GENETIC TESTING IN HEALTH CARE PRACTICES (ADAPTED FROM AN EMPIRICAL STUDY)

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The article contains the results obtained during an empirical study of health care practices among people of a large Russian city implemented in a combined strategy in 2020–2021. Our focus remains on the reference of citizens to the procedure of DNA diagnostics as a novel instrument of health-saving behavior and attitude to genetic knowledge in general. The obtained data allow concluding that genetic testing is not widely popular among population today, as only 9,5% of those interviewed have ever done it. DNA diagnostics is more frequently used by young women and men with high income and don't trusting modern medicine, which probably reflects the actual condition of the market of genetic services in our country. Apart from financial possibilities, involvement into consumer genomics is influenced by insufficient trust in DNA information, and suspecting that players on the market of genetic services obtain economic profit. However, the most important argument against it consists in the discovered discrepancy between perception of genetic data as something inevitable and currently popular ideology of healthy lifestyle, meaning that a person can influence the outcome of the efforts made. As a result, research participants are not willing to become the everlasting 'patients-in-waiting' even in case of existing symptoms, but implement their 'right not to know'. Under these conditions, an important task includes organization of active promoting awareness that unlocks potential, capabilities and limitations of genetic diagnostics.

Keywords: genetic testing, health care, telephone survey, semi-structured interviews, patient-in-waiting, social attitudes

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ГЕНЕТИЧЕСКОЕ ТЕСТИРОВАНИЕ В ПРАКТИКАХ ЗАБОТЫ О ЗДОРОВЬЕ (ПО МАТЕРИАЛАМ ЭМПИРИЧЕСКОГО ИССЛЕДОВАНИЯ)

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Статья содержит результаты эмпирического исследования практик заботы о здоровье жителей крупного российского города, реализованного в комбинированной стратегии в 2020–2021 гг. В фокусе нашего внимания обращение горожан к процедуре ДНК-диагностики как современному инструменту здоровьесберегающего поведения, а также установки в отношении генетического знания в целом. Полученные данные позволяют заключить, что сегодня генетическое тестирование не пользуется широкой популярностью среди населения, лишь порядка 9% опрошенных когда-либо прибегали к нему. К ДНК-диагностике чуть чаще обращаются молодые женщины, а также мужчины, имеющие более высокий доход и не доверяющие современной медицине, что, вероятно, отражает состояние рынка генетических услуг в нашей стране. Помимо финансовых возможностей на вовлечение в потребительскую геномику влияют недостаточное доверие информации о ДНК, а также подозрение игроков рынка генетических услуг в получении экономической выгоды. Однако наиболее важным аргументом «против» выступает обнаруженное расхождение между восприятием генетических данных как приговора и культивируемой сегодня идеологией здорового образа жизни, предполагающей способность человека влиять на исход собственных усилий. В результате участники исследования не желают становиться пожизненными «пациентами-в-ожидании» даже при имеющихся симптомах, а реализуют «право не знать». В этих условиях важной задачей становится организация активной просветительской работы, раскрывающей потенциал, возможности и ограничения генетической диагностики.

Ключевые слова: генетическое тестирование, забота о здоровье, телефонный опрос, полуструктурированные интервью, «пациент-в-ожидании», социальные установки

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Novel therapeutic and preventive technologies made possible owing to success of genetics achieved in recent decades are becoming widely spread today. First and foremost, it's about DNA diagnostics that reveals the risk of various, primarily hereditary diseases. In the light of pressing discoveries, genes become the main embodiment of risk, but not the body itself [1]. Thus, using the potential of genetics is considered as a significant aspect of well-being control. As a result, on the one hand, a person obtains instruments for better, modern and technologically advanced health care. On the other hand, use of innovations entails burden of additional responsibility and need to participate in medical decision making.

Applying DNA technologies in medical practice gives birth to a set of complex ethical, philosophical and legal

issues comprehended by representatives of socio-humanistic disciplines [2, 3]. It is much more rarely that investigators examine how genetic knowledge penetrates the daily life of a modern person, and how it is used or rejected. Though important empirical studies of professional culture of genetic scientists and their communication with patients appear to date [4–7], a general picture of using genetic innovations in our country remains unclear. The work by Yu. Voynilov and V. Polyakova [8], which shows that the Russians are rather suspicious about biomedical technologies, is an exception that proves the rule.

As the areas of using genetic research go far beyond orphan diseases, their prophylactic and preventive potential for the entire population is stressed (especially in case of consumer genomics). It is important to understand the extent to which the Russians use the novel scientific achievements to care about their health, how they follow the obtained recommendations and what attitudes they have towards genetic knowledge in general. In this article, we'll try to answer the questions, relying on the results of the empirical study with inhabitants of a Russian megalopolis.

EMPIRICAL STUDY DESIGN

To find out and describe how (biomedical and digital) innovations are used by modern citizens in the practices of health care, a combined empirical study was implemented. During the first stage, 90 semi-structured interviews with citizens of large Russian cities (mostly Saint-Petersburg, Moscow, Ulyanovsk, Petrozavodsk) applying different technologies of health care were conducted in August 2020 — April 2021. Informants manifesting significant activity and being aware of health issues are in the center of attention. A question about the experience of DNA diagnostics was asked in 17 interviews. Study participants were selected based on the method of available cases with subsequent use of the snowball effect. A part of the interview was held in the distance mode using such platforms as Zoom, Skype, MSTeams, WhatsApp.

The questionnaire for phone survey of Saint-Petersburg's residents implemented at the second stage of this research in August 2021 was developed based on the results obtained during the interview and with the aid of the Resource Center of the Scientific Park of Saint-Petersburg State University 'Center for Sociological and Internet Research'[1]. Representativity was determined in a quota sample by gender and age. The data were processed using SPSS Statistics (ver. 23) with implementation of method of correlation analysis (Spearman's test). P (Sig) < 0.05 was considered significant. Correlation coefficients were estimated with the Chaddock's scale. Though the found interrelations were weak, they resulted in reasonable suggestions about the processes currently occurring in the sphere of health care.

Qualitative and quantitative methods combined in this research provided a complex idea of new practices of health-saving behavior. On the one hand, common tendencies were described and general population was characterized. On the other hand, semi-structured interview results enabled a deeper interpretation of digital data providing contexts not discernable behind the common distributions.

17 interviews with informants aged 26 to 69 (2 men and 15 women) were utilized at the first stage. Phone interview respondents were represented by 861 people with 56.2% of women and 43.8% of men. Among them, 21.7% were 18–29 y. o., 19.9% were 30–39 y. o., 15.8% were 40–49 y. o., 17.7% were 50–59 y. o., 25.0% were 60 years of age and older. About a half of those interviewed (51.7%) complained of chronic diseases. As basis for this research were citizens of Saint-Petersburg with a higher level of life as compared with many Russian cities, the results can't be applied to the entire population of the country. At the same time, they can characterize citizens of other large Russian cities with a certain degree of conditionality.

Though we mainly concentrated on digital technologies, study participants were asked questions about experience in genetic testing as well. We tried to describe the variety of using innovative technologies by citizens to take care of their health. In this article, only one situation was considered: experience in DNA diagnostics irrespective of motivation, both in the presence of symptoms, and for prevention and prophylaxis.

STUDY RESULTS

9.5% of those interviewed (9.1% of men and 9.9% of women) underwent genetic testing to find the risks of development of different diseases. The majority of them did it more than one year ago. COVID-19 pandemics could influence the parameter by shifting priorities in health care towards the new virus. Nevertheless, it is obvious that the rate of using genetic technologies to care about the health of megapolise inhabitants is not large yet and significantly yields to the use of digital technologies by popularity. As a comparison, 48.7% of respondents have ever done digital self-tracking, 32.5% visited forums and social networks devoted to health issues, 25.2% used telemedicine.

There were no fundamental differences in referral to DNA diagnostics depending on education, marital status, estimation of well-being by a respondent, control locus regarding health and presence of chronic diseases. Meanwhile, certain variations were found in the groups of men and women as far as the use of technology goes. In women, the practice of genetic testing is associated with age: the rate of referrals is slightly decreased with aging (0,115[2]), which is explained by involvement of women into the field of reproductive genetics [6]. During the interview, the informants noted that they came across genetic testing while being pregnant or in case of reproductive disorders: '*except for screening during pregnancy, that's all'* (W, 39).

In certain cases, a husband entered the area of 'genetic control' as well: '*Listen, it wasn't me, but my husband who did the testing. After an unsuccessful pregnancy he did some genetic testing to find out whether he had genetic abnormalities. When he was told that it was OK, he calmed down and went on living. And a healthy child was born'* (W, 34).

The study participants failed always to explain the meaning and results of these examinations. Women who didn't have an experience in DNA diagnostics are often informed of the procedure possibilities, plan to use it while getting ready for the birth of a baby and consider the step important: '*Yes, I heard about it, this is rather interesting. I didn't do the testing. But I will do it when I decide to have a baby. I mean, to know about genetic diseases'* (W, 32). We believe that the current market of reproductive genetics remains one of the most popular and demanded.

Among men, weak, but statistically significant correlations are reported between involvement into DNA diagnostics and

[1] Here and elsewhere, it's Spearman's test p<0.01, unless otherwise stated

[2] Frequency of using certain practices is measured according to the scale from more specific to less specific resulting in a negative correlation coefficient in case of positive connection direction.

income level: the procedure is more frequently used by those with a better financial and economic situation. One of indirect parameters of material wealth is a possibility to obtain medical assistance based on VHI program or on a fee basis. In spite of the fact that for the whole sample obligatory medical insurance is particularly popular, among the men who have ever done genetic testing, 42.9% made a last visit to the doctor on a paid basis (while obligatory medical insurance was used by 34.3% only) vs 22.5% of those who have never done this testing (0.186[3]). Thus, genetic testing among the group was more strongly sought for by those with a higher income and who can refer to commercial medicine. High cost of genetic testing as a sound reason for its refusal was mentioned by informants during the interview, as shown below. The lack of trust in healthcare and need to (re)check the diagnosis and medical recommendations belong to a factor of finding genetic health risks among men. In this group, the procedure is more frequently used by those who rechecked medical prescription during the last year (0.147). DNA diagnostics is probably considered as an instrument that satisfies the need of modern patients in their well-being control and incentive to find out the reasons for its worsening.

One of the key objectives of this study is to detect combinations between various health promoting practices. As a result, it has been found out that the use of genetics potential is associated with involvement into certain digital and traditional ways to support good health. And again, slight differences in the groups of men and women are observed. Experience of genetic testing is related to searching information on the Internet (0.114) in men and to visiting forums and online communities devoted to health issues in women (0.119). Moreover, men who underwent DNA diagnostics (0.179) are more prone to share information about convalescence or living with illness in social network than women (0.109). Both men and women combine genetic testing with telemedicine (0.142 for men and 0.134 for women). Meanwhile, men tend to correlate DNA diagnostics with such modern methods of health care as control of nutrition (0.116) and attention to mental well-being (0.170). It can be seen that determining health genetic risks is currently included into a wider repertoire of good health support practices and combined with digital and traditional options. Those interviewed who mentioned the experience of genetic testing manifest significant activity in relation to other modern practices of health saving behavior. Besides, the found relations between the biomedical and digital technologies can be explained by the use of the latter to obtain data about the possibilities of genetics. The fact was also mentioned by informants during the interview.

If analysis of quantitative data allowed to reveal and describe some general regularities of genetic testing prevalence among citizens of a large city, then the interview results enable to frame assumptions about social attitudes regarding this technology and motives of its using (not using). Informants included people who participated in the procedure of DNA diagnostics as well as those who had no similar experience; who were aware or poorly aware of these possibilities. We were interested in situations and complex trials such as compiling DNA profile and determining the risk of a certain disease development. During the interview, the issue of using the potential of genetics to obtain data about the origin and mapping resettlement of ancestors was discussed. However, we won't go into detail about this. It should be noted that in this case the procedure is assessed as entertainment, and the obtained data are considered as unreliable and inaccurate.

When analyzing qualitative data, types of attitudes to genetic diagnostics were identified. They were determined considering the presence or absence of experience in a similar procedure. Among informants who have never had DNA testing, there are proponents and opponents of genetic screening: those who plan to use it in the future and those who believe that the procedure is useless. Counterarguments can be systematized as follows.

1) High cost of a complex genetic testing. Access to technologies depends on financial capabilities and region of the person. Though citizens of large cities have certain advantages in this respect, the cost of services is considered significant for them as well. '*On the one hand, I didn't do the testing because it is very expensive, but it is not that simple. A complete screening costs a pretty penny'* (W, 39). Economic resources influence the decision to select a set of separate parameters for diagnostics: '*Not a complete testing, as it is expensive. I am not ready to pay a fantastic sum for it*' (W, 42).
2) Distrust in the obtained results, which are considered as unreliable. The unreliability can be interpreted in two ways. First, genetic knowledge is perceived as doubtful and insufficiently authoritative. We suggest that certain contribution into such comprehension of genetic data ensures its penetration into media space (social networks, television). '*You know, genetic testing goes like this: my grandmother and mother both had vegetative vascular dystonia, I was diagnosed it too, but finally a genetic disorder was found' (laughing)* (W, 29). Second, the companies that provide the services of DNA diagnostics are suspected of pursuing mainly economic interests and getting profit. '*No, I believe that all these centers have only one purpose of making as much money as possible. They tell a pack of lies'* (M, 53). Those who promote genetic testing are suspected to have a hidden agenda as well. '*No, no, I heard, but I didn't pass, and there was no thought of passing such a thing. It seems to me that this is more of an advertised event, and even considering that it is being done, at least I have come across, well, no one from my friends has done it, and what I see is, let's say bloggers do it for advertising, this is more of an advertising move, a trick'*. (W, 39).
3) Unwillingness to know the results of DNA diagnostics, certain health fatalism. The informants are not aware of their risks and prefer to remain in the dark following the principle of '*what you don't know can't hurt you'* (W, 35). Though they understand the advantages of genetic testing such as prevention and prophylaxis, study participants explicitly refuse from the possibilities as they don't want to live waiting for the disease. '*… I am afraid of these results, because it seems to me that when you know about the Parkinson disease, that will affect you in the future, you can learn to appreciate what you have today. It's better to have what to remember, than to wait for something bad to happen… Now, in one year or 10 years. It's like playing ostrich, though. Because some diseases can be prevented if you know the predisposition'* (W, 39). The key meaning of this argument is to avoid information about the disease until the symptoms and accordingly anxiety are manifested ('*I don't want to know about that*' (W, 31; W, 39)) and unwillingness to become 'a patient-in-waiting'. '*How can I continue living if I know about something bad?*' (M, 39). It is important to note that in this case the informant commonly determines on his own whether he needs the procedure

[3] Frequency of using certain practices is measured according to the scale from more specific to less specific resulting in a negative correlation coefficient in case of positive connection direction.

and doesn't communicate with a doctor. '*No, doctors never say things like that. I found it out on the Internet. It wasn't a doctor who told me this'*. (M, 39). Though the study participants show significant activity and awareness about health preserving issues and use different modern technologies for that, it is the consequences of genetic testing capable to cause changes in their lifestyle and self-perception that are of the utmost concern.

Although the 'fatalistic' ideas are popular, some of those interviewed reported their intentions to refer to DNA diagnostics in the future following the principle 'forewarned is forearmed'. '*Unfortunately, I haven't taken the test, but I would like to take it. I'm interested in this story. I heard many opinions, and not everyone trusts it. It just kept out of my way, or I saw it when I couldn't afford it. But I believe the testing is important, considering the possible hereditary risks'* (W, 28).

The sampling also included informants experienced in genetic examinations. However, they have different attitudes towards the use of obtained data.

1) Information acquired during complex diagnostics is an element of identity and gives a sense of control over health and life in general. '*I don't like surprises. I want to know it all beforehand. Then I can be ready for anything. Knowledge is a determinant factor to me. If I know, I will act somehow. Or I may not act, but with my informed consent'* (W, 26). Health turns into achievement being a result of hard and day-to-day work. In this case, a family nature of genetic testing is manifested through informants' narratives [9]. '*I am interested in cool things, like whether I have a genetic predisposition to muscular dystrophy or loss of vision or hearing, I don't remember which one. It is really important, because later we can both have the test and understand what genetic information can be passed to our children'* (W, 26). It should be noted that it is the patient who acts as an initiator of complex genetic screening.
2) The situation looks different in case of genetic determination of the present diseases. As a rule, in this case the procedure is carried out following a doctor's recommendation, and the obtained data are not used and do not change the informant's lifestyle. Genetic data are considered as something inevitable, guidance for inactivity; there is a conviction that nothing can be changed. '*It wasn't my initiative… I obtained a positive result… When I first knew about that, I was very upset, because of very unpleasant perspectives. I was nervous. If the disease could be arrested, I would arrest it. But it's genetic, and no arrest is possible. I know that all methods of struggling with it will be used in vain. My neurologist told me that it was impossible. I am not waiting, but I understand that it is similar to death. You understand that you'll die. You don't know when. Are you waiting for the death to come? No. But you understand that it's inevitable*'. (W, 42). It can happen that the existing symptoms don't impair the informant's life quality, and DNA data do not change his/her lifestyle. '*I have a genetic disease. To confirm it, I needed to do genetic testing. I did it and the disease was confirmed. It was about a certain disease that was suspected. But I use the information because doctors need it to understand that I don't have hepatitis. I inform them of it on a constant basis so that they don't worry if my skin turns yellow and this produces no influence on my lifestyle'* (W, 37). The fact that the idea of DNA diagnostics belongs to a doctor, but not a patient, influences motivation of the latter and implies subsequent using (non-using) of the data, which is alienated from the informant.

CONCLUSIONS

Based on the results obtained during the empirical study it can be concluded that genetic testing is currently not widely popular among population, as only 9,5% of those interviewed have even done the testing. Although traditional social and demographic parameters and certain values of health behavior do not determine involvement in genetic testing, differences in the groups of men and women were revealed. DNA diagnostics is slightly more popular among young women and men with a higher income, and do not trusting modern medicine. We suggest that the discovered variations reflect the condition of the market of genetic services in our country. The segment of reproductive genetics is the most developed one. Access to consumer genomics is determined by financial and economic possibilities. The use of genetics potential is embedded into a wide repertoire of modern ways of health promotion with digital practices being the most popular among them.

Apart from financial possibilities, involvement into consumer genomics is influenced by not sufficient trust in genetic information and suspicion that players of the market of genetic services pursue economic purposes. But the most important disadvantage is that genetic information is perceived as sentence, which is not known by the study participants until it is put into execution (when the symptoms occur). The attitude is rather interesting because it can be traced in those who acquired values of a healthy lifestyle and demonstrated intense self-care. Informants avoid genetic information because risks and health mean the same as the presence of a disease and genetic profile respectively. It makes any activity associated with their own well-being meaningless and creates a sense of losing control over their life. One of the most important principles of healthy lifestyle ideology is an ability to improve health and prevent diseases using various practices and manipulations; the future is not predetermined; it is open for different variants that depend on the efforts taken by a person. In case of genetic testing, there is a firm belief that the future can't be changed. This must be the reason for higher popularity of digital technologies that make people confident about possible control of their health and well-being. As a result, study participants don't want to become the everlasting 'patients-in-waiting' even in case of existing symptoms, but implement their 'right not to know'.

We assume that the discovered attitudes to DNA diagnostics can be explained by insufficient notification of general public of a probabilistic nature of genetic knowledge and multifactorial type of the most diseases. As a rule, a patient comes to know about the potential of genetics from the Internet and mass media, and takes a decision about the testing independently. When a doctor (who is commonly not a genetic professional) recommends the procedure, he shares an opinion about the inevitable nature of the obtained results and the future of the patient.

Paradoxically, that widely spread ideas about genetics contradict the cultivated healthy lifestyle ideology when a person can improve his/her health. Thus, impediment for turning the practices of genetic testing into routine consists not in sufficient readiness of a patient for active self-care, but in a need for producing a possible influence on the outcome of own efforts. Without promoting awareness that exposes potential, possibilities and limitations of genetic testing, close 'doctor-patient' communication, attaining genetic knowledge by non-major medical professionals, involvement of population in DNA diagnostics will remain a complex task.

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