Journalists’ Union. To conclude, the authors present a series of moral principles that they believe to be particularly relevant for journalists covering issues of bioethics.

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Forward

There were several factors that catalyzed the authors to embark on a new edition of the *Bioethics and Journalism*. Previously published books^{1,2}, as well as seminars held in the Russian cities of Moscow, Dagomys, Kazan and Barnaul and the Armenian city of Yerevan have attracted the attention of journalists who focus on issues concerning biomedicine. However the limited reach of these sources did little to satisfy the existing interest. Additionally, in the time that elapsed since the publication of previous editions, the Russian public has become deeply engaged in a string of serious bioethical discussions, particularly concerning doctors' rights to commit infanticide against newborns with birth defects and/or developmental disabilities. Analysis and discussions of bioethical issues in the media have become a tremendously important outlet for educating and increasing the ethical consciousness of journalists.

On February 17, 2010, the Russian Journalists' Union held the 40th hearing of the Public ad hoc Board for Media Appeal in Moscow. The board issued an unequivocal ruling against journalists for abusing their rights and responsibilities. As a result, the Union developed a set of fundamental ethical norms to guide journalists reporting on stories pertaining to life, death and human suffering.

For many years, the issues surrounding bioethics have been of top priority to UNESCO. It is our intention that this publication be a step toward the implementation of the principles and objectives of the UNESCO Universal Declaration on Bioethics and Human Rights.

¹ Tishenko PD, Yudin BG. Problems of Bioethics in the Mass Media. [In Russian] UNESCO; 2006; p.93.

² Tishenko PD, Yudin BG, editors. Bioethics and the Mass Media: Recommendations for Journalists. [In Russian] UNESCO; 2008; p.60.

I. Introduction: Journalism at the Cradle of Bioethics

First steps

Albert R. Jonsen, one of the leading American bioethicists, declared November 9, 1962 as the birthday of bioethics. On that day, *Life* magazine published an article by young staff writer Shana Alexander, entitled: “They Decide Who Lives, Who Dies: Medical miracle puts moral burden on small committee.”¹ Around the same time in the Artificial Kidney Center at Swedish Hospital in Seattle, WA, Dr. Belding H. Scribner created one of the first functional artificial kidneys.

Using this device, chronic hemodialysis has significantly increased the life expectancy of patients suffering from kidney failure. However, because the device could not be made available to all those in need, a controversial dilemma arose: which patients should receive hemodialysis, and which should not? Who should be given the opportunity to live, and who should be refused that opportunity? Scribner and his colleagues were strong activists for racial and gender equality and believed that the wonders of biomedicine should not perpetuate new forms of discrimination that give priority of life-saving treatment to one group over another.

To ensure a fair, non-discriminatory procedure in this experimental situation, Scribner proposed the creation of a public decision-making structure. Soon thereafter, the first ever *ethics committee* (later called the “God Committee”) was established in Seattle. The committee was made up of seven local lay persons, including a minister, a banker, a labor leader, a surgeon, a

¹ Alexander S. They Decide Who Lives, Who Dies: Medical Miracle Puts a Moral Burden on a Small Committee. *Life*; November 1962.

housewife and a state government official. Alexander documented the work of the committee, describing the heated discussions among its members as they grappled to find common ground on the profound challenges placed before them. Who, for instance, should receive treatment: a war veteran or an adolescent boy who has yet to leave a footprint in the world? A local congressman, or a housewife and mother of several children?

Jonsen noted that those who established the committee had made a monumental breakthrough that would forever impact the development of bioethics: doctors alone cannot be expected to solve the critical ethical dilemmas born of medical science and practice. It became apparent that doctors would have to collaborate closely with specialists from different humanitarian fields as well as with the public.

The mass media has become indispensable in facilitating an open dialogue on these topics, which can come to include the most intimate of relationships – between a pregnant woman and her unborn child – or basic global survival. The importance of the latter problem is underscored by American oncologist Van Rensselaer Potter, who coined the term “bioethics”. In any situation, the balance between scientific knowledge and universal human values is of principal importance. In 1988 Potter wrote: “Bioethics remains what it was originally – a system of morality based on biological knowledge and human values, with the human species accepting responsibility for its own survival and for the preservation of the natural environment.” This goes hand-in-hand with an earlier passage from Potter written in 1970: “Mankind is urgently in need of new wisdom that will provide the ‘knowledge of how to use knowledge’ for man’s survival and for improvement in the quality of life.”²

Alexander’s writings sparked a heated debate in the media, drawing attention to the moral dilemmas emerging as a result of developments in the fields of biology and medicine. The media attention on bioethics catalyzed a wave of public interest, which, in turn, led to a series of scientific publications and, ultimately, the establishment of bioethics research centers.

² Potter VR. Bioethics: The science of survival. *Perspectives in Biology and Medicine*, 1970, 14 (1): 127–53.

A new impulse stimulating research on these topics arose as a result of public discussions in the media regarding the first successful experiment in heart transplantation. On December 3, 1967, South African surgeon Christiaan Barnard transplanted a heart from one person to another. Barnard saved the life of a man who was terminally ill by removing the still-beating heart of a woman who had suffered irreparable brain damage as a result of a catastrophic car accident. Public opinion was split in its assessment of the surgeon's achievement. One side lauded Barnard as a pioneer exploring a whole new realm of medical technologies, while the other accused him of murder – after all, death was customarily declared only when the heart irreversibly stopped beating. Opponents believed that by removing her beating heart, Barnard had murdered a critically wounded woman.

Although it is true that doctors can incontrovertibly identify permanent damage of specific organs such as the brain, it is beyond their mandate to decide whether a person who has irreversible brain damage but whose heart is still beating be considered dead. As a result, it was decided that, in order to address this question, doctors must work with specialists from a variety of humanitarian fields. In order to respond to this critical concern, a leading American doctor and professor of anesthesiology Henry K. Beecher assembled a multidisciplinary working group at the Harvard Medical School. In 1968, after undergoing painstaking discussions and consultations, the working group proposed to equate brain death with the complete death. The legislative backing for this new criterion mobilized the rapid evolution of transplantology throughout much of the industrialized world. In Russia, for instance, this criterion was adopted in 1992 in connection with the new “Law on transplantation of human organs and/or tissues”.

Beecher – with tremendous support from the mass media – is credited with attracting public attention to problems associated with scientific experimentation on human beings. On June 16, 1966, Beecher's article “Ethics and Clinical Research” was published in one of the leading

medical journals, the *New England Journal of Medicine*. In his article, Beecher, citing exclusively publications from medical journals, presented evidence of unethical experiments on human subjects (i. e. patients) carried out in the most prestigious American medical institutions.

The issues arising alongside progress being made in the fields of biological and medical sciences (i. e. “biomedicine”) inevitably and dramatically impact the average person and have thus increasingly made headlines in the media, kindling heated discussions. It is these discussions that lie within the domain of bioethics, a budding field with only several decades of accumulated knowledge.

There is no question that bioethics is a science, and today there are many experts who have devoted their careers to studying it. However, in many ways, bioethics is an atypical science, so it is important to distinguish the special character and relationship of this field with the mass media. Traditionally, discussions about the coexistence of science and the media have focused on the function of the media best described as ‘popularization’. Because of the esoteric nature of the true meaning behind many scientific discoveries, the mass media has gone to great lengths to distill complex concepts and put them into terms that are accessible to the general population.

Although the function of popularization is of critical importance this is not the media’s sole intent in regard to bioethics. *Bioethics, a field that continues to emerge as a consequence of developments in modern biotechnology, is critically dependent upon the mass media, where such discussions most organically reside and without which the field simply could not exist.* In other words, bioethics could only materialize in a world with pervasive media presence.

How can this uniqueness of bioethics as a science be explained? In order to answer this question, it is important to note that traditionally, science has been perceived as a body of knowledge not subject to influence by human interests or desires, but rather prescribed by virtue of the field’s authority. After all, what sensible human being would consider questioning the laws of physics or chemistry? Of course one could attempt to create

perpetual motion, but we can hardly expect for such an endeavor to prove fruitful, for it contradicts the laws of nature.

Bioethics is on the opposite end of the spectrum. Of course, it makes no attempt to revoke the laws of nature – its intentions lie elsewhere. The science of bioethics focuses on filling the gap left by the fact that technologies arising out of contemporary biological and medical research do not come with instructions on what to do with them in different situations. Biomedical experts are able to explain how to properly use this or that technology and they can carry out necessary interventions. However, when it comes to deciding whether or not to conduct an intervention in the first place, the choice should reside with the patient (or the lay person).

Bioethics is therefore endowed with the mandate of guiding patients in making independent choices. Examples include questions such as: should someone undergo genetic testing that can show that, with age, he will incur a heightened risk of developing disorders such as Alzheimer's disease, for which there is no cure? Should a pregnant woman subject the embryo developing in her womb to diagnostic tests if the results of those tests may lead her to consider an abortion? Should a patient participate in a high-risk biomedical study if there is a high chance that she can improve her own health? Should someone donate a kidney to a relative even if the absence of that kidney can cause serious health problems for the donor in the future?

In each of these situations, the individual is faced with a difficult and deeply personal choice, for which he/she must take full responsibility. In each case, the repercussions of that choice may prove life-altering not only for that individual, but for his/her loved ones. The tremendous risks and liabilities associated with such decisions serve as the instigating factors behind the impassioned public discourse around bioethical issues. Naturally, the media serves as the most fertile ground for such discussions.

The field of bioethics faces a number of other difficulties. One key challenge is the fact that differences in opinion do not necessarily arise out of an inaccurate understanding of the problem by one side or another. Instead, these differences are often the result of differing value systems and personal

interests, whereby what is acceptable to one person can be completely unacceptable to another. However this divergence of personal values, which determines how individuals make decisions in critical situations, need not be eliminated from the equation. On the contrary: the very essence of such open discussions lies in giving people the opportunity to express themselves and then listen and consider the arguments of others so that they are empowered to make a conscious, weighted – or, bioethically speaking, well-informed – decision.

Without the active engagement of the media, not only would existing and future consumers of biomedical technologies have nowhere to obtain basic information, they would also be deprived of the opportunity to make truly informed decisions on critical, life-changing issues. As such, it is imperative to maintain the bond between bioethics and the mass media if they are to achieve the common goal of helping the average citizen navigate the convoluted and often frightening world of newly emerging biomedical technologies.

In the 1970s, the world saw rapid expansion in the field of genetic engineering. Media coverage on this topic instigated a debate about the potential dangers associated with the use and consumption of genetically modified organisms. After all, in addition to the benefits of these products (which serve as the justification for their creation), they may also contain elements that may be dangerous for humans and other living organisms.

It is pertinent to mention the events surrounding the development of one of the key methods of genetic engineering: recombining DNA molecules. This method allows scientists to separate DNA strands in specific places and insert DNA molecules that belong to completely foreign organisms. Although there is clearly tremendous potential associated with the ability to manipulate living organisms, concerns were being raised about how these new organisms would interact with their environment: Might they destroy other life forms? Do they have the potential to become carriers of new and dangerous viruses? Researchers working in the field were the first to raise concerns about the potential risks of recombinant DNA, but

it didn't take long, with help from the media, before the discussion spilled over into the general public.

In response to these questions, scientists took unprecedented action, placing this form of experimentation under a temporary moratorium that became known as the Asilomar moratorium, named after the California city where the 1975 international Asilomar Conference on Recombinant DNA was held. As a result of the conference, a decision was reached that experiments be categorized into groups based on the potential risks. Subsequently, scientists developed specific safety regulations addressing each of the categories. It was also decided upon at the conference that scientists should abstain from conducting experiments deemed most dangerous until more conclusive proof regarding the degree of risk became available.

The events surrounding the Asilomar moratorium not only evoked public interest, but also catalyzed the growth of public involvement in influencing both scientific policy and the direction of future research. As a result, public opinion has come to play an important role in affecting resource allocation for more preferential, socially acceptable research topics. Today, this trend is particularly well articulated in relation to genetically modified food products and research for developing new medicines, prevention, diagnostics and treatment of various illnesses. A high level of community action can only exist when and where the media is fulfilling its mandate as a fertile ground for open dialogue and equal representation for all positions.

New relationship between bioethics and the mass media is closely interwoven into the general context of the essentially new type of relationship between biomedicine and the mass media, which was not characteristic in previous times.

II. Human Beings as Guinea Pigs: Recent and Distant History

We will begin the discussion drawing from recent headlines.

BBC US & Canada, October, 1, 2010, 22:14 ET

US medical tests in Guatemala 'crime against humanity'

US testing that infected hundreds of Guatemalans with gonorrhea and syphilis more than 60 years ago was a “crime against humanity”, Guatemalan President Alvaro Colom has said.

President Barack Obama has apologised for the medical tests, in which mentally ill patients and prisoners were infected without their consent.

Mr Obama told Mr Colom the 1940s-era experiments ran contrary to American values, Guatemala said.

The US has promised an investigation.

Syphilis can cause heart problems, blindness, mental illness and even death, and although the patients were treated it is not known how many recovered.

Evidence of the programme was unearthed by Prof Susan Reverby at Wellesley College. She says the Guatemalan government gave permission for the tests.

No offer of compensation has yet been made, but an investigation will be launched into the specifics of the study, which took place between 1946 and 1948.

White House spokesman Robert Gibbs said on Friday the news was “shocking, it’s tragic, it’s reprehensible”.

In an interview with the BBC, Mr Colom said the test subjects were “victims of rights abuses”.

“There’s been a very strong reaction in the Guatemalan media and by my compatriots,” he said.

“Of course, there may have been similar incidents in other countries around the world, but speaking as the president and a Guatemalan, I would have preferred that these events had never happened on this soil.”

The joint statement from Mrs Clinton and Health Secretary Kathleen Sebelius said: “Although these events occurred more than 64 years ago, we are outraged that such reprehensible research could have occurred under the guise of public health.

“We deeply regret that it happened, and we apologise to all the individuals who were affected by such abhorrent research practices.”

In his phone call to President Colom, Barack Obama reaffirmed the United States’ unwavering commitment to ensure that all human medical studies conducted today meet exacting US and international legal and ethical standards, the White House.

President Obama also “underscored the United States’ deep respect for the people of Guatemala and the importance of our bilateral relationship”.

The study by Prof Reverby shows that US government medical researchers infected almost 700 people in Guatemala with two sexually transmitted diseases.

The patients – prisoners and people suffering mental health problems – were unaware they were being experimented upon.

The doctors used prostitutes with syphilis to infect them, or inoculation, as they tried to determine whether penicillin could prevent syphilis, not just cure it.

The patients were then treated for the disease, but it is unclear whether everyone was cured.

Prof Reverby has previously done research on the Tuskegee experiment, where the US authorities measured the progress of syphilis in African-American sharecroppers without telling them they had the disease or adequately treating it.

*The experiment ran from 1932 to 1972, with President Bill Clinton eventually apologising for it.*³

Russian doctor and writer V.V. Veresaev could have very well sat on the witness stand in the above case against the American physician researchers.

Involuntary Human Experimentation – V.V. Veresaev

More than a century ago, in 1901, Russian writer and medical doctor Vikenty Vikentyevich Veresaev (1867-1945) first published his *Memoirs of a Physician* in the Russian journal *Mir Bozhiy* (*The World of God*). This publication quickly generated tremendous interest that didn't fade for years to come. Suffice it to say that, during his lifetime alone, Veresaev's *Memoirs* were republished as a separate volume 14 times in Russian. After the first Russian-language publication, English, French and German translations quickly followed.

It is fair to say that Veresaev's *Memoirs* were, in fact, the catalyzing force behind the explosion of interest in medical ethics, the central focus of the author's work. With unseen candidness, sincerity, emotional fervor and, most importantly, courage, Veresaev divulged the fiercely guarded secrets buried deep within the medical professional community. His writings sparked yet another debate, scrutinizing the conventional wisdom dictating what information a patient should have about a physician prior to submitting to his/her care. In Veresaev's opinion, the act of protecting institutional secrets is unjustified as an end in itself – particularly when done at the cost of preserving other, more critical values such as patients' health, rights and dignity.

In the last century, medical practice, science and ethics have undergone tremendous transformations. Even so, much of Veresaev's

³ US medical tests in Guatemala 'crime against humanity'. *BBC US & Canada*. October 2 2010. http://www.bbc.co.uk/news/world-us-canada-11_457_552 (Accessed 15 June 2011).

writing is as relevant today as when it was first published. He brought to light some of the most pressing and complex ethical issues that doctors face every day.

It is important to note that the perspective from which Veresaev chose to write was critical to his book's success: He did not take on the air of a *know-it-all* privy to ready-made solutions for every potential moral collision that practicing doctors might encounter. On the contrary: he clearly stated that in many real-life situations, doctors do not, in fact, have any morally sound options to choose from. Consequently, the doctor is forced to make decisions that may garner criticism both from colleagues and patients and for which he is left sole responsible.

Some of the most stirring pages of Veresaev's *Memoirs* are devoted to a topic that, unfortunately, receives little attention in medical ethics literature. He writes about the effect on patients, particularly women, who undergo medical examinations conducted by medical students. He writes: "We learn off our patients – that is the reason for treating patients in clinics. If any patient does not want to be seen by a student, he/she is immediately transferred out of the clinic. Should a patient not be similarly concerned about all these experiments and demonstrations?"⁴

Veresaev harkens back to the 1840s when medical students had no clinical practice – this proved disastrous for their future patients. Despite that, he writes: "Here we stumble upon a contradiction that we will continue to revisit time and again: the existence of medical schooling – the most humanitarian science of all – is unfeasible without trampling on the most fundamental aspects of humanity."⁵

After close analysis of this dilemma, Veresaev reached the following conclusion: "What is the solution to this problem? I certainly do not know. I only know one thing: medical practice is indispensable and there

⁴ Veresaev VV. *Memoirs of a Physician. Collected Works in Four Volumes [Sobranie sochinenii v chetyrekh tomakh]* Moscow: Pravda; 1985; p. 230.

⁵ *Ibid.*, p. 238

is no other way to learn. However, should circumstances be such that *my* wife or sister find herself as a patient in a syphilologist's office, frankly, I would say that I have not the slightest concern for medical school and that *patients cannot simply be walk all over* just because they are poor."⁶

In this context, it is critical to note two issues. The first is that Veresaev is open and sincere in depicting the moral difficulties that medical doctors must inevitably face in their day-to-day practice. In other words, by virtue of its character, the medical profession is such that, even for individuals guided by an impeccable moral compass, as physicians, they are faced with a brutal reality that demands them to make decisions and take actions that they know will result in some degree of tangible detriment to the patient.

However, this aspect of the medical profession is not intended as a pardon or resignation to malevolent practice simply because suffering is unavoidable. The solution does not lie in turning a deaf ear to such situations – our conscience will not allow that. According to American philosopher Robert Nozick, the decision to compromise one moral imperative in order to honor another possibly more important one is quite common. Even so, they need not escape from our moral radar. Instead, in the words of Nozick, they should leave “moral footprints”.⁷

We now encounter one of the main themes of Veresaev's book: he takes a strong stand against allowing the full brunt of ethical violations to fall upon the shoulders of the poor – those residing on the lowest rungs of the social ladder and who are most vulnerable.

Veresaev also places particular emphasis on issues regarding patient trials or, in his words, “doctors' experiments on living people”.⁸ Veresaev's reasoning and observations are particularly relevant today, not only as a basis for comparison with contemporary biomedical research practices,

⁶ *Ibid.*, p. 238. (Second italics added by author Yudin BG.)

⁷ Nozick R. Moral Complications and Moral Structures. *Natural Law Forum*, 1968, 13: 1–50.

⁸ Veresaev VV. *Memoirs of a Physician*. p. 285

but also as a substantiation of the ethical norms and demands regulating biomedical research. The relevance of this issue is contingent upon the fact that, in the last 100 years, the quantity and variety of experiments on human subjects has skyrocketed and it is precisely this trend that underlies the power of modern medicine.

In regard to medical experiments on human subjects, Veresaev writes that, unlike most other questions in the field of medical ethics “for which there are no conclusive answers”, these questions “have only one unequivocal solution”. Veresaev chose to limit his analysis to one area of experimentation, namely venereology since it is an area exclusive to human beings (i. e. there is no equivalent in animals). Contemporary ethical standards for conducting experiments demand that there be preliminary experimentation on animals. In accordance with the World Medical Association Declaration of Helsinki (2008): “Medical research involving human subjects must conform to... adequate laboratory [experimentation] and, as appropriate, animal experimentation”.

Veresaev’s harsh criticism of venereology is that “every step forward... is stained by a transgression.”⁹ In order to support this hypothesis, Veresaev meticulously described – citing relevant journals and publications – nearly 20 amoral (or as Veresaev puts it, criminal) studies carried out in different countries in the second half of the 19th century.

It is important to note that, in the West, Veresaev’s book was rediscovered in 1972 when American physician Jay Katz published his voluminous tome *Experimentation with Human Beings*, an anthology covering every facet of ethical analysis regarding human experimentation. For every large passage that Katz used from Veresaev’s *Memoirs*, he inserted the following footnote: “In every case where it was possible, citations from Veresaev’s book were tested by original sources; in every case their accuracy was proved.”¹⁰

⁹ *Ibid.*

¹⁰ Katz J. *Experimentation with Human Beings*. Russell Sage Foundation, NY; 1972; p. 284.

There is no real need to retell the substance of the experiments that Veresaev has written about in his book. Instead, we will attempt to single out those ethical principles, which, according to Veresaev, must unequivocally be addressed in conducting experiments and the violation of which draw his harshest criticisms. This category of experiments includes those that carry no evidence of scientific value but that, nonetheless, inflict irreparable damage on the subjects. “The pure-growth method [used in the gonococcus vaccine] employed by Max Bokgart, was considerably flawed and his experiment carried little scientific weight.”¹¹ Notably, a key consideration fueling the discussion on experiments with insufficient scientific value and tremendous risk for study subjects, is that – likely as a result of inadequate preliminary research and unfamiliarity with the literature – it is proven again and again that data from many experiments already exists. Veresaev also notes that in many cases, syphilis vaccines, for example, are tested on a large number of people even though there is no benefit even from a purely scientific standpoint.

Nonetheless, it is standard scientific practice to confirm and reconfirm data received from scientific studies. This strict system is particularly critical as it relates to findings on human illnesses and potential treatments. Veresaev’s writings provide valuable insights into this topic as well. He states that because medical experiments carry the inevitable danger of putting human lives at risk, researchers must adhere to ethical standards that demand vigilance in finding ways to eliminate, or at least minimize, unnecessary suffering and unjustified risk for their subjects.

Next, Veresaev’s addresses ethical norm of patient consent. To make his point, he quotes physician, professor and civic leader V.A. Manassein in his sharp criticism of one particular study: “It is hard to tell,” writes Manassein, “what is more shocking: the cold-bloodedness of a scientist who would allow the most malignant form of syphilis to develop in a patient

¹¹ Veresaev VV. *Memoirs of a Physician*. p. 286.

simply to gain a clearer picture and ‘expose that patient to a larger circle of doctors’, or the researcher’s initial logic, that would have him/her expose a patient to such a terrible and at times life-threatening disease, without even getting the his/her consent.”¹²

It is worth noting that the abovementioned quote refers to physician and professor Christian von Hubbenet from Kiev, who attempted to develop a vaccine against syphilis. In the words of Hubbenet himself, his study subjects were “in robust health” – a 20-year old paramedic and a soldier, both of whom came to the hospital with bladder infections. In this situation, the patients did not give consent. However, even if they had given consent in accordance with all applicable standards, it would have carried no legal or moral weight since both subjects were the experimenter’s subordinates.

To keep on the topic of contemporary standards, we would like to focus on another topic of ethical concern. In analyzing Hubbenet’s study – along with many others – Veresaev found that the names of study subjects were being openly disclosed. In those times, this practice was widespread. However today, it is considered a fundamental violation of the laws of confidentiality as such disclosure can result in serious emotional damage for the subjects. In fact, in his book, Veresaev uses only initials when describing three very young girls who were targeted to be infected with syphilis. “In the original [document]” he wrote, “the full names and even last names of all three girls were used.”¹³

However even in several cases where experimenters claimed to have conducted studies with the consent of their subjects, Veresaev places the legitimacy of their documentation under serious scrutiny. He quoted Assistant Professor A. G. Ge in Kazan: “A study was conducted on a woman suffering from Norwegian leprosy, who had never had syphilis and *who gave her consent for the study [sic!]*”.¹⁴ It would take a healthy imagination

¹² *Ibid.*, p. 292.

¹³ *Ibid.*, p. 296

¹⁴ *Ibid.*, p. 295 (*Italics added by Veresaev*)

to believe that this consent could even be possible or have any value! In an even more flagrant example, a scientist supposedly obtained consent from three girls, ages 13, 15 and 16, to be infected with syphilis. “Even if they did, in fact, give their consent,” writes an angry Veresaev, “did these children truly understand what they were agreeing to and, consequently, how could their consent be taken seriously?”¹⁵ It then follows, that consent is not simply a formality: it is imperative that consent is truly conscious, voluntary, well-informed and given by a fully competent individual. In the case of children or people who are incompetent, a legal surrogate may give consent on their behalf.

The Case of Marina A.

A pregnant, married woman Marina A. came to see a geneticist. Marina, who belongs to one of the indigenous peoples of the Northern Caucuses, is accompanied by her brother. The doctor, respecting women’s right to individual, free choice and in keeping with the principle of confidentiality, asks the brother to wait in the corridor. The brother refuses, stating that he represents the patient’s family and that decisions must be made by the family and not by the patient alone. The woman does not object to him staying.

Here the doctor is faced with a moral dilemma. From one perspective, this could be considered a case of familial abuse that infringes on a woman’s right to make independent choices as guaranteed by the law. If this is the case, then the brother should leave. On the other hand, perhaps the right to independent choice is incompatible with the personal, traditional beliefs of the patient. In this case, the brother should stay.

Problems of this sort that arise in the medical field (and, in more general terms, the conflict between globalization and anti-globalization) have no common resolution.

¹⁵ *Ibid.*, p. 296 (*Italics added by Veresaev*)

An article by famous Russian bioethicist O. Kubar¹⁶ focuses on an interesting example of this issue, involving a thyroid transplant conducted by head doctor of the Kolomna Engineering Plant, B.V. Dmitriev, in consultation with the famous Russian lawyer A.F. Koni.¹⁷

In exploring the ethical and legal perspective of a doctor's right to transplant tissues and organs from one person to another, Dmitriev asked himself the following question: "Does a doctor have the right to inflict even minimal and quickly-reparable damage to a healthy person in order to help another?" To answer this question, Dmitriev formulated a perfectly sound (even by the strictest measures of contemporary bioethics) and comprehensive set of norms for informed and conscious donor consent. In his article, Dmitriev outlines the principles as follows:

[The doctor] must refuse to transplant parts of the body from minors and the mentally incompetent. For the transplantation of homogeneous live tissues, only adults with full mental capacity can serve as donors. The doctor – based on his own knowledge and the results of rigorous scientific studies – must be able to ensure a speedy recovery from any harm caused by the removal of any part of the body. The doctor must be meticulous and thorough in explaining to the donor all potential side-effects and dangers that may follow as a result of the operation. Only after this explanation can he obtain the donor's consent.¹⁸

Dmitriev also points out that in cases where written consent is provided – particularly in the presence of a witness – it is not only the patient that is protected, but also the doctor is shielded from potential liabilities.

Now, returning to Veresaev's *Memoirs*, we can see that the author was most troubled – indeed almost in a state of despair – over the way in which the medical community perceived cruel medical experimentation. "What is most evident in light of conducted experiments," he wrote

¹⁶ Kubar OI. Ethical and Legal Issues of Human Research: From the History of 20th Century Russia. *Chelovek [Humankind]*. 2001; 3: 115–122.

¹⁷ Dmitriev B with commentary by Koni A. *Medical Review*; 1917; Vol. LXXXVII; 13–16 (618–631).

¹⁸ *Ibid.*

bitterly, “is the shameful indifference one encounters from the medical community in response to reports of these atrocities... One would imagine that the first such experiment would preclude a recurrence – that the first such researcher would be shamefully and permanently exiled from this professional community. However, this is not the case.”¹⁹

In his reproach of physicians’ indifference, Veresaev went so far as to call for the establishment of external controls over the medical profession: “...the time has come to stop waiting for doctors to emerge from their inaction: citizens should take their own measures to protect themselves from scientific zealots who have forgotten the difference between human beings and guinea pigs”.²⁰ In actuality, the attitude of the medical community toward experiments carried out on human subjects remained largely unchanged until the 1960s when the first edition of the aforementioned World Medical Association Declaration of Helsinki was approved.

This Declaration set out new publication requirements for scientific journals: articles had to include full disclosure and verification indicating that the experiment being described was carried out in adherence with the principles set out in the Declaration. The main significance of this requirement was that it distributed responsibility for inhumane, unethical experiments between the experimenter and his/her colleagues, as they would now be required to give their full consent in order for the researcher’s work to be published.

Additionally, in recent decades, questions relating to the ethical and legal regulation of medical experiments are no longer under the exclusive domain of the medical community. Today, many countries throughout the world have enacted laws outlining the necessary procedures for conducting experiments; protecting the health, rights and dignity of subjects; and regulating the study preparation and implementation processes. The passing of such legislation caused the

¹⁹ Veresaev VV. *Memoirs of a Physician*. p. 299.

²⁰ *Ibid.*, p. 300.

public to become cognizant of the role it can play in defending the interests and wellbeing of study subjects.

The first reactions to Veresaev's *Memoirs* began to appear even before the work was published in its entirety. Most of the reactions were unfavorable and, as expected, came from medical professionals. A substantial portion of the attacks focused on the chapter dealing with experimentation.

Under these circumstances, Veresaev proved himself as a master of debate. Already by December 1901, *Rossiia* newspaper published his editorial entitled "To my critics". In June 1902, Veresaev prepared a comprehensive work entitled "On *Memoirs of a Physician: A response to my critics*".²¹ This work was published in the 10th issue of the journal *Mir Bozhiy* (The World of God). In January 1903, Veresaev added substantially to this text.

Judging from his exaggerated reaction, it appears that Veresaev was unprepared for the harsh rebuke he received from his critics. He struggled to find explanations for their reactions but ultimately came to the bitter conclusion that their position comes not from the egoism of any individual within the profession, but rather it lies much deeper and is "rooted in the parched, crippling imprint on the soul that an individual receives by mere virtue of belonging to the profession.

"Such a person views the wide range of life's occurrences through the narrow view of the immediate and practical interests of his profession. These interests, in his opinion, are also of primary importance to the entire world, and any attempt to elevate himself above those interests, consequently, inflicts irreparable damage not only on the profession but on all people."²² From this perspective, continues Veresaev, if we are to address the profession's darker side, we "must do so with utmost care and

²¹ Veresaev VV. On *Memoirs of a Physician: A response to my critics. Collected Works in Four Volumes [Sobranie sochinenii v chetyrekh tomakh]* Moscow: Pravda; 1985; p. 426–427.

²² *Ibid.*

secrecy so as not to shake outsiders' faith in the profession and the strong principles within which it is based..."²³

As a result of these discussions, there arose a collision between conflicting positions on how to maintain the credibility of the medical profession in the eyes of the public. One side believes that it is best to keep such secrets out of the public eye even if they have the potential to result in human suffering and spilled blood. The other camp holds to the opposite, pushing for open condemnation of those individuals within the practice who violate ethical norms and, in so doing, jeopardize the reputation of their profession. This debate, instigated by Veresaev, is a topic of immense sensitivity for the professional community and has become the subject of a wide range of contemporary writings both on biomedical and scientific ethics. In this literature, those who air out the dirty linen, so to speak, and inform the public of ethical violations by this or that member of the professional community have been deemed whistleblowers.

In the notes to "*On Memoirs of a Physician*", Veresaev goes to great lengths to elucidate his thoroughly conceived understanding of the essence of medical ethics with all their accompanying contradictions. "There is not a single science," he writes, "that comes into such intimately close and multifaceted contact with humans than medicine... A real, living human being himself provides, so to speak, the entirety of the content for the study of medical science. He is the most indispensable educational material for students and new doctors; he is the immediate object of study and experimentation by physician-researchers; and, of course, the practical application of our science is, yet again, closely interwoven with the many different interests of that same human being. In short: medicine is borne of man, goes through man and returns to man."

The interests of medicine (and similarly science) are constantly colliding with the interests of the living individuals – subjects. That which is of vital importance for science – i. e. the good of humanity – can be agonizing, harmful and even deadly for the individual. This

²³ *Ibid.*, p. 427.

conundrum breeds a whole slew of phenomenally difficult and complex contradictions.”²⁴ It is important to remember that these words were written in the very beginning of the 20th century, throughout which – and particularly after the world discovered the brutal experiments conducted in the Nazi concentration camps – the problem so sharply formulated by Veresaev had seized the attention not only of doctors and medical researchers, but of all humanity.

What should take top priority: the interests of science and all of humanity or the wellbeing and interests of the individual? Only at the closing of the last century did fundamental international documents such as the Declaration of Helsinki and the Council of Europe Convention on Human Rights and Biomedicine establish a consensus to prioritize the interests of individual human beings over the sole interests of science or society.

Naturally, consistent with his humanitarian position on the issue, Veresaev provides a solution for this dilemma: “The greater good, progress and scientific advancement: we are willing to sacrifice in their name only if that sacrifice is borne of our own free will,” he noted. Later he continued: “Under such circumstances, the question of individual rights in the face of attempts by medical science to encroach upon those rights inevitably becomes the primary, central question of medical ethics. The question of how to escape this conflict cannot and should not be dismissed until there is a viable solution.”²⁵

Importantly, Veresaev believes that the field of medical ethics must itself undergo profound and fundamental transformation, widening the scope of the types of issues that it addresses. He writes: “However regrettable, we must admit that our field of science still has no ethical foundation. After all, it is insufficient to limit [the definition of ethics] to those specialized, corporate ethical standards that focus exclusively on standardizing the interaction between doctors and the public, or between doctors themselves. There exists a need for a more sweeping, philosophical

²⁴ *Ibid.*, p. 411.

²⁵ *Ibid.*, p. 443.

branch of ethics that must, first and foremost, address in its entirety... the interrelatedness of medical science and the living individual... As for this universal question, to my knowledge, it has never even been raised.”²⁶ Incidentally, on this issue, Veresaev anticipated the course of events many decades in advance. Indeed, his “universal question” took center stage in biomedical ethics even if only in the last decades when it became known as bioethics.

The key for understanding the fundamental differences of the opposing schools of thought in medical ethics (and for understand the position of Veresaev himself) lies in Veresaev’s debates with a physician named M. L. Kheisin in Krasnoyarsk, Russia who, in 1902, published a brochure entitled *On the Issue of Doctors* – a counterargument to Veresaev’s *Memoirs*. In substance, however, the clash between Veresaev and Kheisin’s positions goes above and beyond a simple debate on a specific book or the personal traits of the authors.

Veresaev acknowledges his opponent’s candor and states: “Dr. Kheisin thoroughly dissects the only part of my book that can realistically become the subject of serious debate, namely its ethical-philosophical part. He is absolutely correct in stating that the central question at hand is that of the relationship between a living human being and scientific progress. Similarly, he has accurately identified the central tenet of my book, which is to place above all else the interests of that very human being.”²⁷

Having deemed Veresaev’s stance “unsophisticated,” “sentimental” humanism, Kheisin proposes taking a wider lens to this issue.²⁸ From this wider point of view, the central priority becomes “advancing progress”, which requires a different set of criteria: “Advancements made for the good of all mankind always come at the cost of individual interests and personal suffering.”²⁹

²⁶ *Ibid.*, p. 429.

²⁷ *Ibid.*, p. 437.

²⁸ Kheisin ML. *On the Issue of Doctors*. Krasnoyarsk: 1902; p. 24.

²⁹ *Ibid.*, p. 21.

The question is, who are these people who will be sacrificed and forced to suffer in the name of “advancing progress”? And who decides who will be the victim? Kheisin’s classification provides some clarity in answering these questions. Firstly, he writes that “the overwhelming majority of experiments are carried out on imbeciles – paralytics progressing into the final stages of illness at which point one can hardly distinguished between man and animal – also on patients with malignancies in the final stages of development; and so on. People may ask: what right does a person have to shorten, even by one day, the life of another? I believe that if the benefits from that experiment are enormous, then this theoretical humanism must be sacrificed... I do not know what benefit lies in standing up for the interests of such sick patients.”³⁰

Around the 1920s, German physicians and biologists began to develop similar ideas – they began to speak of “lives that are not worth living” and they categorized such lives much the same way as Kheisin. Soon thereafter, Hitler’s regime took these ideas as a guide for action, and there appeared not only doctors who were willing to give written confirmation that the life of this or that person was not worth living, but also executioners willing to administer euthanasia. However it soon became clear that the boundaries of such categorizations, and consequently the number of “lives not worth living”, are prone to expand indefinitely. It appears that the trend of appraising people’s lives from the perspective of how useful it is to society inevitably leads to social barbarism if not complete destruction.

It is difficult then to disagree with Veresaev’s sarcastic response to Kheisin: “Dying, Sir Kheisin, is dreadful, as is suffering on one’s deathbed, and every member of society needs the guarantee that, one fine day, they won’t be visited by Sir Kheisin in the mask of a doctor, saying: ‘This person can hardly be distinguished from an animal: take him to the laboratory!’”³¹

³⁰ *Ibid.*, p. 34

³¹ Veresaev VV. *On Memoirs of a Physician: A response to my critics.* p. 440.

Next in Kheisin's classification are "experiments on completely healthy individuals". Here he makes a unique case: "In discussing the issue of experimentation, we must remember the psychology of people seeking truth... What should such a person do? He cannot, after all, make himself the subject. As such, he must either convince others or, ultimately, he may allow himself to cross the lines of permissibility. Who gives him this permission? Which takes priority: the authority of one's own deepest, strongest impulses or formal authority?"³² It is clear that, for Kheisin, the last question is merely rhetorical: from his point of view, the authority lies with he who acts out of power. In reality, there may be an alternate interpretation of this passage, namely that desecrating moral norms will result not so much in guilt, as in calamitous repercussions for he who is unable to manage his own overwhelming impulses. It is shocking that these musings are those of a doctor, whose profession, at its core, deals with helping the weak, sick and afflicted and regarding their interests, and not one's own boundless impulses, as the highest priority.

Kheisin's classification has one last category of experiments, which he himself calls "a small group of inoculations done without any justification". He writes: "Such experiments are symptomatic of the perversion of contemporary thought and there should be no ambivalence towards them."³³ One could rightfully wonder who would be granted the power to decide – and by what standard – whether a case be categorized as permissible impulse or unjustified "perverse thought". This, however, is not the point. In any case, Veresaev's participation in this intense debate in response to Kheisin's feeble work, was guided by a different set of intentions. By exposing Kheisin's cynicism, Veresaev hoped that his opponent's brochure would serve as a metaphorical mirror: "It may be that some of my critics, having looked into this 'mirror', will recognize that the ideas Sir Kheisin has formulated and shared so frankly are the

³² Kheisin ML. *On the Issue of Doctors*. P. 35–36. (The first set of italics added by the authors, Tishenko PD, Yudin BG)

³³ *Ibid.*, p. 36.

same ideas that have been, on a subconscious level, residing in their own minds.”

Needless to say, in the last hundred years, the practice of conducting experiments on human subjects has changed and continues to change in a variety of ways. It is important to note above all else that in the last several decades and throughout the world, there has emerged a complex system of ethical and legal regulations regarding experimentation. This regulatory system relies on two fundamental mechanisms: (1) there must be a preliminary expert evaluation of *all* research proposals, and (2) it is mandatory to obtain voluntary, informed consent either from the subject of the experiment or his/her legal representative. As of today, this system has yet to take any concrete form, but it is rapidly developing, albeit with some difficulties and contradictions. The field of experimentation continues to come up against ever changing ethical dilemmas.

For quite some time after the Nuremburg Trials, experimentation was seen exclusively as a source of risk for participants. That said, it is evident that the objective of ethical regulation is unequivocal, that is, rigorously protecting participants from risk. In recent years, however, the situation has been changing dramatically so that, more and more, people have begun to see participation in studies as an opportunity to reap personal benefit. Such benefits may include receiving new and presumably more effective diagnostic and treatment opportunities; access to expensive medicines; etc.

Such changes have complicated the objectives of ethical regulation. On one hand, there is a need to measure the potential risks and benefits for participants undergoing experimentation. On the other hand, as participation in experiments has become something of a privilege, there arises a new challenge, namely ensuring equitable access to that privilege. Today, for instance, there is consensus that members of so-called vulnerable groups, such as children, pregnant/breastfeeding women, ethnic minorities, inmates, etc. – groups that used to warrant special protection from experimentation – should be granted special access to experiments that anticipate benefits for their subjects.

Finally, at the time of the writing of Veresaev's *Memoirs*, the topic of experimentation dealt only with the interests of two (often conflicting) groups: doctor (experimenters) and patients (subjects). However, with time, the number of stakeholders began to grow. There arose ethics committees, conducting assessments of research proposals. Another cast of major players that have taken the stage are pharmaceutical companies, which today are the primary drivers and sponsors of a variety of studies. The latest version of the Helsinki Declaration introduced another group, whose interests must be considered in planning experiments, namely the population from among which study subjects are to be recruited. Finally, another stakeholder group involved in the preparation and implementation of experiments are contract research organizations, i. e. commercial firms that specialize in finding experimentation sites, recruiting participants, developing studies and analyzing results.

The consequence of this evolution is that both biomedical experiments as well as their ethical assessments have become somewhat industrial in nature. And yet, despite these tremendous changes, we can in no way discount the questions that Veresaev raised. We must not allow ourselves to view the moral charge of his memoirs and his unique but penetrating treatment of the issues surrounding medical ethics as something of the past.

III. Life Dilemmas as the Foundation for Bioethics

Today, we are faced with a world cultivated largely by the mass media, folklore, journalism, literature, film and other forms of artistic expression. In this regard, journalism is particularly important as it shapes the linguistic context that colors – like a prism – people’s perception of the world around them. The result of a language concentrated on collaboration is civil society – a language of hate creates a world that, analogous to the cold war, can be deemed a “cold civil war”. When a person declares “This is my opinion...” it can, for the most part, be assumed that this perception occurs only as a result of having verbalized, visualized and experienced it in communication either with him/herself or with others. If individuals’ natural linguistic context – by means of which they form perceptions of themselves and their surrounding world – is made up of violent rhetoric, they will view the world accordingly. Herein lies the tremendous burden of responsibility of the journalist: the responsibility for the world in which we live.

The mass media is a reflection of the stories that we constantly tell and retell – both to ourselves and others – about the world we live in. With the emergence of biomedical technologies came a new world that had not, until then, had a language to describe it. In order to understand the problems associated with this field, it was first necessary to develop a narrative, a story that creates a fixed linguistic point of reference upon which future discussions could be built. Additionally, the story must be told in such a way that it sheds light on those forces that compelled us in the writing of this book with the hope that we are able to plant a seed in the reader’s mind that will grow into a similar interest. A compelling

story is but a means to an end – the kindling a spark that will drive readers to explore further the unique world of the technology of life. However, to begin, this world must first be fully revealed in its most axiomatic and enigmatic form. This is the main objective of this narrative.

It is up to the reader to assess how successful we accomplish this task. We would like to note that the narratives presented here are heterogeneous in nature – some are purely descriptive accounts of this or that situation while others are more journalistic, presenting a fully developed set of arguments. The narrative is a specific kind of social technology that forms a distinct space that harnesses an astute awareness of individuals and societies.

Letter from Fedor Shapkin

In January 1994, the editor of the Russian newspaper “Rossiskiye Vesti” (Russian News) received a letter from a reader named Fedor Makeyevich Shapkin. Below is the text of the letter exactly as the author wrote it and as it was published in the paper on February 11:

Kill me!

Circumstances are such that due to illness, I must die a death full of misery and suffering.

I asked the doctor to prevent this miserable death by means of an artificially induced, painless death. He refused: “I have no right,” he said. “I could be indicted,” and so on.

My friend’s dog fell terribly ill so he took it to the veterinarian. There, they gave the dog an injection and she peacefully fell asleep for all eternity.

We have a more humane attitude toward dogs than we do toward people. Is it because of their loyalty? In India, they deify cows – we, dogs.

The devil had me born in the Soviet Union. Maybe it would have been better had I been born a dog?

Will there ever be a law giving citizens of Russia the right to a peaceful, painless death?

*F. Shapkin
18 January 1994*

An ill patient suffering unbearable pain demands the right to euthanasia – a procedure carried out by a doctor that, despite its “humaneness” (i. e. quick, comfortable and painless), is considered murder. However, if that right is granted by law, murder will be transformed – both in our language and in our minds – from an act of crime into an act of mercy, joining the ranks of countless other routine social mechanisms threatening to destroy key pillars of our society. In other words: good begets evil. Or is there nothing “good” about it to begin with? Perhaps before offering or requesting such services, it is imperative that we address one important anthropological question: Can non-existence be considered a condition more desirable than existence tainted by suffering? After all, it is only on these grounds that euthanasia can be discussed in the context of a medical treatment. Doctors are called upon to relieve suffering – in other words, the worst condition should be improved by virtue of their actions. This is the essence of mercy. However we simply do not know what it truly means to stop existing. Shapkin euphemizes the word ‘death’ using the well-known metaphor ‘sleep’ – “the dog fell asleep for all eternity”. This widely accepted metaphor masks our unknowing and, in so doing, protects us from the horrors of death. However in reality, we have no way of knowing what lies beyond. The optimistic atheist belief that nothing lies beyond is also a risky metaphor. Under such conditions of not knowing, the more sensible choice appears to be opposing euthanasia, the “easy” death. After all, we mustn’t forget the Hippocratic oath: “First, do no harm!”

Nonetheless, it mustn’t be assumed that the position of those opposing euthanasia is flawless from an ethical standpoint. This discussion revolves around cases plagued by such tremendous suffering that even the use of pain medication is futile. In fact, ever increasing doses of medication actually hasten the onset of death by slowing down the patient’s

respiratory system. Nonetheless, doctors who oppose euthanasia have no other solution at their disposal to ease patients' unbearable pain. At the same time, the doctors cannot simply distance themselves: the patient and his/her family will demand that the doctor *at least do something*. In such situations, doctors are doomed to choose: either they will – as supporters of active euthanasia – intentionally bring upon death, or they must accept death as an inevitable side-effect of medication, which they administer in their humane adherence to the demand “Thou shall not kill!” Regardless, the result will be one and the same.

At the Dentist's Office

Here is a typical example from our everyday lives. A line of patients waits to see the dentist. Suddenly, the office administrator walks by, paying no attention to the people in line. He opens the door of the dentist's office and snaps angrily: “Natasha! Why have you referred so few patients to the x-ray office? They aren't going to make any money today!” The patient enters the examination room. After a quick exam, the doctor says: “Please take this referral and go to the x-ray office”. “Is that really necessary?” asks the patient. The dentist replies “Let's do it, just in case. You never know...” As they say: a healthy patient is just a patient without a diagnosis.

The issue here is not only that, in this situation (a common one in the service market), the patient will overpay for services, but that every additional x-ray, much like any excess medical intervention, can cause harm to the patient's health.

Can we defeat death?

Below are excerpts from an informational material published by the Russian Transhumanism Movement:

The evolution of genetic engineering makes it possible to improve the human genotype. The problems facing humanity today are so colossal, that they require the attention of individuals who are

talented in a variety of fields, who are highly advanced and evolved, who are in ideal health and who possess supreme physical and mental capabilities. Such people can be produced by means of genetic and cellular engineering. These methods can be used on newborn babies and adults alike. Individuals will have the ability to enhance the capacity of their children's bodies and minds. Objectively speaking, there is nothing wrong or unethical about this practice. There have already been world-famous scientists – including [James] Watson, co-discoverer of DNA – who said that, in substance, human idiocy, for example, can be considered a genetic disorder that will be curable in the future...

Of course there will be those who, unencumbered by the necessary knowledge, may try to ban the use of such technologies in order to legitimize their own ideological or lobbying interests. However, the history of technological advancement indicates that, in due time, their efforts will be in vain.

It is not likely that this progress will stop at correcting [human] deficiencies. Having cured disease and stopped the aging process, people will turn their attention to improving their bodies, adjusting them in accordance with their personal plans and desires. Individuals will have the ability to freely construct their bodies and minds, adding new abilities, such as the possibility of living under water, flying, living off solar energy, and even adding new subdivisions to the brain and new organs to the body. Modification enthusiasts will have the ability to make their bodies look like those of animals or mythological creatures like centaurs or mermaids...³⁴

Naturally, the context of such discussions is the potential for future developments as opposed to realistic, pending possibilities. However, let us imagine that these predictions come true sooner rather than later. Let's say, for instance, that geneticists decode the mechanisms of

³⁴ Russian Transhumanism Movement. *Genetic Engineering [Article in Russian: Gennaya Enzheneriya]*. <http://www.transhumanism-russia.ru/content/view/38/36/> (accessed 15 June 2011).

aging and death and, in turn, find a way to deactivate genes that limit individuals' lifespan. Will people ever truly become immortal? Even if nature ceases to be the source of death, there is another source, which grows in direct, positive correlation with the growing power of humanity, and that is *free will*. This free will gives people the ability to use scientific and technological advancements – including developments in genetics and nanotechnologies – against one another, developing new, more effective technologies for waging war and committing mass and individual murder.

As opposed to idiocy, which can easily become the subject of transformation, free will cannot be transformed without obliterating the very essence of what it means to be human. Although it may be possible to brainwash part of the populace, there must remain those individuals who retain their capacity to exercise free will and, in so doing, hold control over the others. Among those individuals who retain their free will and who therefore wield unprecedented power, there will always be those who choose to use that power against their own kind. The more power they have, the easier it will be for them to destroy not only separate individuals but humanity as a whole.

As a result, the future of humanity may not be eternal life, but rather the threat of ruthless self-annihilation.

Biotechnological implications for the sexual revolution of the 21st century

The sexual revolution, which was predicted by psychoanalysts such as Wilhelm Reich, Erich Fromm and Herbert Marcuse, did not dwindle down after the extravagant “free love” experiments of hippies in the 1960s. The progress of biomedical technology has created unprecedented conditions for the most radical, revolutionary transformation of human sexuality, and that transformation may very well occur in this century. This transformation will occur by means of

a total deconstruction of sexuality into a kind of human *construction set* for consumers. It is important to note that this discussion deals only with preconditions, or tendencies of cultural development, the realization or non-realization of which is dependent on other factors such as politics, economics and ideology. Our discussion does not yet include the evaluation of such tendencies. It is of principal importance to first identify and describe them and at least, for a start, recognize that they can be potentially serious problems.

We'll begin with a brief explanation. People are constantly refining themselves. However, despite providing the most radical transformation of what it means to be human, biomedical technology is a field that has been marginalized by scientific and lay communities alike. The fact that these technologies are off the radar of the general population is not surprising. However, with biologists and doctors, the situation is more puzzling. Who, if not they, can truly understand the essence of this matter? After all, what can a philosopher, or better yet, a bioethicist, understand of problems associated with cloning if he/she has not laid eyes upon a microscope or any other modern scientific technology? As a rule, lay people do not read scientific articles published in specialized journals. They rely, instead, on summaries rewritten in popular scientific sources. One who lacks knowledge and understanding has no right to affirm or contradict any position. Such discussions are common among doctors and biologists. Ultimately, micromanipulations on the cellular and molecular levels do not occur in nature, rather they are the brainchild of scientists and are conceived outside the limits of their professional expertise. Although scientists may know better than anyone else what they are doing, they have no understanding, scientifically speaking, why they are doing it. In addition, although a scientist may monitor the consequences of his/her actions with the help of a microscope or other technologies, he/she is categorically unqualified in assessing consequences that may arise on the level of human consciousness

or community structure. This aspect of the issue will dominate the discussion from here on.

Sexuality is one of the most intimate and archaic precursors of human consciousness. It is rooted in the very foundation of the human identity and its intrinsic physical manifestation in the natural world. Biomedical technologies transform the physical characteristics of sexuality, creating a clearing for the revolutionary destruction of traditional (and the creation of completely new) forms of human embodiment.

Abortions

The termination of unwanted pregnancies has been practiced since time immemorial. However only on the cusp of the 19th and beginning of the 20th centuries did abortions become a medical concern and the subject of scientific study and technological advancement. Initially, abortions were intended as a medical intervention designed to help women for whom labor posed a life threat – in other words, it was a reparative procedure combining the ideals of preempting danger and saving lives. Within that context, medical abortions were rejected only by the most radical of religious leaders. This reconstructive procedure became available only by means of the development of new, scientifically proven abortion technologies.

No sooner had doctors developed relatively safe methods of conducting abortions, than there arose a whole new range of possibilities and motivations for their utilization. Again, the emergence of these new possibilities was initially driven by purely reparative, i. e. medical goals. Abortions carried out by personal request and conducted by random individuals all too often ended in severe injury to the woman's health and, all too frequently, in death. Saving lives and preventing foreseeable harm to women's health were the driving arguments that led to the legalization of abortion on request, particularly considering the technological capabilities were already available.

Ironically, it was the next stage of the legalization process – which varied in speed from country to country and occurred under the guise of a women's rights movement – that preserved the procedure's integrity as a medical intervention. Retaining the perception of abortions as a medical imperative necessitated a fundamental shift in the original concept of the holistic nature of human beings. Simultaneously there had to emerge a new concept of suffering, characterized by shortages and disadvantages of the essence and existence of human beings. What kind of 'integrity' do abortions restore? Certainly not the same integrity envisioned in the initial stages of its evolution as a purely medical procedure. The idea is not that saving lives is the fundamental value, or definition, of preserving integrity, but rather restoring women's freedom, granting them the right to plan their lives and operate within their own discretion. In other words, this new trend of modifying the human reproductive process on personal request has engendered the redefinition of the initially reparative (i. e. medical) nature of this procedure. It is this very redefinition that has preserved the procedure's status as a medical intervention.

The ever-changing transformation of the concept of 'integrity' occurred in tandem with the evolution of the European culture. The childbearing process, once a natural occurrence and virtually unavoidable as an attribute of human sexuality, became subject to rationalization, control and planning. Anthropologically speaking, the widespread use of medical abortions led to the divorce, figuratively speaking, of the concepts of childbearing and sexuality.

Even so, advances in abortion technology took only a first and relatively small step toward the deconstruction of human sexuality. It was the development of contraception that caused the most radical changes.

Contraception

Much like abortion, the use of contraception has a long history. However the transformation of contraception into a form of medical

intervention and a topic for research occurred relatively recently, attracting the attention of the masses only in the latter half of the 20th century. The ideological underpinning for the medicalization of contraception can be found in the very ideology fueling the medicalization of abortions, namely the preservation of individual “integrity”, whereby freedom of choice becomes the top priority. The selection of contraceptives; recommendations for safe use; the development of countless mechanical, chemical and biological contraceptive elements – all this falls organically within the scope of a doctor’s mandate.

The direct consequences of relating to contraception as a reparative medical procedure are numerous practical, social and psychological innovations. A case in point is the modification of the human being such that there have emerged new images and prototypes of human life such that sexuality has been effectively divided into sex, which progresses relatively independently, and family, where the focus remains on childbearing.

The diversification that grew out of these anthropological changes is referred to in the literature as the “sexual revolution” of the 1960s. Its effects are not only the emergence of new forms of human life, but an even more radical and unforeseen transformation of the human body into a construction set used to build the intentions and dreams of the consumer. For example, the distinct separation of sex from childbearing has deemed irrelevant (within the realm of sexuality) the division of people into male and female. Thus, the idea of heterosexuality as a natural state of being is disappearing. Instead, it is becoming, much like homosexuality, just another possible kind of sexual orientation.

The transitional stage of human sexuality is related to the transformation of the reproductive process.

New Reproductive Technologies

Abortions and contraception afford individuals only external control over their reproductive process, either by preventing it to begin

with or by terminating it once it's already begun. New reproductive technologies interfere with the body's natural flow, giving rise to yet another set of anthropological consequences. Due to the reparative (i. e. preserving integrity) intentions upon which the initial stages of development were based, these technologies continue to be justified on medical grounds: The 'illness' that they treat is infertility. In this case, treatment is not intended to fix something that is 'broken' within a woman or a man, but rather to create artificial systems that replace natural ones.

It is important to note that, in such cases, the problem can only be "fixed" by means of technological transformations of the reproductive processes themselves. Artificial insemination, which the medical field adopted from animal breeders, became widespread at the end of the 1970s and beginning of the 1980s. Almost immediately, technologies for extracorporeal fertilization (i. e. "test tube" fertilization) – whereby the fertilized embryo is implanted into a woman's uterus – were developed and began to spread. As mentioned in earlier examples, innovations that create new processes with the intention of preserving human integrity inevitably lead to the further deconstruction of human sexuality.

Abortion and contraception technologies have managed to separate sex from childbearing, although childbearing is still (at least for the time being) associated with family. Artificial reproductive technologies have similarly transformed natural forms of familial self-identification, i. e. mother, father, son, daughter, grandson, granddaughter, grandmother, grandfather and so on. Each of these roles has now effectively been split into two parts, namely into "biological" and "social" functions. For example, the role of a biological father – i. e. a sperm donor – can be quite different from that of a social father who actually raises the child. In the case of test-tube fertilization, there are situations in which one or even both of the parents can have split roles. Also, an egg fertilized in a test-tube can just as easily be implanted into the uterus of the future social mother or a surrogate, adding yet another element to the equation. In other words, it is possible for a child to have two fathers and three mothers;

three mothers and one father; two parents from each side; and so on and so forth. In the more common case, whereby the social mother also carries the child, there also arise complexities of self-identification. For example, if a woman donates an egg to her sister, she will be both the child's biological mother and social aunt. As such, the natural family unit is morphing into a kind of construction set where, by choosing different elements, one can create a variety of combinations.

The analogy of the body to a construction set epitomizes the transformation of human body parts, such as sperm and eggs, into marketable commodities. In addition, there is a growing demand for the services of women willing to carry and birth test-tube babies.

In short, as new reproductive technologies are invented, people become more and more apt to deconstruct their own sexuality.

It is worth noting that the increasing role of technology in the reproductive process goes hand-in-hand with the increasing role of technology in providing sexual pleasure. Artificial vaginas, for instance, were developed by scientists for collecting sperm from donors, and have quickly made it to the counters of sex shops right alongside the vibrators. Such technology has become so widespread that some brothels in Southeast Asia have even become the stage for fierce competition between members of the world's oldest profession and mechanical sex devices.

The next jump in the radicalization of human sexuality occurred with the introduction of transsexuality.

Transsexuality

Not surprisingly, the extravagant medical procedure used for sex change operations initially emerged in the form of a medical intervention to treat various forms of hermaphroditism. In this case, however, the intervention was not designed to restore individuals to their "original state", but rather to create something entirely new. Thus the essence of the medical treatment is more constructive than reconstructive.

This constructive element is particularly evident considering most such procedures are conducted to treat problems of a psychological, rather than biological, nature. This occurs when individuals come to the realization that they cannot go on living in the male or female body that they have inherited, so they turn to doctors for surgery and hormone therapy. This has allowed medical technology to construct a human gender by the request of the “patient”, essentially creating a man or a woman out of pure biological potentiality. In other words, the human body has, in essence, become a construction set and consequently, the foundation of sexuality, which lies in identifying oneself as a woman or a man, has become a social construction set.

In 2008, the media reported that a man named Thomas Beatie, 34, gave birth to a baby girl. Beatie was born and lived as a woman until he underwent a sex-change operation in 1998. Beatie was married but his wife was unable to produce a child so, having retained the necessary organs, he decided to undergo a new course of hormone therapy that temporarily restored his ability to bear children. He gave birth to his daughter using donated sperm and then, with the help of doctors, returned to being a man.

Cloning

In spite of their innovations, transsexual technologies have retained the distinguishing features of the male and female genders. Cloning is a reproductive technology that produces a human being not from two people (i. e. mother and father) but from one person, indiscriminant of gender. Such procedures remove female and male indicators, which have, throughout history, determined the dynamics of our cultural evolution as well as the personal development of each individual. Yet again, advocates for cloning base their strongest arguments on medicine, citing cloning as a solution for a variety of medical problems (e. g. certain types of infertility) or the need to help persons who have lost a loved one and who wish to

alleviate their suffering by creating a clone (a biological copy) of the person they lost.

It is becoming evident, however, that the development of reproductive cloning, which by virtue of its creative nature, consists of constructive procedures, is an equally powerful force in deconstructing the most fundamental attributes of human sexuality. Reproduction will be detached from the most primal elements of humanity, namely the differentiation between man and woman. In reality, this differentiation will become inconsequential, much like in the case of homosexuality. It will be nothing more than a sexual orientation that can be changed at will.

The next foreseeable development that will undoubtedly contribute to the multifaceted deconstruction of human sexuality will be the creation of the artificial womb.

The Artificial Womb

The medical community's dream of creating an artificial womb is not surprising. The successful actualization of this undertaking will place the entire reproductive process – from conception to birth – in the hands of scientists. In the process, a number of congenital pathologies and their treatments will be discovered more quickly than ever before. Additionally, women will be free from the risks associated with pregnancy and childbirth. Even now, thousands of women die every year during childbirth. Thus the argument in favor this technology on medical grounds is more than justified.

That said, the creative (i. e. constructive) attributes of these types of “treatments” are also becoming increasingly apparent. After all, the issue at hand is concerned with the most radical modification of the human condition. For the first time in history, the most fundamental biological process will be extracted from the domain of the human body and entrusted to a mechanical device.

It is important to draw a distinction between the artificial womb and other artificial organs, such as kidneys, liver, heart, lungs, etc. The difference lies in the fact that traditional artificial organ systems support the life of an original body given by nature. In other words, they are used to compensate for the work of damaged organs. The artificial womb, on the other hand, will extract from the human body (deeming it almost inconsequential) a natural process and transform it into a technical system. Femininity will become a kind of “sexual orientation” that has nothing to do with the idea of motherhood. Additionally, there will be a radical transformation in self-identification for people ‘conceived’ through the cloning process and born from a machine. After all, such an individual’s only natural connection to another human being will be through donated cells.

The “Happy Pill” of the Future

Likely the last piece of the puzzle to complete the deconstruction of human sexuality will be the developments of modern psychopharmacology—the development of a “happy pill” — a new family of anti-depressants that are coupled with various forms of physical pleasure that may include sexual gratification. Individuals will be free from the risks associated with recreational sex. The dangerous chain of the spread of HIV, hepatitis and other sexually transmitted diseases will be broken. Humanity will become healthier and happier. Of course, there is a high degree of ambiguity about what, if anything, intrinsically “human” will remain in this kind of humanity.

This ambiguity is a clear indication that behind of all these biotechnological innovations, the complete annihilation of the essence of humanity may have already begun. The shadow cast by unfathomable, uncontrollable and unpredictable risks is growing. Traditionally, the scientific world viewed ‘risk’ as a consequence of insufficient scientific knowledge. Today, however, risks are growing and globalizing as a direct

result of scientific progress. Incidentally, these risks are not limited to the physical world, but also to the metaphysical one – namely the risk of losing the very essence of our ‘humanness’. These threats are particularly real considering they often go unnoticed by the very doctors and biologists who make the decisions to pursue various technological innovations.

Epilogue

In our examples, there is an element of what in moral philosophy is known as the “slippery slope” argument. In order to achieve what appears to be a beneficial end, it may be necessary to take a small step away from traditional, absolute, unconditional values. However it is as a result of this very step, regardless of how small, that man finds himself standing atop a figurative slippery slope. In fact, even by simply taking the liberty to begin on this journey, he deprives himself of a reference point for where to stop. He rids himself of his nagging conscious that would stand in the way of reaching his desired, virtuous goals – particularly because each step, in and of itself, appears to be so small. The result is a steadfast downward spiral. For the progressionists, it appears as an upward movement. For followers of Ecclesiastes, this is but another in the endless string of battles between good and evil.

This, however, is not a new phenomena, finding its basis specifically within the realm of human culture. The Biblical story describing the fall from grace has countless analogous accounts from other ancient sources describing the same (or similar) events. Contemporary biotechnological achievements vest the human psyche with *yet another* (of countless calls in the past, present and future) call to overstep its own boundaries. We must resist innovations that destroy the essence of humanity and strive to preserve ourselves unchanged and as created by nature.

There is, however, another perspective on biotechnological progress, which is transforming the human existence both in substance and in form. After all, that which makes humans human is not a preexisting

absolute bound by traditional taboos and moral restrictions. Rather at its foundation lies that very urge to overstep existing, ready-made structures: the tendency of self-transformation and the creative energy to devise ever-changing forms of the essence and existence of humanity.

The situations addressed in this text were intended to demonstrate the critical contradictions and aporias that are inextricably tied to advances in biological and medical science. It is these difficult issues that provide fertile ground for the growth of the field of bioethics.

IV. Social Justice as the Most Acute Bioethical Issue in the Russian Federation

Problems of social justice in health care are being widely discussed throughout the world. However in this chapter, we will present a case study of those discussions as they are currently unfolding in the Russia Federation.

We will begin with some clarification regarding social justice in the context of bioethics and human rights. There are two main questions to address. Firstly, why is social justice in health care being addressed outside the realm of the medical profession? In reality, bioethics is an interdisciplinary field that brings together philosophers, religious leaders, lawyers, sociologists, biologists, journalists and, of course, physicians. However, could it be that this very same diversity actually risks compromising the discussion of social justice in health care? More specifically, might the invasion of dilettantes, who haven't the slightest understanding of how health care is organized, resort to, instead, simply trying to remedy the slip-ups of specialists?

Secondly, what sense is there in involving human rights in a discussion on social justice and bioethics? Notably, the subject of human rights has not gained much "popularity" in Russia in recent times. Even when addressed, it is done only insofar as it relates to political rights, such as freedom of speech, religion, assembly and so on. However, and not to belittle the importance of those rights, it is important to note that they alone are insufficient for sustaining human life. There exist other equally important rights, such as socio-economic rights, including the right to work and be appropriately compensated for that work; the right to education; and so on. Another set of rights, that can be called *vital rights*, include the right to life, health (more commonly referred to as the right to healthcare), preserving one's integrity

and personal dignity, etc. Without ensuring this last set of rights, there can be no demand for any of those previously mentioned.

We will now attempt to address the abovementioned issues. To begin, it is important to understand that providing equitable access to the full spectrum of health services is not the concern of physicians alone, but of each and every Russian. Naturally then, it is clear that any debate on related issues must include the input of all those affected by past, present or future transformations of the health care field.

In connection with this, there are two interconnected circumstances to consider. First: Russian citizens do not currently receive any credible information about actions being taken to reform the health-care system. Secondly: it is imperative that citizens *not only have a solid grasp of what is happening in regard to health-care reform, but that they actually take an active role in affecting it.*

At first glance, bringing politics into a discussion regarding health care may seem inappropriate: after all, politics is an area dominated by statesmen. It is an inviolable statement of fact, however, that these kinds of politics do exist. Unfortunately, existing health-care structures systematically fail to acknowledge the opinions and views of Russian citizens regarding their perception of the government health system; what they consider to be top priorities; and what they perceive as just and unjust. Those individuals, who are in the position to affect health policy, do not even entertain the idea of studying and considering the public's perceptions and opinions as a reference point in their decision-making.

It is a common assumption that, in recent years, the Russian population has grown apolitical. This might be true if we were to measure political participation by examining citizen interest in party platforms or even by the proportion of people participating in elections. However, the reality is that the political livelihood of a population cannot be defined by such narrow parameters. There are a variety of issues that arise in civic life that elicit the genuine interest of Russia's citizenry, and it is these processes and phenomena that should take center stage from a political standpoint.

A case in point is the public response to the enactment of Federal Law 122 on the monetization of benefits in 2005. As it turned out, not only were regular citizens uninformed about and unprepared for the changes called for by the new law, but the same rang true for a majority of those people who were directly responsible for enforcing it. The impassioned reaction of the Russian public not only demonstrated that they were able to express their opinions in the form of serious protests, but that the administration's attempts to carry out reforms over the heads of its citizens would not be taken laying down.

There is no question that gathering and extrapolating the opinions and positions of the Russian public and ensuring their authentic participation in the development of policy related to health or any other areas of social importance such as education, is no simple feat. After all, the range of opinions on what is just and what is unjust in the existing health system is vast beyond words. There are tremendous challenges in identifying this range of opinions, systematically organizing them and conducting public debates on relevant issues. Currently, there is no methodological foundation for achieving these ends, particularly on such a large scale. However despite the challenges, this is the only real way to develop health-care policies that the population will accept as fair and just.

It is important to remember that the concept of justice lies at the heart of ethics. Consequently, it makes perfect sense to use the field of bioethics as the stage upon which to construct and refine the mechanics of creating a participatory civil society that is fully engaged in developing and enacting health-care policy.

The role of social justice in guaranteeing the health of the population is one of the most highly debated topics in bioethics today. Its importance is reflected in the UNESCO Universal Declaration on Bioethics and Human Rights. Although the UNESCO Declaration is far from the first international document to outline the principles and norms of bioethics, its uniqueness lies in the delineation of a series of new traits and distinctive features. The power of these distinctions lies in the fact that the Declaration

was developed by the widest possible array of experts, representing all regions of the world: it truly the product of the international community. More so than any international document on bioethics preceding it, the UNESCO Declaration addresses the specific problems and interests of the developing world. The text of the Declaration clearly demonstrates the shifting interest in bioethics resulting from the growing number of people in third-world countries who are opening their eyes to these problems. Consequently, there is an accompanying shift in emphasis regarding the interpretation of key bioethical principles.

For instance, previously, social justice, which today is one of the driving principles of bioethics, was far lower on the list of priorities. However due to recent developments, social justice has come to the forefront, specifically as it pertains to individual health as well as access to and quality of medical services. This shift in focus is the result, in large part, of the growing role of the developing world in shaping the global bioethics agenda.

Problems of social justice have taken center stage both for bioethicists from developing countries as well as for the field of bioethics as a whole. One of the main topics of discussion is ensuring equitable access to new biomedical innovations. Many of these innovations provide tremendous opportunities for rehabilitating and sustaining individuals' health. However today, access to such opportunities is far from equitable. It is particularly troubling that the gap between those who have access to new technologies and those who do not is actually growing at an alarming rate rather than shrinking. In fact, this gap, which is becoming colossal in size, has been recognized by the international community as one of the most pressing problems in health today. To put it in perspective, currently, 90 percent of resources spent worldwide on biomedical research focus on curing illnesses that affect only 10 percent of the world population. Conversely, only 10 percent of funding for research goes to studies seeking cures for illnesses affecting the other 90 percent of the population!

Returning now to the situation in Russia, it is worth noting that, slowly but surely, there has been growing appreciation for the need to move

health care to the top of the list of priorities not only for the government, but for civil society as well. Nonetheless, there arises again and again a strange, albeit familiar, phenomenon. Although we are constantly told that the most worthy use of funds is investing in people in such a way that it benefits both the individual and the general population, when the time comes to form budgets at all levels, it just so happens that everything associated with the health of the population, falls under the heading of “losses”.

Meanwhile, the substantial growth of Russia’s high-tech industry in recent years, has led more and more companies to recognize the correlation between maintaining a successful business and retaining and developing highly qualified and extensively trained personnel. Because for such companies human capital is the most critical asset, they have developed special programs to protect and enhance employee health.

One major challenge has been citizens’ lackadaisical attitude toward their own health. Many Russians have preserved the paternalistic mindset inherited from the Soviet and pre-Soviet eras whereby they rely predominantly on the government to take responsibility for their health. The government is attempting, however, to gradually shift that responsibility onto the shoulders of its citizens. Little by little, the population’s attitude toward personal health has been changing: this is no small feat and it provides a glimpse of hope for the future.

As time goes on, we can only hope that Russian bioethicists will be more thorough in addressing social justice concerns. The field of bioethics has incubated a number of important mechanisms that are worthy of implementation in other areas. Such mechanisms include informed consent and ethical review, which allow laypersons (i. e. end-users of medical innovation) to truly have a say in decisions about their health.

V. Bioethical Commentary on the Case S. Mitina and S. Shtarkova v. *SPID-info*

On February 2, 2010, the Public Board for Media Appeal met in the Central House of Journalists in Moscow to review a petition from parents of disabled children against the Russian newspaper *SPID-info*. In 2009, the newspaper published an article by Alexander Nikonov entitled “Finish them off so they don’t suffer!” The article called for killing babies born with genetic or psychosomatic disorders. From a bioethical standpoint, there are several possible angles from which to view this event.

First off, the journalistic community is faced with a serious question: in what context and using which journalistic tools is it justified to discuss a topic so sensitive as the right to life of a congenitally disabled baby? The entrepreneurial laws governing mass media demand high-interest stories and reward provocative perspectives on various issues. The question, then, is how to avoid causing harm in the process and how to prevent triggering additional pain for people, who already find themselves in a difficult life situation. After all, in the field of medicine, such cases are a dime a dozen.

Then there arises a counter-question: how, and by means of which tools available to civil society, is an individual to respond to a journalist who, in his/her opinion (or in the opinion of a certain group), has overstepped acceptable boundaries, resulting in moral trauma either for an individual or the community? Should victims or their sympathizers be limited in what they are permitted to say while expressing justified anger? Can it be that, in some cases, the language of even well intentioned criticism may contain the very root of aggression? We live, metaphorically speaking, in a language-based world, which demands protection of and careful attention to all persons wishing to publicly express their thoughts and opinions.

Thirdly, it is critically important to establish a protocol for resolving conflicts. In Russia, when conflicts arise, the Public Board for Media Appeal forms an ad hoc committee, which, in essence, acts as a professional ethics committee. Both sides of the conflict must recognize the Board's jurisdiction, thereby creating the legal framework for reaching a resolution. The opening chapters of this book addressed the "invention" of ethical committees and their expansion worldwide.

Lastly, the Board, in fulfilling its function as an ethical committee, not only made a decision regarding the specific circumstances of this case, but also developed a set of norms and recommendations for journalists covering topics pertaining to human suffering. We will compare these norms to similar ones already being implemented throughout the world.

To begin, below is a compilation of materials on the given case.

"Finish them off so they don't suffer!"
by Alexander Nikonov

The birth of a retarded child into a family is tragic. People have children to bring them joy, not suffering. THAT IS WHY THE MAJORITY OF NORMAL PEOPLE TURN THEIR DEFECTIVE CHILDREN OVER TO THE GOVERNMENT. Our government is kind and keeps [these children] far from the public eye as the sight of [them] is not for the faint of heart. Our orphanages are already no bowl of cherries, so asylums for the mentally unstable are a complete disaster. On first thought, it may seem more fitting for a retard to be raised in a family, but this impression can be misleading.

The fact is, families who bring home a mentally retarded child often fall apart. As a rule, the man is unable to withstand the torture, so he leaves. As a result, the woman's anguish intensifies. It continues to grow with every passing year as the woman begins to realize that, in her old age, not only will her child not be a source of support, but he will be a burden on her until the day she dies. And still worse [is the question of] what will happen to that child after [the mother dies]?

At least in an asylum retards are raised around people similar to themselves, allowing them, at least in some way, to socialize under supervision. Where will a 40-year-old retard go when he is suddenly bereaved of his mother's care? Who needs him?

Wouldn't it be more humane to euthanize such children at birth? After all, the destruction of a newborn is, in essence, no different from an abortion or a so-called partial birth (or post-natal) abortion. The result in both cases is the termination not of a conscious being, but only a mold for a potential being in the future. [And what] if that mold proves to be defective? Today there is much talk in the world about euthanasia, whereby an ill person, experiencing excruciating pain, requests that his doctors end his life in order to alleviate his unbearable suffering, and the doctors agree. But there are times when the patient cannot himself request this final act of mercy, such as when he is in a coma, from which, the doctors say, he will never recover. In essence, the person turns into a "vegetable". At this point, [the patient's] closest relatives step in and ask the doctors to disconnect the "vegetable" from life support. I am convinced, that the same right should be extended to parents of newborn retards, because their illness is incurable. The life of an inadequate person causes nothing but suffering. He cannot make the request for it himself: someone must help him.

This is what we call being humane.³⁵

Petition to the Board from Snezhana Mitina and Svetlana Shtarkova

Respectful colleagues!

The newspaper "SPID-info" (No. 25, 2009) published the article "Finish them off so they don't suffer!" by A. P. Nikonov.

³⁵ Nikonov A. Kill them off so they don't suffer! [Article in Russian: Dobei chtob ne muchilis]. *Spid-info*. December 2009. http://www.presscouncil.ru/index.php?option=com_content&task=view&id=365&Itemid=31&limit=1&limitstart=1 (Accessed 15 June 2011).

On an aside, I'd like to point out that the year in which the article was published was designated "The Year of Equal Opportunity" in Moscow.

I understand that our country guarantees freedom of speech and that one could say that this article is but the personal opinion of the author, and he has every right to express it.

However, the author is not raising a disabled child, so his sweeping generalizations and conclusions about the lives of such children and their families, and his use of terms such as "hell", "suffering" and "burden" are nothing but speculation as the article has no sources and no concrete examples. I, as the mother of a disabled child, proclaim that, based of my personal experience, the given argument has no basis in reality and is therefore invalid.

In describing disabled children, the author uses the words "retards," "defective" and "vegetables" while parents who choose not to give up their children to an orphanage are deemed not to be 'normal'. This crosses the line of personal opinion and is simply disrespectful and offensive.

The author insists that disabled children have no place in a family. In so doing, he plants a seed in the reader's mind that disabled children should be left in orphanages – after all, that is, in his opinion, what "normal people" do. This is, in its own right, the propaganda of social orphanacy. And although there is no prohibition in our country's legislation against placing children into orphanages, the Constitution of the Russian Federation states that every child has the right to a family and that raising children in a family is a top priority.

The very title of the article is outright extremist and discriminatory: "Finish them off so they don't suffer!" The Convention on the Rights of Persons with Disabilities, signed by the Russian Federation in 2009, reads: "'Discrimination on the basis of disability' means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field."

Russians today have inherited from the Soviet Union a negative, disrespectful image of disabled persons. Now, the government and disabled persons themselves are trying to break this stereotype and instill a tolerant and considerate attitude toward people with limited abilities. Not only do such articles not contribute to these efforts, they actually get in the way. This is evidenced by the countless cruel and demeaning comments left on the author's Live Journal page.

Perhaps SPID-info has a certain image and readership that leads its editors to harbor thoughts that there is no need to pay attention to "such people". Nonetheless, the newspaper has a circulation of 700,000 and the author is a famous journalist and writer who has received several awards, including those granted by the state.

Article 5 of the Code of Professional Ethics for Journalists in Russia states: "In carrying out his/her professional duties, [the journalist] must counter extremism and infringement of civil rights on any grounds including sex, race, language, religion, political or other views, and – in equal measure – social and national origins.

Journalists must respect the honor and dignity of people who become the subjects his/her professional attention. He/she must refrain from all derogatory insinuations or commentaries regarding race, nationality, skin color, religion, social origin, sex and – in equal measure – individuals' physical deficiencies or illnesses."

Article 7 of the Declaration of Professional Conduct of Journalists states that "a journalist must be aware of the dangers inherent in inciting discrimination by means of the mass media, and he/she must take all possible measures to avoid even unintentional discriminatory provocation on the grounds of race, sex, sexual orientation, language, religion, political or other views, and national or social origins."

I believe, that by publishing his article, the author, Alexander Nikonov, is in complete violation of both principles.

Based on the above arguments, I ask the Board to review my complaint with the intention of publishing an apology from the journalist, Alexander Nikonov.

*Snezhana Mitina
Svetlana Shtarkova*

Resolution of the Public Board for Media Appeal

Moscow, 17 February 2010

No. 43

The 40th session of the Public Board for Media Appeal ad hoc committee consisting of the Chairman of the Chamber of the Media Community Mikhail Fedotov (presiding), and members Eugeniya Abova, Sofia Dubinskaya, Aleksei Venediktov, Yassen Zassoursky, Alexander Kopeik, Irena Lesnevsky, Irina Petrovskaya, Nikolai Svanidze, Svetlana Sorokina; members of the Chamber of Media Consumers Leonid Borodin, Yury Kazakov, Alexei Kara-Murza, archpriest Alexander Makarov, Dmitry Oreshkin, Henry Reznik, Georgy Satarov in accordance with Article 7.5. The committee reassessed the resolution of the Public Board of 2 February 2010, No. 42 “On the complaint by Snezhana Mitina and Svetlana Shtarkova against the newspaper SPID-info in connection with the publication of the article by Alexander Nikonov entitled “Finish them off so they don’t suffer!” and came to the following decisive resolution:

RESOLUTION

1. It is the belief of the Board that the problems facing persons with physical handicaps (including children with disabilities) and their families must, much like euthanasia, be published and discussed in the media. However, the publication of materials regarding these issues requires extreme care, compassion and sensitivity. A journalist writing on such topics and an editor publishing such materials must be aware of the complexity, profundity and delicacy of the issues at hand. Demand on the part of the public for materials on this topic can in no way serve as justification for intentionally provoking controversy or resorting to sensationalism.

The article “Finish them off so they don’t suffer!”, published in the newspaper SPID-info in Alexander Nikonov’s column, does not fulfill the above criteria. The author’s position, by his own admission, has no basis in any in-depth research on the topic. The objective of

this article – both on the part of the author and the publisher – was to attract readers by provoking a scandal around an issue that, quite to the contrary, requires from journalists and editors alike a most cautious, guarded and tactful attentiveness to each word.

2. *The Board takes into consideration the position of the European Court on Human Rights, which states that the right to self-expression “is applicable not only to information or ideas that are favourably received or regarded as inoffensive or as a matter of indifference, but also to those that offend, shock or disturb the State or any sector of the population” (The Sunday Times v. The United Kingdom, 1979); and “journalistic freedom also covers possible recourse to a degree of exaggeration, or even provocation” (De Haes and Gijssels v. Belgium, 1997). In the opinion of the Board, “journalistic provocation” may include methods of information-gathering (such as when journalists take on other professions to report on them) or presentation (e. g. a headline with shock-value), which may be deemed necessary or ethically justified in a particular situation. In any case, the use of “journalistic provocation” must be aimed at protecting the interests of the public.*

The Board sees Alexander Nikonov’s column as nothing more than provocation for the sake of creating a buzz around the author’s own persona at the expense of certain sub-groups of persons with disabilities and their loved ones, all of whom have the right to noninterference in their private lives. The newspaper’s gross violation of this most delicate sphere of human relationships is offensive and has been the cause of suffering, perpetuated by the journalist’s use of derogatory, stereotypical references that are held to be entirely unacceptable for any publications on the given issue. Thereupon, the Board brings to attention the requirements set out by PACE [Parliamentary Assembly Council of Europe] Resolution 1003 (1993) On the Ethics of Journalism: “In journalism, controversial or sensational items must not be confused with subjects on which it is important to provide information. The journalist must not exploit his duties for the principal purpose of acquiring prestige or personal influence.”

3. *In any publication that either directly or indirectly addresses questions of life, death or violence, the journalist must operate out of the*

understanding that the right to life takes precedent over all other rights and liberties. The Board has observed clear discrepancies between the text of the column under investigation and the author's verbal testimony in the course of the hearing. In his statements, the author insists that he is an advocate for parents' right to free choice in determining the fate of their disabled children. However, the text of the column affirms that, in the opinion of the author, the only sensible choice is to end the lives of such children. This conclusion is evident even from the title of the article "Finish them off so they don't suffer!", which can be interpreted as a direct incitement to end the lives of children with disabilities. All of these factors blatantly contradict the Journalists' Code of Professional Ethics of the Russian Federation (1994), which states: "the journalist fully acknowledges the dangers of restrictions, persecution and violent reprisals that his work may incite."

4. According to the Declaration of Principles on the Conduct of Journalists, ratified by the International Federation of Journalists in 1954, "The journalist shall be aware of the danger of discrimination being furthered by the media, and shall do the utmost to avoid facilitating such discrimination based on, among other things, race, sex, sexual orientation, language, religion, political or other opinions, and national or social origins."

The Journalists' Code of Professional Ethics of the Russian Federation (1994) also demands [journalists] to respect the honor and dignity of those people, who become the subjects of their professional attention. "The journalist shall refrain from the use of any disparaging claims or remarks regarding race, nationality, skin color, religion, social origin, sex and physical insufficiencies or illnesses."

PACE Resolution 1003 (1993) "On the Ethics of Journalism" established a similar principle, namely that "the media have a moral obligation to defend democratic values: respect for human dignity, solving problems by peaceful, tolerant means, and consequently to oppose violence and the language of hatred and confrontation and to reject all discrimination based on culture, sex or religion."

Under the circumstances, the Board unequivocally asserts that the column by Alexander Nikonov incites discrimination against disabled

children by refusing them the right to life, and similarly, against their parents – refusing them the right to be considered sensible individuals.

5. The Board ascertains that the editorial board of the newspaper SPID-info – marketed as a popular science publication – having made the choice to publish the scandalous column on euthanizing disabled children, should not have relied exclusively on their standard disclaimer that states: “The views and opinions expressed in this article are those of the author and do not necessarily reflect the position of the editorial board.” Having made the author’s column on euthanizing disabled children overtly scandalous, the editorial board should have taken care to balance the accentuated journalistic provocation of its writer by providing additional information from different points of view. Due to this neglect, the editorial board bears equal responsibility with the author for the gross violation of the rules governing professional ethics in this case of reporting on the problems of children with physical insufficiencies and their families.

6. Having taken into consideration the title and text of Alexander Nikonov’s article in their entirety, the Board considers this publication to be a prime example of immorality and journalistic unprofessionalism.

7. The Board also states that, in adherence with Decision No. 42 on 2 February 2010, the newspaper SPID-info must revisit the issue of disabled children and afford the petitioners, Snezhana Mitina and Svetlana Shtarkova, the opportunity to set forth their opinions on the matter. As agreed upon with the petitioners, the newspaper published an article entitled “Children are for pure joy”, which expressed the perspective of a mother raising a disabled child. Additionally, the newspaper published key sections of Resolution No. 42.

Under the given circumstances, the Board invites the editorial board of SPID-info to host a discussion among its staff and inform its readers about this new Resolution.

8. The Board appeals to the editors of other print and internet media, as well as TV networks and radio stations, with a call to exercise vigilance in fashioning well-rounded and thoughtful discussions around real (as opposed to scandalous) issues related to sustaining, treating, adapting to, raising and educating children with disabilities.

9. The Board reminds both sides in this case that, based on the moral obligations they took upon themselves in signing the agreement recognizing the professional and ethical jurisdiction of the Board, the Resolution presented here puts an end to the given debate. Their case will not be examined further either in court or in any other federal or local government institution.

10. The Board requests that:

The editorial board of the magazines “Zhurnalist” (Journalist) and “Informatsionoe Pravo” (Right to Information) publish the above Resolution.

The Faculty of Journalism of Moscow State University in the name of M.V. Lomonosov as well as the journalism faculties of other universities discuss the Resolution of the Board with colleagues and students studying professional ethics.

The Russian Federation’s Public Chamber Commission on communication, information policy and freedom of speech in the mass media take account of the above Resolution of the Board.

The above Resolution was approved by a majority vote with two dissenting votes.

Chairman of the Board,

M.A. Fedotov

Professor and Doctor of Juridical Science

Bioethical Commentaries

Despite our emotional immersion and, in some measure, our involvement in this case, it is not the objective of our commentary to express our personal reflections. Instead we will address the specific questions posed at the beginning of this chapter as they relate to the above case.

First and foremost, we must render a full account of what methods and tools journalists have at their disposal to justify covering such a sensitive topic as the right to life of a newborn with congenital birth defects.

The Board provides a clear answer to this question, citing the European Court on Human Rights, which states that freedom of self-expression “is applicable not only to information or ideas that are favourably received or regarded as inoffensive or as a matter of indifference, but also to those that offend, shock or disturb the State or any sector of the population”³⁶ and that “journalistic freedom also covers possible recourse to a degree of exaggeration, or even provocation”.³⁷

This right is universally recognized. On one hand, it lays the foundation for one of [society’s] most fundamental values, namely freedom of speech. On the other hand it solves, at least in part, the technical challenges of focusing on certain issues of interest and relevancy. It is worth noting that the concept of free speech as a liberal value emerged only at the end of the 18th and beginning of the 19th centuries. Freedom of speech does not exist in and of itself: it exists only as a public process of debates with clashing values and ideas that, eventually, lead to a conclusion that serves the public good. *The objective is to reach a decision not by means of force (i. e. governmental, religious or other) but by means of open discussion* with the participation of people who believe in different gods and who adhere to different conceptions of good and evil; truth and illusion.

Hence the question is not simply a matter of an individual’s public self-expression as value in and of itself – this is inevitable in any publication. In keeping with the liberal ideal, it is no coincidence that the Board states: “In any situation, the use of ‘journalistic provocation’ must have as it’s main objective protecting the public interest”. In this case, the public interest does not coincide with the interests of the government. All too often, governments operate not in the interests of their people, but in the interest of the ruling elite.

³⁶ European Court of Human Rights. *The Sunday Times v. The United Kingdom*. Strasbourg; 1979.

³⁷ European Court of Human Rights. *De Haes and Gijssels v. Belgium*. Strasbourg; 1997.

The concept of freedom of speech may be tied to another seemingly obvious judgment of the Board: “A journalist writing on such topics and an editor publishing such materials must be aware of the complexity, profundity and delicacy of the issues at hand.” The truth is that the word “complexity” is not limited to describing the difficulty of solving a problem, such as proving a mathematical theorem, for example. Problems that possess only one possible solution may be difficult without, scientifically speaking, being “complex”. Freedom of speech is essential for solving the *complex problems of humanity*. In fact, understanding these problems assumes the possibility and the need for diverse approaches and positions. Meanwhile, the solutions lie in several possible outcomes, none of which can be accepted as absolute truth. When making the case to a reader or a viewer on a particular issue, a person cannot simply stand up and declare, “Well, this is how I see it!” After all, this might incite another person to get up and say, “Well, I believe something different!” What are these gentlemen left to do? Should they charge at one another into a physical confrontation, after which the winner is deemed to have been correct? Or should they await the arrival of an esteemed lord to state his judgment? The ideal of free speech assumes that there is another way: open public discourse that moves toward reaching a general consensus. The above experience of the Board serves as a prime example of this very approach to solving complex conflicts.

In other words, the emphasis, appropriateness and timing (the three conditions deemed by the Board to determine tastefulness) of using different perceptions, ideas or approaches must be based not on our, or someone else’s, personal values, but on honest, open discourse. Herein lies the value of recognizing dissidence – and not for the sake of political correctness, but rather with the understanding that we must not only politely accept, but indeed anticipate conflicts regarding complex human circumstances. Differences in opinion are unavoidable and taking them into consideration is critical.

It is a prerequisite for effective public discourse that people identify with one another as self-contained individuals rather than representatives

of the anonymous collective powers that be. It is for this reason that the Board reproduced the *Journalists' Code of Professional Ethics of the Russian Federation* (1994), which demands of journalists to respect the honor and dignity of those individuals who become the subject of their professional scrutiny. “ [The journalist] must refrain from all derogatory insinuations or commentaries regarding race, nationality, skin color, religion, social origin, sex and – in equal measure – individuals’ physical deficiencies or illnesses.”

Despite addressing a wide range of circumstances, bioethics places special emphasis on society’s most vulnerable groups. As such, it is appropriate that the Board condemned Nikonov’s publication, stating that his “gross violation of this most delicate sphere of human relationships is offensive and has been the cause of suffering, perpetuated by the journalist’s use of derogatory, stereotypical references that are held to be entirely unacceptable for any publications on the given issue”.

Another precondition for protecting freedom of speech in the public arena is a consensus of non-violence among all participating parties. Both sides of the given case agreed to the legitimacy of resolving their conflict within the framework of the Board and, in so doing, took the first and most important step to this end. Unfortunately, that is where they stopped. After the resolution was reached (just as before the case was considered), *the opponents continued to use aggressive rhetoric* that completely precluded persons with dissenting opinions from engaging in the discussion. If someone describes his opponent as a ‘fascist’, ‘bastard’, ‘moral moron’, etc. and her opinions as ‘putrid’, then his arguments cannot be defended by the right to free speech and they are deemed illegitimate for public discourse no matter how logical they may appear. These arguments, by virtue of their disparaging nature alone, fall on deaf ears. Abstaining from linguistic assault (which can be considered the weapon of a cold civil war) is an absolute prerequisite for nurturing a fruitful civil dialogue.

VI. Essential Ethical Principles for Journalists Covering Health Issues

We will now describe several considerations about the role of medical journalism in today's society. More specifically, we will focus on the realities of medical journalism in Russia, keeping in mind that many countries throughout the world are experiencing similar issues.

First, it is important to acknowledge that the role of medical journalism can be multifaceted. Official Russian news sources report that healthcare in modern-day Russia has retained the positive traits characteristic of the Soviet-era health system, namely that it is free – the only difference lies in contemporary legislation's adoption of a policy of obligatory health insurance. These sources similarly report that the system is constantly being strengthened, financing is improving and new programs developing high-tech medical centers are emerging. High-profile physicians express their gratitude to the authorities, all the while requesting more and more resources to help their suffering patients. Patients, too, are unanimous in their gratitude. Of course there are flaws, but they have been identified and all guilty parties have been admonished. Within the coming months, they will be held to account and report. In other words, things aren't so bad.

Changing the channel, we encounter a journalistic investigation exposing the squalor of provincial health centers; bribery among medical personnel in clinics and hospitals; cancer patients being thrown to the whims of fate; deception of patients receiving state benefits; fraud in commercial medical institutions; patients being maimed by incompetent doctors; and a friendly lashing of medical workers making the slightest effort to obtain remuneration from their suffering patients.

Moving on, we flip to a commercial broadcast in which the actual commercial content is concealed by the expertise of a renowned professor. This professor, having meticulously washed his hands after an operation – but without removing his surgical gown – and having smartly and meticulously expounded upon yet another pressing health issue, will mater-of-factly suggest a treatment, preventive medication or a medical center in which you will undoubtedly be attended to by equally brilliant and qualified professionals.

Next, we encounter a straightforward advertisement that is not veiled in a guise of “objectivity”. This commercial offers, with reassuring optimism, a miracle cure that promises to treat (quickly and with no effort) conditions including: substance abuse; alcoholism; hair loss; weight gain; gastritis; bloating; prostatitis; oral health problems; constipation; and so on. To be fair, there are those ads that do, in passing, mention possible side effects and complications. However they do so only in passing and most lack even that. “Doctors” appear in such ads as wizards or magicians capable of curing patients suffering of every imaginable and unimaginable ailment – so long as you can pay.

Then there are talk shows; medical theater; reports of treatment and self-recovery; reenactments of life stories; intrigue; climax; catharsis. In a word: entertainment. Of course they also provide advice and information, but not just any information will do: it must be appealing and lighthearted. Much like cooking shows, entertainment is a priority: the material must pique the viewer’s interest. Rarely do viewers charge for the stove or dive into an ice-hole to apply knowledge gained on baking a cake or reinvigorating one’s health. It is sufficient to experience the pleasure of the theatrics – of being entertained. And it makes no difference whether the conversation is about the newest fad diet or a legislative initiative on euthanasia: entertaining viewers is the only objective.

Finally there is one more, almost negligible, source that is but a drop in the ocean. Occasionally, the news stream and documentary films provide information that educates and spreads scientific knowledge in the

traditional sense. But, again, it is but a drop in the ocean – a feeble trickle in a tempestuous flood of information.

Another tremendous source, which in recent years has grown so fast that it has become almost ubiquitous, is the internet: home to virtual journalism ranging from official sources to blogs and chat rooms. Here, one can find anything and everything: commercials; information; shame; gossip; PR; shopping; shows; politics; healthy lifestyle campaigns; erotic massage; religious preaching; advice on how to buy low and sell high or how to lengthen life and minimize suffering; and so on.

Despite the varying roles within the media world, two remain most prevalent and far-reaching. First, there persists a demand for the journalist (still heavily associated with the authorities) to retain his/her old-fashioned, Soviet role as a “social organizer”, functioning both as a teacher and overseer. There has however, in recent years, been increased emphasis on the educational component. From an ethical standpoint, alignment with the authorities is fraught with dangers including the loss of professional autonomy; becoming party to the propaganda of ideas characterized by ever-changing political campaigns; keeping silent on socially relevant events; and becoming involved in preparing partisan, “special-request” materials.

Secondly, journalists working in the sphere of health often find themselves in the role of salespeople promoting various media-related products, such as PR, entertainment, commercials, etc. Despite considerable differences in the kinds of relationships they cultivate with their clients and the temptations that may color their decision-making, these “journalist-salespeople” face the same dangers as their state-influenced colleagues, namely the loss professional autonomy; contributing to the dissemination of one-sided information in the interest of their clients; and the preparation of “special-request” materials.

The main difference between these groups is their use of sensationalism. While for the “journalist-salesperson” sensationalism is

essential for the successful promotion of medical products, for the state-sponsored journalist, it is but a mechanism for diverting the attention of the masses away from legitimate, verified information. In all else their circumstances are similar so it is more or less accurate to discuss the universal ethical principals guiding their reporting on health-related topics. Although health journalists share in many of the same ethical principles guiding all other journalists, there is one key distinguishing factor, namely that spreading inaccurate medical information can cause irreversible harm to citizens' health. This factor inevitably bestows upon them a particularly high burden of responsibility.

To expound upon the key ethical principles guiding journalists working in the health arena, we turn to American journalist Gary Schwitzer.³⁸ In his article "A Statement of Principles for Health Care Journalists", Schwitzer focuses on four key principles: *professionalism, autonomy, accuracy and accountability*.

Professionalism

Health care journalists can be divided into two categories based on education: doctors who become journalists and journalists who specialize in medical reporting. Of course it would be ideal for journalists to be educated in both fields, but such cases are few and far between. Therefore, taking into account the specificity both of medical information and of the language used by the media, it makes sense to increase journalists' professional qualifications on an individual basis and through seminars, round tables, etc. These efforts will compensate for the knowledge that both abovementioned groups may lack.

Unfortunately, doctors embarking on a career in journalism often arrive with the ill-conceived notion that their medical expertise and ability to write a grade school-level essay are sufficient qualifications for becoming

³⁸ Schwitzer G. A Statement of Principles for Health Care Journalists. *The American Journal of Bioethics*; 2004; 4 (4): W9.

a journalist. What they fail to realize, however, is that journalism operates in a different linguistic context, one that is specific to the public arena and that requires being studied. In fact, the job of a journalist covering health-related issues is not so much the simplification of scientific findings for the uninformed masses, but rather the translation of scientific jargon into the language of the mass media, with its own lexicon and specific style.

At the opposite end of the spectrum lie media products whose primary purpose is to entertain viewers. Hence, there are those journalists who do not see a pressing need to have a strong grasp of the medical issues they cover.

The professionalism required of journalists reporting on health issues is in a class of its own. It is no coincidence then, that professionalism is one of the top ethical virtues affecting this field.

Autonomy

Earlier in this chapter, we briefly touched upon two forces that can affect the behavior of journalists: power and money. However these sources of temptation, which may provide journalists with financial security or access to critical sources of information, must not overshadow the fact that the real “value” of a journalist lies specifically in his/her ability to resist these forces, retaining his/her dignity and maintaining working relationships with all partners. After all, only an independent, unbiased perspective will earn the trust of viewers, listeners and readers. Of course journalists who are prone to submission and corruption are more convenient for media clients, however neither these clients nor the audiences to which they cater are much intrigued by such reporting.

Accuracy

Journalists writing about health-related problems often encounter subjects with loyalties to their own interests, objectives and values.

Consequently, it is virtually impossible to produce strictly objective, accurate information. Thus, the journalist's motivation must be grounded in the desire to produce the most accurate and credible reporting possible, as any inaccuracy or falsehood can lead to irreparable damage for their audiences.

Responsibility

Like everyone else, journalists navigate through life with their own set of loyalties to family, friends, coworkers, employers, political leaders and the population as a whole. Though the journalist may feel responsible to each of these groups, at times, they can come into conflict with one another. It is futile to seek universal solutions for such contradictions and this leaves the onus of making appropriate judgments on the moral maturity of each individual journalist.

Thus the concept of responsibility is twofold: (1) responsibility for one's actions and publications and (2) responsibility to one's own journalistic calling.

VII. Conclusions & Recommendations

In concluding our discussion of the problems associated with journalism and bioethics, we would like to take the liberty of offering several recommendations. These recommendations are the aggregate of our ponderings and personal experiences as a result of having collaborated with journalists in the field. Our recommendations are not set in stone and do not purport to be conclusive or irreversible. Quite the contrary: the intention behind these propositions is to provoke an engrossed debate among journalists on how to mitigate the ethical challenges that they face day in and day out. Understandably, any effort to force or prescribe recommendations from the top down (or even from somewhere off to the side) will be doomed to failure. Norms can only be truly applicable and functional when they are developed within, and accepted by, the journalistic community itself.

In discussing recommendations for journalists reporting on bioethical issues, it is important to note that there already exist a number of documents spelling out norms directly related to this field. Of course we are referring, first and foremost, to the UNESCO Universal Declaration on Bioethics and Human Rights. This document has set out principles that must constantly remain on the radar of journalists covering bioethical issues. Article 1 of the Declaration states: “This Declaration is addressed to States. As appropriate and relevant, it also provides guidance to decisions or practices of individuals, groups, communities, institutions and corporations, public and private.” Similarly, journalists, both as individuals and as members of groups, communities and corporations, are among those being addressed by the Declaration.

Another document that imposes specific moral obligations on journalists in Russia, including those covering bioethical issues, is

the aforementioned Journalists' Code of Professional Ethics of the Russian Federation. We referred to this Code for developing the below recommendations.

Finally, we would like to acknowledge that bioethics, both historically and by its very nature, continues the evolution of traditional medical ethics, which existed even in the times of Hippocrates, and which inspired his renowned Oath. Thus, journalists writing about problems of bioethics must also adhere to the fundamental principles of medical ethics.

The principle "First, do no harm!", coined by Hippocrates and directed at medical professionals, has gained much renown throughout the ages. However this principle has long outgrown its exclusivity to the medical practice and has, by some, been deemed the fundamental pillar upon which the entirety of human morality is built. Thus, its applicability to journalism is also undeniable.

Article 3 of the Journalists' Code of Professional Ethics of the Russian Federation states: "journalists... will take all possible measures to avoid causing harm, to whomever it may be... either through omission or inaccuracy". This pertains to the information that they disseminate as well as the information that they choose to give commentary on. We must keep in mind, however, the challenges involved in identifying the full spectrum of individuals who may be harmed by any given publication. Thus, particularly when covering medical issues, special care must be taken in identifying all possible affected parties.

A case in point: Several years ago a group of journalists exposed the alleged violation of the law in a hospital in Moscow. The violation had to do with the pronouncement of an individual's death and the subsequent removal of his organs for transplantation. It is of course possible that the journalists were motivated by a desire to prevent harm caused by doctors who, in similar cases, may be too quick to pronounce individuals "dead". However, one of the results of this exposure was a widespread fear among doctors to harvest organs for transplantation. Ultimately, the reporting

caused a tremendous amount of harm, as many people died waiting for organs that could have saved their lives.

Similarly, it is not uncommon for publications reporting on the achievements of unrecognized healers, miracle products, drugs, etc. to bring harm to their audiences. It is likely that, just as above, authors may operate out of good intentions, hoping to help those in need. However, are these journalists prepared to take upon themselves responsibility for every adverse event that occurs as a result of their reporting? To be clear, it is certainly not the objective of our recommendations to discourage journalists from exploring these types of issues. However, in working on such publications, it is critical that journalists engage in a serious inquiry to ensure that all possible measures have been taken to prevent harm – it could be as simple as stating that the treatment being described is still subject to clinical trial.

If we now turn our attention to the principles of the UNESCO Declaration, we can see that, generally speaking, all 15 are relevant not only to doctors, researchers and politicians, but to journalists as well. Below, we would like to highlight those principles that are most relevant for journalists.

The most fundamental principle, spelled out in Article 3, speaks of the respect for “*human dignity, human rights and fundamental freedoms*”. It also has a provision stating that the “interests and welfare of the individual should have priority over the sole interest of science or society”. In essence, this principle establishes the criteria for assessing the suitability of various medical methodologies (including those associated with the organization and operation of health care systems) and evaluating how to best use them to benefit the individual. The Journalists’ Code of Professional Ethics of the Russian Federation has an analogous clause (Article 5): “Journalists must respect the honor and dignity of people who become the subjects of their professional attention.”

The world of medical innovation – including genetic testing that provides information about patients’ current and future health –

increasingly places *individuals in the position of having to make potentially life-changing choices and taking upon themselves full responsibility for those decisions*. In other words, the individual has the right to full autonomy as stated in Article 5 of the UNESCO Declaration. The tremendous role of the mass media in helping individuals make these choices is undeniable.

One principle in Article 8 of the Declaration deserves special attention. This principle states that individuals seeking medical care or participation in biomedical research are, as a rule, especially vulnerable. It is imperative that this principle be taken into account not only by doctors working with patients, but also by journalists who intend to report on the patients are attempting to overcome. The same caution should be employed in reporting on specific vulnerable groups including children, pregnant women, persons living with HIV/AIDS, etc.

Article 9 addresses the need to protect individuals' *privacy and confidentiality*. This norm has historic origins and can be found in the lines of the Hippocratic Oath. Naturally, this principle is particularly relevant for journalists, considering that violations of privacy are most often perpetrated by the media through the disclosure of confidential information without a subject's prior knowledge or consent. Just recently, for example, a prosecutor in a high-profile case in Russia revealed the suspect's medical diagnosis to the media. The prosecutor made no effort to secure the suspect's consent in this disclosure.

A related norm resides in Article 11, which calls for the *prevention of social discrimination and stigmatization*, be it against an individual or a group, on the grounds of illness, genetic makeup, etc. Article 5 of the Russian Code has a similar clause: "*The journalist shall refrain from the use of any disparaging claims or remarks regarding race, nationality, skin color, religion, social origin, sex and physical insufficiencies or illnesses.*"

Article 14 of the UNESCO Declaration addresses another important point, namely that the *promotion of health and social development must be the central purpose not only of governments, but of all sectors of society*. It then follows that the journalistic community, in light of its tremendous

influence, is called upon to cover issues of access to and quality of medical care, social justice in health and other relevant subjects.

The UNESCO Declaration not only sets out these 15 principles, it also has sections devoted to their implementation and the accomplishment of the Declaration's mission as a whole. In this regard, we must be especially attentive to the provisions in Article 18, particularly clauses (2) and (3). The first calls for the need to continuously engage society in an ongoing debate on bioethical issues. Not surprisingly, this responsibility falls largely on journalists. Similarly, clause (3) states that it is the role of the mass media to cultivate "opportunities for informed pluralistic public debate, seeking the expression of all relevant opinions". It is clear that this norm is infringed upon when reporters leading discussions on bioethical issues deem particular viewpoints untrue, unworthy or unacceptable and, in so doing, prevent them from being aired or defended. It is important to remember that disagreement with a point of view is insufficient ground for excluding it from the public dialogue.

One of the challenges that journalists covering bioethics face is "foster [ing] debate, education and public awareness of, and engagement in, bioethics" (Article 19 (d)). It is important to remember, yet again, that bioethics is a special type of science: It can only exist and evolve in proportion to the amount of media coverage it receives and the degree to which it becomes the subject of public interest and discourse.