



## Narrative medicine in the framework of empirical social research: the Russian context

Medicina narrativa enfocada a la investigación empírica social: el contexto ruso

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**ABSTRACT** This article contains the results of the empirical analysis carried out in 2012-2016 which sought to examine whether patients' narratives of their illness were present in doctor-patient communication and whether this subjective story was significant to both sides of the medical communication in Russian somatic disease medicine. The research was carried out in four stages and combined qualitative and quantitative methods, analyzing the perspectives of patients, doctors and medical students through surveys and interviews as well as looking at online doctor-patient communication in health forums. In all four stages, the results of the research showed that little value was placed on the subjective experience of disease in doctor-patient interactions. The topic of narrative medicine is new to Russian social studies, making the results of this research an important contribution to the establishment of narrative medicine as a global idea advocating the universal therapeutic and ethical value of patients' stories of illness in the "remission society," in which chronic pathologies dominate.

**KEY WORDS** Narrative Medicine; Doctor-Patient Relations; Chronic Disease; Social Networking; Russia.

**RESUMEN** Este artículo presenta los resultados de un análisis empírico llevado a cabo entre 2012 y 2016, que buscó entender si las narrativas de los pacientes están presentes en la comunicación médico-paciente y si esta historia subjetiva es significativa para ambos lados de la comunicación médica en la medicina somática rusa. La investigación se realizó en cuatro etapas y combinó métodos cualitativos y cuantitativos, analizando las perspectivas de pacientes, médicos y estudiantes de medicina a través de encuestas y entrevistas e indagando además en la comunicación médico-paciente en foros virtuales. En las cuatro etapas, los resultados de la investigación mostraron que se otorga poco valor a la experiencia subjetiva de la enfermedad en las interacciones entre médicos y pacientes. El tema de la medicina narrativa es inexplorado en los estudios sociales rusos, por lo que los resultados de esta investigación constituyen una contribución importante en pos de establecer la medicina narrativa como una idea global que promueve el valor universal en términos terapéuticos y éticos de las historias de enfermedad en la "sociedad de remisión", en el cual dominan las patologías crónicas.

**PALABRAS CLAVES** Medicina Narrativa; Relaciones Médico-Paciente; Enfermedad Crónica; Red Social; Federación de Rusia.

## NARRATIVE MEDICINE IN "REMISSION SOCIETY"

In the 1980s, on the basis of empirical studies, US social psychologist Elliot Mishler defined the relationship established between doctor and patient during therapeutic appointments as a fight between the "voice of the lifeworld" and the "voice of medicine."<sup>(1)</sup> He demonstrated that in a typical therapeutic session the voice of the lifeworld is suppressed for the benefit of the voice of medicine, hence there are rigid boundaries within which patients are permitted to express their understanding of their problems. The phenomenon of the hegemony of medical discourse in the definition of disease as well as the disagreement among languages used to describe the disease – biomedicine's cognitive object on one hand and personal experience on the other – have long been recognized. In the Modern era, the patient approves of being defined by medical discourse, accepts the *sick role* and acquires medical terms when needed. Famous Canadian sociologist and medical anthropologist Arthur Frank is the creator of the term "remission society" paradigmatic in modern sociology of medicine, which describes the prevailing state of pathology at present as chronic, as well as the author of a personal reflexive diary devoted to his fight with cancer.<sup>(2)</sup> He writes that in the Modern era "the ill person not only agrees to follow physical regimens that are prescribed; she also agrees, tacitly but with no less implication, to tell her story in medical terms."<sup>(3)</sup>

At some point, however, patients understand that in doing so they may deprive themselves of the language describing the existential dimension of their disease, belonging to the scope of the ontological opportunities of human beings. This leads to a phenomenon observed within the past three decades: the patient's will to return to narrative subjectivity. From the patients' perspective the practice of writing and publishing personal disease narratives (which are

numerous at present) is interpreted as a new cultural politics and a new ethics of patients' "appropriation" of their own conditions, presupposing both the expression of the individual aspect of the disease *experience* and the possibility that the experience can be *conveyed* in an intersubjective communication that establishes *narrative communities* around a given disease. Such stories of disease act as alternative *counter-narratives* to the institutionally prevailing clinical narratives (diagnostic histories), attempting to rationalize existentially the disease itself, whether in fighting the disease or in living with it if victory is unachievable.

Notably, *narrative impulses* for such patient's actions are sometimes provoked by doctors, a symptom of a new trend that started in the mid-1980s. The first systematic works in the area of medical anthropology that made an attempt to outline and to substantiate this trend were *Stories of Sickness*<sup>(4)</sup> by Howard Brody and *The Illness Narratives*<sup>(5)</sup> by Arthur Kleinman, published at almost the same time. They were followed by the research works of Catherine Montgomery Hunter<sup>(6)</sup> and Anne Hunsaker Hawkins,<sup>(7)</sup> a series of articles on "literature and medicine" in *The Lancet*,<sup>(8)</sup> the British anthology *Narrative based medicine*,<sup>(9,10)</sup> and various collections of works on medical narrative ethics.<sup>(11,12)</sup> In recent decades both in theory and practice we observe a real process of justification of non-medical disease discourse, and the subjective and intersubjective meanings typical of such a justification process, appearing within the medical institution. The most prominent researchers of medical humanities, many of whom are doctors themselves, have consistently differentiated *illness* from *disease*,<sup>(5,13)</sup> writing that the rupture between them is entirely objective and functionally beneficial to medical manipulations; if nothing is done to compensate this rupture, it leads to a dramatic aggravation of the "medicine-society" and "doctor-patient" dichotomies. And this cannot but have a negative effect on therapy results in each particular situation. Doctors say it is necessary to build bridges between these poles, and particularly to introduce into

therapy the patient's narratives expressing subjective and cultural meanings of the disease, so as to make the therapy not only more ethical but also more *efficient*.

On the one hand, immanent medical ethics interpreted as *care ethics* is more and more frequently defined as narrative.<sup>(14)</sup> On the other hand, the efficiency of treatment can only be achieved based on a high level compliance by the patient, possible only in the process of the coordination of *histories* – the medical history and the history and mythology of the patient's disease. The discrepancies in interpretations, expectations, narratives, mythologies and languages describing the patient's condition that occur among doctors, patients and their families will never promote the success of treatment, especially in the "remission society" where disease merges with biography and is prolonged in time, and a great deal happens in the silence of the patient's interpretation of his or her own symptoms. Therefore, doctors start to consider patients' narratives (both written and spoken) as the window to the world of real human suffering as well as a way to access individual constellations of pathological symptoms and their causes.

In this way Rita Charon, doctor and one of the leading ideologists and promoters of the "narrative turn" in somatic medicine as well as the author of *Narrative Health Care*<sup>(15)</sup> and the term "narrative medicine" itself, introduces concepts such as "narrative knowledge," "narrative competence," and "bearing witness." These concepts are intended to reveal new therapeutic and ethical horizons for medical experience even in the epoch of medicine's overall technification and dehumanization. These ideas are gradually gaining institutional support and have already been implemented in some US clinics, units and medical educational programs. As an example, in order to develop practitioners' or medical students' "narrative competence," Charon and her team implement the practice of having doctors write a *reflexive diary* ("parallel chart") in which they describe in detail everything that happens in the process of therapy as well as

the patients' particular features, complaints, words, metaphors, and life stories related to the disease. The diaries are discussed publicly afterwards. These and other pedagogical practices are expected to develop all the "narrative competence" components that Charon specifies: attention (the ability to concentrate in the presence of the patient); representation (the ability to reproduce non-medically what was said by the patient); and affiliation (the ability to create, in conjunction with the patient, other doctors and relatives of the patient, an informal community of care).<sup>(15)</sup>

Narrative medicine at present provides numerous possibilities for doctors' and patients' potential and real practices in "remission society." Such possibilities, however, are hardly medical anthropology's object of interest, especially in Russia, despite the fact that Russia represents a marked "remission society" – chronic illnesses notably dominate in the pathology structure and act as a prevailing mortality factor.<sup>(16)</sup> Additionally, the Russian healthcare system is notorious for enormous gaps in credibility between doctors and patients and between patients and medical institutions. In the never-ending process of bureaucratic healthcare reforms these gaps continue to widen.<sup>(17,18)</sup> In this kind of environment interest in *doctor-patient* communicative practices in clinical interactions has increased in social studies in Russia. Such practices have become the subject of systematically executed theoretical and empirical studies.<sup>(19,20,21,22)</sup> However in most cases legal, deontological, psychological and economic aspects of *doctor-patient* communication are analyzed. In studying such aspects, empirical researchers specifically report an "increase in stress"<sup>(23)</sup> as well as intensification of conflict in relationships between doctors and patients. The topic of the patient's story, the importance of doctors considering the significance that the patient attaches to his/her illness, and the question of the patient's communicative recognition in therapeutic interaction are rarely touched upon in the anthropology and sociology of medicine in Russia. Moreover, these topics

are not developed as the subject of empirical studies. As a rule, *doctor-patient* communication is understood as the discursive dimension of the doctor's verbal behavior,<sup>(24,25)</sup> and such types of empirical studies have been carried out nationally. Indeed, it is important to highlight that patients' stories about their suffering and patients' narratives (both oral and written) are traditionally appreciated in the context of psychotherapy or psychiatry, not in somatic disease medicine.

In light of this lack of emphasis on patients' narratives in Russia, over the course of several years we carried out empirical research to answer the following research question: is the patient's story about his/her suffering (patient's narrative) included in Russian somatic disease medicine in the framework of a regular *doctor-patient* communication at a polyclinic or hospital, and is this "subjective" story significant for both sides of the medical communication? Such a research topic is novel within Russian medical humanities.<sup>(26)</sup>

Fieldwork was carried out from 2012 to 2016. It was conducted in four stages and, taken as a whole, was based on a combination of quantitative and qualitative methods. The first stage dealt with patients suffering from chronic somatic pathologies and the second with the doctors curing chronic diseases and working in state clinics. The methods and results of these stages have been published in depth in Russian<sup>(26,27,28,29)</sup> and will be described more generally in this article. The third stage looked at the perspective of medical students. The study of patients, doctors and students in the first three stages of the research process took place in the city of Samara, the center of the third most densely-populated agglomeration of Russia. Finally, for the fourth stage the representation of online discursive *patient-doctor* communication was examined to achieve a fuller picture and to triangulate the data obtained in the first two stages. The results of stages three and four will be described here in greater detail.

## METHODOLOGY

The design of the study as a whole presupposes the application of Mixed Methods Research<sup>(30,31,32)</sup> of a parallel type, where quantitative and qualitative research methods are not used in chronological and logical sequence (one after another), but are used for analysis of various aspects of one and the same subject.

### First stage: Patients

We employed the rigid quantitative version of the method of semi-formalized interview, which is a combination of open-ended and closed questions. Data from the quantitative survey were processed using SPSS. The sample included 600 chronic patients chosen by quotas according to the following criteria: type of disease, gender, age. In order to establish the quotas by disease type, statistical reports on disease incidence among Samara citizens in the year of 2011 were utilized.<sup>(33)</sup> The respondents underwent treatment in various departments of Samara state hospitals and clinics (gastroenterology, urology, oncology, pulmonology, dermatology, otolaryngology, ophthalmology, cardiology etc.). In addition, 43.2% of respondents were male and 56.8% were female and ages ranged from 15 to 70, with most respondents over the age of 40.

### Second stage: Doctors

The professional group of doctors was surveyed applying the two qualitative methods: in-depth and focus group interviews. The purpose of the latter (which followed the in-depth interview) was to clarify the doctors' views with the help of discussion, to find out the pros and cons of the involvement of patient narratives in medical practices. In-depth interviews were carried out with 35 doctors working in Samara state hospitals and clinics, selected using

the purposeful sample method using the following criteria: area of professional activity (cardiology, ophthalmology, therapy, gastroenterology, oncology, endocrinology, pulmonology), period of time working with chronic patients (at least one year) and age. As a result, 7 doctors under the age of 35 years, 17 doctors between 35-50 years of age and 11 practitioners over 50 years of age took part in the survey.

The in-depth interview guide with doctors contained more than twenty questions. The interviews were carried out face-to-face in a friendly atmosphere at the informants' workplaces (the city's medical institutions which included staffrooms, in-patient hospital training rooms).

Twelve other informants participated in the focus group interview. The participants of the focus group interview were selected by means of the same criteria as in the in-depth interview, except that for the age criterion, the informants' age was limited to the range of 35-50 years. The age range limitation on the one hand provided the homogeneity required methodologically for the focus group interview and, on the other hand, focused on middle-aged doctors as the most numerous group among practitioners in general. The focus group interview was held on a single occasion involving all twelve participants. It took place in a properly equipped classroom of Samara National Research University and lasted for 1 hour and 10 minutes. The interview was filmed and later transcribed. The in-depth and focus group interview transcript processing did not involve the use of special software programs.

### Third stage: Medical Students

Medical students acting as research subjects took classes at Samara State Medical University, which is one of the largest medical universities in the country and is included in the International Association of Medical Schools in Europe. The structure of the University consists of 11 faculties, 80 university chairs, 51 hospital departments, and

seven research institutions. Every year more than 8,000 students study at the University.

Research on the students of Samara State Medical University was carried by means of the in-depth interview method with a total of 30 participants. This type of interview allows a wider scope of information to be obtained, both explicit (the direct answer to the interviewer's question) and non-explicit. The purposeful sample method was applied with the following criteria: faculty and year of study. The study participants were made up of students from the General Medicine faculty and internship of the medical university. The therapeutic faculty is the largest of the university, with the greatest number of students (more than 2,000). It is in this faculty that doctors are prepared for what they will deal with in their future professional activities with chronic patients – the object of medical care in narrative medical practices. We interviewed fifth- and sixth-year students as well as interns, who are considered to be nearly graduate specialists, "almost doctors." The interview guide contained eighteen questions. The interviews were held face-to-face in the rooms of the residence hall where medical students and interns live as well as in the classrooms of the medical university clinics where they were having their practical training.

All the ethical standards relating to the first three stages of the analysis were respected: all the informants were aware of the research objective, the interviewers obtained the informed consent regarding participation in the research and the publishing of research deliverables in scientific sources after audio and video (in case of focus groups) recordings were transcribed and made anonymous. The approval from a research ethics committee of Samara National Research University, named after S.Korolev was received.

### Fourth stage: Online *doctor-patient* discourse and practices

We analyzed online medical communities (websites) characterized by wide geographical coverage, shared interests

of participants of these communities and the discussion of real life patients' medical problems in the offline world. The online communities functioning on the basis of the Internet sites (forums) in the Russian language were shortlisted for the purposeful sample method analysis. The main criteria for this selection were: a thematic focus on some serious chronic disease; a great number of site visitors (over 7,000 visitors); site developers belonging to a patient group (in order to avoid sites with probable marketing orientation); site updating on a daily basis; and interaction among site users. In accordance with the specified criteria the following sites (forums) were selected: Hepatitis forum<sup>(34)</sup>; Forum of life: Forum for sick people to communicate<sup>(35)</sup>; Forum for people living with HIV/AIDS<sup>(36)</sup>; Forum for HIV + people.<sup>(37)</sup>

To obtain sociological data we employed an observational method adapted to analyze localized online communities<sup>(38)</sup> as the most adequate for their empirical study. The online observational method presupposes a certain typology of researcher's roles differing in the extent of their involvement in the community under study. For the purposes of the present research we took on the role of *unregistered user*.<sup>(39)</sup> This research situation does not require informed consent. The findings, however, will be presented in an anonymous way.

## RESULTS

### Stage one: point of view of chronic patients

Our study of chronically ill patients of the city of Samara sought to describe quantitatively the practices of producing narratives as well the motives behind each scenario. The analysis showed that the dominant practices are those of "not telling," of "unborn narratives": only 29.0% of the interviewees tell their illness stories to their doctors often, but the majority (71.0%) hardly ever does so. Approximately one third of the interviewees (26.8%) only sometimes tell their illness

stories. The study showed that such practices of not expressing the subjective meanings of illness on the part of patients are not significantly associated with patient's education, gender, or marital status. The only distinctive factors were age and financial status, which are interdependent to certain extent (with a level of statistical significance of  $p \leq 0.05$ ). According to research data this "conspiracy of silence" is more characteristic of young and middle-aged people (under 50 years of age): in these groups the number of people who never tell doctors about their lives with illness is 1.7-2 times greater than in the groups of older people. People with high incomes produce narratives less often: the number of "silent" patients among them is 1.5 times greater than among people with low incomes. According to the research data, the most typical motive of such behavior is the not having the habit of telling the doctor about feelings and experiences of living with illness.

The patients' silence about "that which is most important" as a habitual practice in the framework of clinical interactions is the consequence of a tacit convention of domestic biomedicine: "The doctor doesn't ask, the patient doesn't tell." Additionally, it is a practice generated by patients' views about doctors which have been formed on the basis of negative personal experience in interactions with them. Such views include: seeing doctors as medical technologists who do not need to know about patients' emotional experiences (79.9% of interviewees); believing that doctors are motivated only by money in their work (51.4%); feeling that doctors have so much work that they have no time to listen to patients (49.9%); perceiving that doctors have mostly a formal attitude toward their work (25.7%). Also, the interviewed patients have motives which reflect their own fears and anxieties, their own experiences of living with illness that make them consider the discussion of illness as demonstration of weakness (9.4%). There is also the fear of being misunderstood (8.1%) and the desire to maintain control over the illness (4.6%).

## Stage two: point of view of doctors

The qualitative study of practicing doctors sought to describe the doctors' attitudes towards the use of patients' narratives in the treatment process and to describe the practices of producing (or not producing) patient's narratives (from the point of view of doctors).

Firstly, the analysis of the transcripts of the in-depth and focus group interview showed that doctors' attitudes toward the use of patients' narratives present a rather miscellaneous picture. Extremely negative doctors' attitudes toward narrative practices are connected with the fact that doctors consider narratives to be useless conversations that have nothing to do with "real medicine": "What's the use of it? I don't let them talk much" (focus group, male, 36 years old, 8 years of experience); "As a doctor I direct my actions toward immediate therapy, abstract questions hardly help the cure, they are useless" (female, 39 years old, 15 years of experience). Within the framework of such an approach, narrative medicine is considered, at best, a "treatment by words" ascribed to psychologists and psychotherapists: "special medical staff should do it, 70% of doctors don't need this information, it's superfluous" (female, 53 years old, 30 years of experience).

At the same time there is also a positive attitude towards the process of patients' telling about their suffering. Patients' stories are viewed as an effective way to establish contact with a patient either during the reception by the doctor or during long medical procedures. In this approach we can say that listening to a patient's story by a doctor or a nurse is a performative form of a communicative acknowledgement of the patient which positively influences the establishment of confidential relations between the patient and the medical staff.

However, the most common attitude among participants is a transitional attitude towards the patients' narrative, by which doctors listen to a patient as part of "common courtesy" but do not encourage or

use the narrative in clinical interactions: "It's deadly boring! Just imagine, I hear the same talk every day. Putting it mildly, it brings you down" (male, 44 years old, 18 years of experience).

According to doctors' opinions, two-thirds of all chronic patients are patients who do not tell stories. Doctors identify those who tell stories about their problems in life connected with illness as those who are aging. Accordingly, "they are people older than 60 or 70, especially people over 80, interested mostly not in medicine but in how to live longer, what is going on in their families, how to exist" (female, 45 years old, 20 years of experience). According to doctors' opinions, the causes producing such narratives are a lack of people to communicate with, loneliness, and social alienation, whether real or imaginary: "They are socially unprotected people, lonely and abandoned by their children" (female, 50 years old, 18 years of experience).

These doctors' narratives speak to the modern social situation in which elderly patients in desperate loneliness produce patients' narratives in the hope to be heard. However, the implication of doctors talking about patients' narratives as the product only of social alienation is that such narratives are dismissed by them as needless and superfluous, "idle talk."

On the whole, the Samara doctors interviewed see practically no possibility of using narrative medicine in Russia. They connect this fact with endless bureaucratic reorganizations of Russian medicine, with the low status of doctors in Russian society, and with the lack of work motivation in this professional group which is "rather inclined to avoid patients" (focus group, male, 45 years old, 16 years of experience).

## Stage three: medical students' knowledge of narrative medicine

The qualitative sociological study of students of Samara State Medical University was aimed at identifying the students' knowledge/

ignorance of the basic ideas of narrative medicine as well as describing the methods of forming narrative competence involved in the learning process (if any).

The analysis of transcripts of in-depth interviews with the students has shown none of the polled informants have heard anything about narrative medicine or are acquainted with its basic ideas, nor have they understood the therapeutic importance of patients' stories about their illnesses during *doctor-patient* communications. In Samara State Medical University there are a variety of academic subjects oriented towards doctor preparation (the surveyed students called them "optional") whose goal is somehow to describe the *doctor-patient* interaction. These are: Bioethics, Medical Ethics, Pedagogy and Psychology, Social Work, and Medical Psychology. One of the surveyed students worded his comment regarding these subjects in this way: "*they kind of teach you how to speak with patients*" (A., male sixth year student). The basic content of these subjects is the description of normative deontological principles, the legal side of *doctor-patient* relations:

*So, they told us in the medical ethics class that the doctor is always wrong, that there are structures which protect patients, but there aren't any state structures or private structures which protect doctors. That is, if a doctor makes a mistake they are very likely to be considered guilty. We were therefore told that we should keep good and detailed medical records because a doctor writes the record not for themselves but for a public prosecutor.* (K., male, sixth year student)

The study showed that the curriculum of the specialty did not pay any noticeable attention to using patient narratives about illness. All informants responded similarly:

*Whether they focused on this. . . no, they didn't. They may have paused to mention it somewhere. Something was said briefly between topics. But to devote the whole*

*lesson or a whole course to communication with patients – no, there was no such thing.* (I., male, fifth year student)

The analysis of interview transcripts also showed that students are practically not taught the art and technique of placing focused attention on the patient, hearing the patient's call and answering that call (this "focused attention" is an element of doctor's narrative competence, according to Charon). Students do not write special reflective diaries (one of technologies which Charon suggests for developing focused attention), where they would express their impressions after communicating with a patient using common (not medical) language and at the same time delving deep into the personal story of the patient related to the disease, learning to see the medical case not only as an objective pathology (disease), but also as the patient experience (illness). Students of Samara Medical University write diaries of completely different type, in which they note only the physiological background of the disease and clinically observable symptoms in full compliance with the biomedical discourse:

*Basically we kept a diary, if the diary refers to the patient's condition and its dynamics: how the patient feels, whether they have pain, whether something appeared, disappeared, changed, or was added. If you mean a personal diary in which I record my impressions of the medical practice every day, then no, of course we have no such thing.* (I., male, sixth year student)

*It's called the disease history. You go to the patient, greet them and ask, "What is your complaint at the present moment?" We are not encouraged to write such diaries. . . . There are certain standards and we have to meet them.* (N., female, fifth year student)

Moreover, the very idea of writing a reflective diary in which a doctor would write their impressions after communicating with

a patient, to further the understanding of the meaning the illness has to the patient seems inappropriate to medical students: *"It sounds very funny to me. . . . It is absurd"* (A., female, sixth year student).

Analysis of interview transcripts showed that there are no trainings which teach doctors and give them skills to develop such reflexive writing: *"They absolutely never taught it, we didn't have such diaries, we didn't have any such training even in psychology classes"* (O., female, fifth year student).

However, most students' images of a good doctor include such components as humanity, sympathy for the patient, compassion, though not always as the first characteristics:

*For me, the doctor is a person who makes every effort for people. He or she should love people and be devoted to the profession no matter what. Because the primary concern of the physician is to relieve suffering and to save sick people.* (M., female, sixth year student)

*A good doctor means empathy, ability to sympathize, because sick people. . . . they suffer.* (E., female, intern)

In addition to this, according to the opinions of informants, medical students get their understanding of the specific character of *doctor-patient* relationships not from special courses but as the result of communicating with practicing doctors, heads of their practices, clinicians: *"This knowledge can be taught only from doctor to doctor, only a doctor can tell how to make use of this knowledge in a better way"* (S., male, sixth year student). It is clear that in this case they are talking not about narrative medicine but about establishing trusting relationships between doctors and patients, which are necessary for the therapeutic interaction.

Overall, the study showed that today students of the General Medicine faculty of Samara Medical University have no understanding of the therapeutic and ethical significance of including the patients' narratives in the care process. The disease as the patient's

experience, not just as a medical diagnosis, has no importance for them. They interpret *doctor-patient* relations either in the conventional biomedical paradigm with its inherent clinical discourse (recording a typified medical history of disease), or in the traditional regulatory framework of medical ethics. Students understand medicine primarily as the scope of medical technology. At the same time, however, from their lectures they are aware of the ethical requirements of the doctor and about the need for empathy and sympathy for the patient, and they also receive practical lessons from medical practitioners regarding how to communicate with patients.

#### Stage four: online *doctor-patient* communications

The qualitative study of online *doctor-patient* communications was focused on the description of the objective content of these communications. Analysis showed that they are characterized by a greater focus on obtaining professional help in a situation of illness. Almost all online patient messages addressed to doctors contain exclusively medical information such as lab results, medication, and information about interactions with medical institutions. If these are narratives they represent exclusively *clinical stories*:

*Good day! I am female, 27 years old, my weight is 53-55 kg and my height is 158 cm. I got the results of a periodic health examination and am attaching them to the message. I took the test on an empty stomach. Indicators: glucose 6.0 (normal range is 3.5-5.5), cholesterol 5.6 (normal range is 3.2-5,8). Should I see an endocrinologist or take another test at another lab? Tell me, please, esteemed doctors.*<sup>(35)</sup>

The field of the content of such communicative practices can be presented by the following classification:

1. Requests for advice in concrete illness situations:

*Seeking advice referring to a professor who uses general electromagnetic hyperthermia combined with chemotherapy for treatment of oncological diseases.*<sup>(36)</sup>

*Hello, please tell me, can I get vaccinated against hepatitis B if I have already hepatitis C??? Now I'm going through therapy with generic sof [sofosbuvir] and dac [daclatasvir]. Should I complete the therapy first and then get vaccinated? What would you recommend?*<sup>(34)</sup>

## 2. Discussion centered around concrete medicines and treatment methods:

*What far-out treatment methods can you recommend?*<sup>(34)</sup>

*Dear doctors, I'd like to know your opinion about electronic cigarettes. How harmful is "rectified" nicotine? Does it cause cancer?*<sup>(35)</sup>

## 3. Crosschecking diagnoses and medical test results:

*Can I trust Fibroscan if my weight is 105 kilograms?*<sup>(36)</sup>

## 4. Asking for help to find good clinics and treatment methods:

*I'd like to know which Moscow clinics offer free treatment to people living in other regions according to medical insurance policy.*<sup>(35)</sup>

## 5. Requesting information about long-run prospects of illness:

*Can the hepatitis virus reappear after 5 years?*<sup>(34)</sup>

Though the online discourse is totally medical in *patient-doctor* communication, there are some nonmedical meanings of disease there, in particular, the meanings which are associated with the cost of treatment: "no extra money and I don't want to make

mistake"<sup>(35)</sup>; "Can a medicine be cheaper in Russia than in India, where it is produced?"<sup>(34)</sup>

There are also subjective complaints that are typical to ordinary offline primary consultations with a doctor. These complaints, these messages are not yet medical:

*For as long as I can remember, I constantly sleep with my mouth open at night. During the day I breathe through my mouth. I fall asleep with my mouth open. But at night my nasal mucous gets dry, I get stuffy, I can't breathe through my nose. . . . I have decided to deal with this problem; I would like to understand what direction to go. Please tell me, what causes should I explore?*<sup>(35)</sup>

The analysis of the patients' narrative practices within such communications shows that those in which the patient goes beyond the medical question of specific diseases in fact get no response. In this case there is simply no *doctor-patient* communication. Such a purely pragmatic and clinical orientation to professional medical help is quite often required by the website. On such sites doctors and moderator explicitly request that patients ask only about specific diseases, using the language of symptoms and test results, in such a way that the appearance of nonmedical stories about illnesses is practically blocked. Unfortunately, virtual communication between a doctor and a patient entirely repeats offline interaction, the analysis of which was presented earlier. In this sense, the triangulation of results from the offline communications confirms conclusions concerning offline *doctor-patient* communication.

At the same time, the analysis produced additional results. People's stories about their illnesses, about what it means to them, what social and existential problems it creates, how it influences the treatment, the relations with relatives, colleagues and doctors, were all present in another virtual communication platform: those dedicated to *patient-patient* exchange. One example is what Frank calls the "quest narrative,"<sup>(3)</sup> connecting illness

with existential transformations:

*Five years ago when I learned that I had only two or three years left to live, I understood intuitively that I shouldn't focus on this thought. . . . That is, I continued to live, I just started to appreciate every moment more. . . . In the difficult moments of life I've always invented a "little help" for myself. . . . What helped me to accept. . . the diminished life span which was left for me was the art of photography. In my early days I used to amuse myself with photography, then I abandoned it for 20 years. . . . When I learned of my diagnosis and stopped drinking. . . I turned to photography again. Here are my photographs.<sup>(34)</sup>*

The subjects of written narratives which are addressed to the patient community try to offer psychological help to "friends in need," to share illness experiences and experiences of struggling with illnesses, or offer help in searching for concrete clinics, doctors, lawyers and drugs. These narrative communities of self-help are regarded by many as families:

*This website represents something familiar for me, like family. Family – this is something near and dear, the most amazing and wonderful people. Years go by and we are always together.<sup>(37)</sup>*

Help is generally given as answers to messages representing the figure of the "wounded storyteller."<sup>(3)</sup> Such messages do not become a coherent story, they have no pragmatics, no reflection, no self-story; they are Frank's "chaos narrative,"<sup>(3)</sup> a written cry for help and undifferentiated expression of pain:

*Just today I was given this diagnosis. I'm just in shock, I can't stop crying and I don't think I'll be able to sleep all night tonight. I can't stand the thought. How will I live from now on? I'm confused, everyone, help me!<sup>(35)</sup>*

However, in online *patient-patient*

communication we also see the "work" of canonical biomedical narratives. The first of these, the "restitution narrative," assumes the structure "Yesterday I was healthy, today I'm sick, tomorrow I'll be healthy again."<sup>(3)</sup> As a classic medical "narrative of progress" it includes a history of diagnosis by doctors, the names of medications and diagnoses, and the sudden life changes after receiving the correct diagnosis. Even in such rubrics as "My story" and "Living with hepatitis C," chronic patients talk about their suffering mostly using the medical language of tests and prescriptions, conceptualizing the disease as an objective pathology defined by biomedicine, without trying to give it any subjective meanings.

## DISCUSSION

A discussion took place recently (February 15, 2017) at the Institute of Philosophy of the Russian Academy of Sciences on "Medical power and medicine without a human being: after Foucault." One of the participants, a former Minister of Health of the city of Arkhangelsk, said: "In Arkhangelsk we carried out a survey among medical schools graduates. Most of them prefer to work far from patients. No one wants to work with the patient, to establish verbal and physical contact."<sup>(40)</sup> The situation of a doctor "fleeing from the patient" (in the words of one of our survey informants), scared of the contact with them, is a dramatic one for the healthcare system. The narrative medicine that cultivates and practices this contact for therapeutic and ethical reasons and teaches this contact to medical students using special methods could be one way to cure the national healthcare's systemic disease. As was shown in the second stage of the present study, doctors themselves vest positive significance in narrative medicine inasmuch as it provides the way of establishing necessary *doctor-patient* contact.

Notwithstanding, studies by US anthropologists demonstrate that situations in which doctors disrupt the partnership that they have created with their patients are not rare. As

Mattingly believes, one of the crucial reasons for this disruption is a separation of ethics and technology, with a great deal of more stress placed on the latter, and a separation of the body – as an object for medical manipulations – from the human being.<sup>(41)</sup> That is why when technology is useless doctors “flee from patients,” seeing no point to their own activities: “While caring or well-intentioned clinicians would, of course, not deny that it is people who suffer and people they treat, the canonical genres into which they are socialized train them to sideline or trivialize this ‘human’ aspect of care.”<sup>(41)</sup> The study of US medical students carried out by Good and Del Vecchio shows that this separation of the body from the human being is at the heart of typical medical training, aimed at the techniques allowing for the manipulation of the patient’s body.<sup>(42)</sup>

Our research has revealed that the medical students of Samara envision

medicine as having a technological nature and, in turn, chronic patients obtain the same vision, which is bound to raise a lot of concern about the future of medicine, especially in government-sponsored healthcare which was the object of our empirical analysis. Meanwhile, in both online and offline communication with doctors, patients have mostly accepted the “narrative capitulation,”<sup>(3)</sup> and have taken the role of “Patient 2.0,”<sup>(43)</sup> patients who want, as our informants state it, “to manage their illness by themselves” and solely in the language of biomedicine. Our research also indicates that contemporary *patient-patient* communication, in spite of being mediated by canonic biomedicine narratives, has the potential for producing and cultivating non-medicalized illness narratives which represent its existential and social meanings and its relation to the human being’s lifeworld crucial for the remission society.

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