Bioethics for Genomic Medicine: Responsibility to Family or Responsibility for Disclosure

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Abstract: Disclosure of patients’ genetic information to their families is a central bioethical topic in genomic medicine. The issue of disclosure to family is often associated with a balance between patients’ autonomy and confidentiality and beneficence of their relatives. Communicating patients’ genetic risk profiles back to their family members gives them an opportunity to benefit from additional testing, screening and prevention of potential disorder, so that bioethicists have offered a several models of communication with families. There is no unified definition of the term “family” in bioethics or health law, although the concept of “family” has an important position in the history of private law. There are many ambiguities about such issues as “What does ‘family’ mean?”, “How can communication about genetic risks be placed in a framework of family responsibilities?”. The analysis of several cases in genomic medicine carried out in the article allows us to delve into ethical, administrative, and legal details of these issues in genomic medicine. Notions of “disclosure to family,” “intrafamilial disclosure,” “family dynamics” and “the best interests of the child” are discussed in the article in this regard. Various models of disclosure are grounded in different concepts of family and family relations. If we consider the health professional’s duty to warn of risks to be the duty to help family members with exercising their autonomy, the health professional is responsible to family and is not responsible for consequences of disclosure. The notion of relational autonomy (based on recognition of mutual obligations of family members) begins to be discussed in law and bioethics, however, it still lacks the ethical underpinning. The further research could be aimed at developing the ethical concept of dependency in family relations.

Keywords: bioethics; relational autonomy; confidence; genetic counselling; genetic information; disclosure to family; familial information; family dynamics; collective agent; family decision-making
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Contents

I. Introduction ................................................................. 120
II. Family in Russian History and Philosophy of Law ...................... 122
III. Bioethical Issues of Medical Genetics: “All in the Family” ............. 125
IV. Cases Scrutinized .......................................................... 131
V. Conclusion. Autonomy, Dependency Relations and Epistemology of Family Decision-Making .................................................. 134
References ................................................................. 136

I. Introduction

In the last two decades, the family perspective of genetic testing has become a subject of discussion in bioethics and health law. Many books and articles are devoted to the tension between patients’ autonomy and potential benefit of family members. Debates about balancing between patients’ confidentiality and interests of family members are getting more intense. Few basic bioethical and legal concepts were revised due to bioethical discussions and court decisions. The English Court of Appeal supplemented the concept of a doctor-patient relationship by adding the notion of the “potential patient” which is defined as a person who may benefit from results of genetic testing (Gilbar and Foster, 2018). Thus, the concept of individual autonomy was replaced by relational autonomy. This approach tends to consider a human as a social being influenced by and dependent from others, first of all, from family.

The so-called “family covenant model” of genetic counselling considers family as an important part of the decision-making process. Family becomes a third party in doctor-patient communication. This
trilateral dialogue allows us to define the boundaries of the patient’s individual autonomy (Doukas and Berg, 2001). At first glance, the decision of the Court of Appeal has a similar logic with the family covenant model. The former implies sharing of the patients’ autonomy between family members, while the latter considers family as a major actor in a dialogue along with the patient. Both of them raise such questions as “What is family?”, “What definition of the term ‘family’ can help us solve the problem of family-relevant genetic findings?”.

Family law and health law usually deal with family issues and family relationships. Family can also be a significant collective, social, and legal entity. This entity can be represented by one or several individuals while it can be composed of more people. These two perspectives, namely “family as a context of relationships” and “family as a participant of relationships” are not easy to combine. Their difference is relevant for the issues of confidentiality, autonomy, understanding of a legal entity (How is family constituted as a collective entity?) as well as for the issue of data ownership. Is genetic information personal or “familial” data? Can anonymized results of genetic tests be shared among family members as a scientific information generated in a lab?

Another dimension of the family problem is an inversion of dependency. Before “the birth of clinics,” patients were dependent from family care. At present, genetic patients control family-relevant information, so that their relatives are dependent from their willingness to share it.

Genetic information is a gift and a curse at the same time (Reynolds, 2020). On the one hand, it helps people to cope with many diseases. On the other hand, it imposes responsibility. Such responsibility can be a part of moral duty of supporting the others’ autonomy, i.e., the health professional is responsible to patients’ relatives (individuals who do not have enough knowledge to make their own decisions). Furthermore, such responsibility can be grounded in the risk-benefit ratio, i.e., the health professional is responsible for sharing the genetic information to people at risk, as this act can potentially protect their health.

The controversy between patients’ autonomy and beneficence of members of their families is not the sole framework for addressing the legal and ethical issue of disclosure of genetic information. The
autonomy and beneficence can be opposed to each other. For instance, the autonomy of family members or autonomy of a family as a collective entity can be opposed to the patient’s autonomy. It is unlikely that the issue can be solved by determining whose autonomy is more important. Beneficence of a patient and health professional based on trust and confidentiality can also be opposed to beneficence of family members.

The conflict between Kantianism and utilitarianism has lasted more than two hundred years. This ethical dilemma is particularly relevant for addressing the issue of disclosure of genetic information. We can consider the notion of “family” from different perspectives based on the chosen line of reasoning (e.g., autonomy or beneficence). On the one hand, family can be regarded as a collective entity having its own interests. On the other hand, the notion of family placed in the ethical and legal context can be viewed as a normative concept. Family presupposes a certain type of relationship, i.e., a hierarchy of legal and moral responsibilities and opportunities. The issues related to family boundaries and other characteristics of family arise in both deontological and utilitarian contexts but can be addressed differently.

These issues were central in various ethical and legal concepts. The next section of the article presents the opinion of Russian historians and philosophers on the notion of family. The third section analyses bioethical aspects of disclosure of genetic information to the patient’s family. The fourth section explores two ethical and legal cases related to the aforementioned issues. The article concludes with considerations for the understanding of a bioethical principle of autonomy extending beyond Kant’s ethics.

II. Family in Russian History and Philosophy of Law

The notion of family was central in ethics, political philosophy, history, and philosophy of law. Even Aristotle considered family as a primary form of social relations (Aristotle, 2006). Much later, scholars began to define family as an independent entity of social and legal relations. M.F. Vladimirsky-Budanov (2005), a Russian legal historian of the second half of the 19th century, suggests that the consideration
of the individual as the main subject of private law is a result of the historical development of the system of legal relations.

“The concept of a person as a subject of private law, which seems so simple today, is the result of long-term efforts of history. Initially, there were public unions (e.g., family, tribal, communal, state unions) formed by the mixture of public and private principles; a physical person was not defined at that time” (Vladimirsky-Budanov, 2005, p. 437).

At the same time, Vladimirsky-Budanov considered the evolution of subjects of private law as one of the key tasks of the history of Russian law. Russian historians and philosophers of law of the second half of the 19th century generated discussions on the legal significance of family. A more active interest in this issue was caused by disputes between Westerners and Slavophiles.

The discussions on the role of peasant families in shaping the moral and political characteristics of the Russian population at that time deserve significant attention. These discussions were not only about the nature of family as a social and legal entity but also about its boundaries.

I.M. Tyutryumov, a prominent lawyer of the 19th century, believed that family is an association with a shared household. Family is primarily characterized by the community of property and property interests (Tyutryumov, 1881, p. 43). By contrast, S.V. Pakhman, a well-known legal scholar, claimed that the peasant family community was united on the basis of family ties (Pakhman, 1879, p. 12). At the same time, the interaction of family members unrelated by blood takes place according to the models of interaction between parents and children or brothers and sisters.

The discussion on the origins and foundations of family relationships taking place at that time may be relevant to the consideration of the role of family in the regulation of medical genetics. The main ethical issues in this field are connected with the discrepancy between the degree of consanguinity and the nature of the social connection. Although family communities discussed by historians could include a significant number of people who were distantly related to each other, positive law had been limited to the concept of a nuclear family even before the
revolution. G.F. Shershenevich, a lawyer of the 19th–20th centuries, states that “Family...is a union of persons related by marriage and persons descended from them” (Shershenevich, 1915, p. 253). At the same time, children are no longer considered members of the family upon reaching the age of majority.

Thus, there have been two sides of the issue of defining family in the history and philosophy of law. On the one hand, it is crucial to draw the boundaries of family as a community of individuals. On the other hand, it is also important to mention the nature of the relationship between family members and determine their duties in relation to each other. The development of genomic medicine has revealed another dimension of this issue. For centuries, family doctors have dealt with intra-family relationships, but the subject of their care was an individual, a family member, or a combination of such individuals (e.g., in case the whole family got the flu). A genetic counselor treats each family as a single entity. He/she makes a diagnosis on the basis of the family history of the disease and the genetic risks which he/she determines as being relevant for the family and its descendants.

Nowadays, the transformation of the doctor-patient relationship is the object of bioethical regulation. This will be discussed in the following sections. At the same time, it cannot be said that the understanding of family as a subject of law has remained an object of historical study only. An analysis of the legal relations that arise in case of the assignment of pensions for the loss of breadwinner showed that the subject of these relations is family (Astrakhan, 1962, p. 153).

Such terms as “family interests” and “family protection” are used in modern law (Tarusina, 2020, p. 23). However, the understanding of family may differ in both cases. Each particular family has its own interests as a social and legal entity. For example, these interests may include housing improvement in connection with the birth of children. A group interest is not limited to increasing the amount of living space per family member. Conventionally, the family’s interest does not imply buying two one-room apartments but living together in a three-room apartment. At the same time, it cannot be said that this family interest is expressed by all members of the family (e.g., newborns or young
children do not have this interest). However, parents and relatives express their interest for the sake of all family members.

The term “protection of family” is often used in the sense of “protection of traditional family relations, that is, relations based on a marriage which is understood as union of a man and a woman.” This is not the only possible interpretation of this term but it clearly demonstrates differences in the understanding of family. In this case, the object of protection in the first place is not a specific family or its unity but the interpretation of family with an ideal image of family relations. This understanding is based on the structure of mutual rights and obligations that arise within the framework of certain social (family) relations. Mutual obligations of family members are not limited by their legal nature. Rather, law forms the boundaries beyond which one can speak of the destruction of family. Thus, laws contain criteria for finding grounds for deprivation of parental rights or recognizing a marriage union as being fictitious. There is no statement of the essence of the relationship between spouses or between parents and children in written law (Tarusina, 2020, p. 25). Civil lawyers who deal with this kind of cases are often forced to rely on ethical concepts of mutual respect for spouses and proper care for children (Tarusina, 2020, p. 25).

With some reservations, we can say that the notion of “family protection” should be introduced in medical genetics especially in relation to cases of informing family members about hereditary risks. That is, a family member who received information from a medical geneticist about existing hereditary diseases should take care of the health of his/her relatives and share information that is relevant to them. At the same time, a genetic counselor always deals with the “interests of the family,” their real boundaries and strategies for collective understanding, or vice versa, their ignorance of medical problems.

### III. Bioethical Issues of Medical Genetics: “All in the Family”

A typical bioethical collision faced by a medical geneticist deal with the issue of informing the relatives of a patient about their possible diagnosis. This collision is usually considered as a conflict between the patient’s autonomy (the right to preserve medical confidentiality)
and beneficence of relatives, family members. The ethical dilemma is that following two of the four basic bioethical principles (the principle of beneficence, non-maleficence, autonomy, and justice) imposes mutually exclusive moral obligations on the health professional and the entire healthcare system. The patient can disclose information about his/her health according to the principle of autonomy, while the principle of beneficence implies duty of care for people at risk. This bioethical collision can also be represented as a tension between a particular family as a subject of care and the image of family relations, the structure of people’s moral obligations towards each other. At the same time, this structure seems to be similar to the kinship system for a medical geneticist.

Issues of family decision-making and family interests were addressed within the frameworks of medical humanities and evidence-based medicine (Siminoiff, 2013). Medical genetics adds two more tightly connected dimensions to this problem. The first dimension deals with rethinking the concept of family. The second dimension relates to genetic ancestry testing. While laws in many countries tend to use more and more inclusive notion of family, the progress in medical genetics inclines courts and general public to handle with biological meaning of family. More than twenty years ago, Canadian courts considered that right to know one’s own genetic heritage is based primarily on medical reasons (Caulfield, 2000). In these cases, the courts never referred to a specific disorder or even to a way of using genetic data. This phenomenon was called the “genetization” of the family (Caulfield, 2002).

Medical genetic testing sometimes influences family health history. Five years ago, Australian bioethicists discussed a very representative case.

**Jordan’s case**

Jordan, a middle-aged paramedic, bought a direct-to-consumer genetic test kit. The result showed that she had an increased risk of Alzheimer’s disease. This risk was detected because she carried the specific variant of the APOE gene. The test also showed that 25% of Jordan’s genetic inheritance is determined to be East Asian. She was surprised as she thought that all her grandparents had European roots.
The crux of the problem is that people with East Asian roots have higher risks of Alzheimer’s disease if they carry this specific variant of the *APOE* gene (Mason, 2017). Therefore, the uncertainty of possible disease progression coincided with the uncertainty in ancestry estimation. Jordan realized her responsibility to inform her relatives about possible risk. However, it might not be necessary as there is no approved method to minimize the risk. Moreover, she did not know who to inform.

Therefore, family issues are the core aspects of bioethical regulation of medical genetics. Even though problem statements do not usually contain the word “family,” they are closely linked to the normative understanding of the structure of family relationships and social subjectivity of each particular family. In Canada, France, Australia, the USA, and the UK, laws, directives and recommendations on intrafamilial communication of hereditary breast and ovarian cancer frequently contain the term “family” but rarely explain its meaning. Thus, three out of four main difficulties in interpreting these documents are related to the questions: “who should be considered as family?; why should patients inform their family members; and how should health professionals be involved in this process?” (Nycum, Avard and Knoppers, 2009).

The remaining fourth question concerns the definition of ethically and legally important characteristics of genetic data as well as the amount of data that can be disclosed to relatives by a patient. The patient has a moral responsibility for disclosing the aforementioned data. The next section of the article shows how the ethical and legal definition of genetic data is linked to the structure of relationships between the patient, his/her family members, the health professional and the genetic laboratory. We will also explore the definition of family boundaries and the structure of family relationships.

The normative (ideal) structure of a traditional family and the structure of a “biological family” may differ significantly. Informing the spouses of patients by a geneticist who deal with the “biological family” is of clinical importance only when it comes to planning the birth of children. However, a traditional nuclear family is usually understood as a union of a man and a woman based on marriage. The survey of
patients of geneticists of the reputable American Mayo Clinic showed that the majority of respondents (97%) were ready to share the results of genetic testing with their spouses or partners. 92.2% of patients planned to inform at least one adult child about the result of the genetic test, 86.2% of respondents would inform at least one sibling, and 70.3% of patients intended to inform at least one parent. In total, almost 3,000 people who took a comprehensive test to determine hereditary cancer risks were interviewed (Finn et al., 2021). It can be assumed that the information about health risks is mainly relevant for parents. However, patients preferred to inform, first of all, their spouses, that is, people who were not genetically related to them. This can be explained by the difference in the degree of responsibility of relatives for the possible care of a person with cancer. It is more likely that spouses will take on this responsibility, but not the elderly parents.

A biosocial model of family has been used in bioethics for a long time (Gilbar, 2005). According to this model, social relationships and biological (genetic) ties can substitute each other. Many European guidelines have broadened the notion of family, recognizing that genetic tests are of interest to the extended family, including legal relatives. Their recommendations qualify sharing information with legal relatives as “intrafamilial disclosure.” The US guidelines do not contain the definition of family, although there is a mention of “disclosure to family” (Black et al., 2013, p. 205).

Authors of medical and bioethical recommendations suggest two ways of understanding family. For some, the disclosure of genetic information is addressed to family as a full-fledged stakeholder. This stakeholder may be represented by one or more people who receive information about the results of a genetic test, diagnoses, and risks, but these results affect the whole family. The health practitioner cannot interfere in the structure of intra-family interactions, since this would undermine the autonomy of both the consulted individuals and family as a whole. Another understanding of family is that the health practitioner’s actions are aimed at maintaining the normative (“ideal”) structure of interaction between family members.

Thus, the understanding of the real subjectivity of family may prevent the doctor from informing the patient’s relatives about the
results of a genetic test. The basic understanding of “disclosure to family” is that the absence of a ban on going to the doctor with a family member. According the abstract structure of family, a healthcare professional can take real steps towards “intrafamiliar disclosure.”

We should also mention one aspect that may not be obvious to people who are not familiar with genomic medicine in the United States. There is a difference in approaches to communication between family and clinical geneticists or genetic counselors. For instance, clinical geneticists hold medical degrees such as MD and have completed one or two year residency training. Genetic counselors are non-medical health-care professionals who help patients and their families to understand their genetic risks and options for genetic testing. In European countries, this profession is gradually being integrated into the system of medical genetic care, but there are different ideas about its place in this system and about the necessary professional training (Paneque et al., 2017). The ethical and legal nature of relationships with patients and their families is similar for clinical geneticists and genetic counselors. However, clinical geneticists focus rather on the clinically significant consequences of disclosure or non-disclosure of information about genetic risks. Genetic counselors are also concerned about the health of the patient’s relatives, but they are much more immersed in the emotional context of family interaction (Dheensa et al., 2016). In this regard, the improvement of the so-called “family dynamics” due to transparency in relations between relatives can be an important ethical decision-making factor. Genetic counselors, weighing the risks and benefits of disclosure, may consider their efforts to inform the patient’s family members as actions aimed at strengthening family relationships.

However, the image of the scales on which the healthcare professional weighs the risks and benefits encourages us to adopt a utilitarian logic to the problem. Dheensa et al. (2016) illustrate the results of their systematic review of the arguments clinical geneticists and genetic counselors turn to when making disclosure decisions by using a picture of scales. In this situation, the “patient autonomy” does not necessarily have a deontological character, it can be considered as a rule utilitarian argument. That is, the obligation to respect the autonomy of the patient and maintain medical secrecy is not a part of
the moral responsibility of the doctor towards the patient. Compliance with these obligations from the perspective of rule utilitarianism is a social convention that brings the greatest benefits in the long run. That is why the factors of autonomy and privacy should be taken into account. Thus, the bioethical principle of autonomy becomes an integral part of the principle of beneficence, and this refers to the comparative weight of different benefits, namely medical and social (“family dynamics,” “privacy,” etc.).

Discussions on disclosure to family and intrafamilial disclosure can also be presented through the lens of deontology. From a utilitarian point of view, healthcare professionals are responsible for patients’ and their relatives’ health. From the point of view of medical responsibility, healthcare professionals are responsible to patients and their families. Although Dheensa et al. (2016) use the wording “responsibility to,” the main arguments in their article are mainly related to “responsibility for.” At the same time, within the framework of the deontological conflict, patients and their families are not necessarily the subjects which geneticists and genetic counselors are responsible to. The collision is that there is a difference in responsibility to a) a particular patient’s family, represented at the doctor’s appointment by patients, and possibly their relatives; b) family in the normative sense (i.e., having a certain type of “family dynamics,” and capable of collectively “managing hereditary risks”). The second type of healthcare professionals’ and genetic counselors’ responsibility refers to the society as a whole, which has certain ethical and legal norms. For example, the situation when a traumatologist identifies injuries on a patient’s body that may indicate domestic violence could cause him/her to violate medical confidentiality. That is, the doctor may, contrary to the prohibition of a capable patient, provide details of his/her condition to law enforcement agencies. From a moral perspective, such an act of the doctor can be considered as being aimed at protecting the family, suppressing actions that contradict the normative understanding of family relations.
IV. Cases Scrutinized

The difference between “responsibility to” and “responsibility for” was highlighted in the discussion between Anneke Lucassen and Angus Clarke on two ethical and legal cases (Lucassen and Clarke, 2021). Anneke Lucassen has a background in the molecular genetics and now she is Chair of the British Society for Genetic Medicine. Angus Clarke is a clinical geneticist working both as a professor and as consultant in the All Wales Medical Genomics Service.

They have outlined their positions in their previous debate. Angus Clarke considers genetic information to be personal. Anneke Lucassen argued that it is a potentially familial information that can and, in some cases, should be shared with relatives who might be at risk (Lucassen and Clarke, 2007). However, they both agree that a patient has no right to veto intrafamilial use of genetic information generated by the genetics diagnostic laboratory. This information can be used to alert the relatives that could be at risk. Besides, information about the type of pathogenic mutation can be used for the benefit of blood relatives (Lucassen and Clarke, 2021).

Lucassen and Clarke suggest that both situations are acceptable, but each of them offers its own rationale for this. Lucassen believes that genetic data understood as family information should be available to all family members. That is, these data, in a sense, belong to the whole family. Clarke claims that data belongs to the genetic laboratory and health service in general. There are no privacy considerations that can be so strong to “override the health service’s duty of care to the relatives” (Lucassen and Clarke, 2021, p. 1).

It was mentioned in the previous section that the issue of the nature of genetic data is also a family issue for ethics of medical genetics. Blood relatives have common fragments of the genome and, with certain probabilities, can be carriers of the same genetic variants. In a certain sense, the family history of diseases is the evidence of these data. It allows the geneticist to formulate a hypothesis about certain genetic variants. The genetic data are generated only in the course of molecular biological diagnostics (genome sequencing, PCR). Genetic data are not given to family as a family tree memory.
The question is which analogy of genetic data will be more fair and transparent. On the one hand, a photo of a family holiday can also be taken by a photographer, but it belongs to the family as a renewing group of people. Even after the death of the participants of the holiday, the photo will continue to be a part of the collective memory of the community of their descendants. On the other hand, information about risk groups and ways to measure and minimize this risk belongs to the health system. Information about the diagnoses of specific patients and pathogenic genetic variants found in them is used by this system in the same way as the data of population genetic studies. In the context of the health care system, the most important information is the information about certain medical risks for a group of “individuals A” and not about the health data of “patient A.” The boundaries of this group and the type of risks are determined by the bloodline and diagnosis of the patient.

Therefore, the question is how separable genetic data are from private medical information. In order to answer this question, Lucassen and Clarke provide a fairly typical clinical scenario.

**John’s scenario**

John has familial adenomatous polyposis (FAP) confirmed through mutation testing. For John’s three children (aged 10, 13, and 15 years), each has a 50% chance that they have inherited the condition and would then benefit from regular gastrointestinal surveillance for polyps and tumours. The information to be made available is (1) the diagnosis... and (2) its potential implications... (3) it is important for any genetics laboratory testing the relatives to have access to the molecular information about John’s APC gene mutation, in order that they can target testing... Channels (of family communication) may be disrupted by poor relationships, geographical distance or for a variety of other reasons such as not wanting to be the bearer of bad news... (Lucassen and Clarke, 2021, p. 2).

Lucassen and Clarke agree that the best option is to convince John to divulge the information himself. However, if he cannot do this, the healthcare professional should try to contact a general practitioner who can invite the patient’s relatives to an appointment and inform them of the risks (in order to do this, their full names and dates of birth are required) (Hyer et al., 2019). According to Lucassen and Clarke, the
strength of the moral obligation to inform family members depends on the severity of the disorder, possible interventions and proximity of relatedness of the relative (Lucassen and Clarke, 2021, p. 3).

All this reasoning does not take into account the age of John’s children whose health is important. Hundreds or thousands of adenomas typically start to develop in the adolescence. In this regard, it is recommended to offer predictive genetic testing to children between 12–14 years of age (Hyer et al., 2019). As both Lucassen and Clarke discuss disclosure in British legal realities, it is worth noting that the National Health Service considers it possible to take informed consent from persons under 16, “if they’re believed to have enough intelligence, competence and understanding to fully appreciate what’s involved in their treatment” (NHS website). The father’s and mother’s refuse to give a consent can be overruled by court “if treatment is thought to be in the best interests of the child” (Hyer et al., 2019).

Lucassen and Clarke do not mention whether healthcare professional activities in John’s case go against conventional notions of autonomy. First of all, children receive information about possible genetic risks contrary to the prohibition of the father. Secondly, the father may not consent to genetic testing of minors. Lucassen believes that disclosure with a help of a general practitioner would not violate the confidentiality of John’s diagnosis. However, there is a possibility that the father would not agree to do genetic screening. In order to solve this issue, the perspective should be changed from bioethical to judicial. The construct “best interests of the child” presupposes the completion of those actions in relation to the child that would be taken within the framework of the normative image of family relations but are absent in reality. At the same time, there are at least nine versions of the normative justification for the cancellation of parents’ decisions regarding the health of their children in the world legal practice. The construct of “best interests” is only one of these nine principles. Thus, parental decisions can be overruled due to respect for children’s autonomy (McDougall and Notini, 2014).

The second scenario, considered by Lucassen and Clarke, relates to the issue of the relationship between consequentialist and deontological principles in bioethics. It concerns non-disclosure of information about
the risk of Huntington’s disease by physicians to the pregnant daughter of a patient who has been diagnosed with it. This case received a lot of publicity due to the ABC case. Lucassen argues that “being unable to exercise reproductive autonomy is akin to not being offered a medical intervention to influence the course of a disease” (Lucassen and Clarke, 2021, p. 3). She also mentions the possibility to separate father’s clinical diagnosis and information about genetic risk. Communicating with the daughter, doctor could only mention that visible father’s symptoms may be explained by genetic factor (Lucassen and Clarke, 2021).

V. Conclusion. Autonomy, Dependency Relations and Epistemology of Family Decision-Making

At the level of bioethical and legal regulations, the solution to the problem of disclosure may be to separate private clinical information from genetic data. The latter can be recognized as either simply belonging to all family members, or being at the disposal of the health service, which is obliged to act on the basis of respect for the autonomy of all family members or their beneficence. However, the focus on autonomy implies broader disclosure powers. The ABC case showed that it is important to not only prevent the development of the disease but also have a right to make decisions based on the most complete information about one’s genetic risks. Such obligations of the health service arise outside of family relationships. Information about the genome of a person and the influence of genetic characteristics on his/her health can be significant for people who are not related to the person’s bloodline (i.e., for those who may have similar de novo mutations).

If we consider genetic information as family data, it is necessary to understand the property of the collective entity that possesses this data. It can be represented as a group subject based on the equality of family members whose ethical position is the sum of equally weighted individual preferences or ideas about duty. In this case, we are faced with difficulties and paradoxes similar to the Condorcet paradox. According to it, collective preferences can be cyclic, even though the preferences of individual voters are not cyclic. The preference cycle described by the paradox is much more likely to occur in small groups than in
large communities (Tangian, 2000). The difficulties of epistemological formalization of collective decision-making (the emergence of a group subject) clearly illustrate the obstacles to legal and bioethical formalization. Family is not the sum of individual autonomies. At the same time, the autonomy of the patient as a family member and the autonomy of the rest of the family cannot be placed on different scales.

The desire of healthcare professionals not to participate in disclosure of genetic information can be motivated by considerations of duty — observance of medical secrecy — from an ethical point of view. Accepting this considerable challenge, experts in the field of bioethics and law have made significant efforts to reconstruct the concept of autonomy. These attempts have led to the development of the concept of relational autonomy, according to which any person is always inscribed in a system of social ties that imply, among other things, the existence of ethical obligations to family members and other people and groups, as well as identification with certain communities (linguistic, ethnic, religious, etc.) (Herring, 2014). This concept finds its application in the field of family law, the decision on the ABC case, and medical law (Gilbar and Foster, 2018). This decision can be interpreted as a recognition that healthcare professionals are included in the system of intra-family obligations and begin to share the responsibility of the patient to the family.

However, the positive meaning of the concept of relational autonomy remains unclear. It can now be described as an element of criticism of the classical, Kantian concept of autonomy and a demonstration of its limited applicability. It is may be possible to add the ethical component to the meaning of this concept due to the development of the views regarding dependency as a fundament of autonomy of one of the greatest ethicists of the 20th century, MacIntyre (MacIntyre, 2001). Such an ethical conception may not begin with the notion of freedom to make rules for oneself, but with a relationship of mutual dependency. According to MacIntyre, the fundamental ethical relationship can be seen primarily in the dependence of the child on the mother. In this regard, the clarification of the normative image of the family and family relations is not one of the aims of bioethical regulation but its basis.
References


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