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RESPECT FOR CONFIDENTIALITY IN GENETIC TESTING: RIGHT OR BURDEN?

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Abstract

In Romania, approximately 78000 individuals are diagnosed with cancer, as per the latest review of the National Cancer Research Institute – GLOBOCAN 2012. While in 5-10% of these patients the tumors are due to genetic inclinations, it means that approximately 3900-7800 of the total annual cases come from families with genetic exposure to cancer. These patients could benefit from oncogenetic testing and counseling. The history of oncogenetics in Romania is very recent, due to the fact that a few years ago, there was no information whatsoever about mutations, polymorphisms or unclassified gene sequencing. This study includes analysis of a family with a family history of colorectal cancer in terms of confidentiality of genetic information and ethical principles. Genetic information, because it is both individual and familial, will always generate ethical conflicts between the duty of maintaining the confidentiality of information and the duty of warn the other family members who are directly involved. The decision to violate the rule of confidentiality is difficult and raises ethical dilemmas. The consequences of violating confidentiality by means of informing a biological relative with regards to the genetic risks must be compared to the benefits of disclosing information by taking medication or by altering one's lifestyle in order to prevent or to improve the condition. Thus, professional genetic counselors should make an effort to talk the patient into disclosing information for the others' sake, and the implicit agreement should be replaced with the explicit agreement, based on the ethical responsibility of each individual.

Keywords: confidentiality, genetic information, ethical responsibility, disclosing information, family history of cancer

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The impact of genetic information

The impact of genetic conditions manifests both at the level of physical health, and at the level of psychological and social status of both patients and families. The personal and permanent nature of genetic conditions can determine a series of negative affects, such as: guilt, anxiety, fury, and a sense of helplessness. Just like in every other chronic diseases, these conditions may need continuous care, permanent preoccupation, and awareness that ...sometimes total cure may not be possible, but only improvement over that specific condition. Genetic diseases also have implications for the health status of the biological next of kin: the diagnosis of a genetic condition with a family member could bear a higher risk in another family member, even though the latter is asymptomatic at present time.

Understanding the social effects of genetic testing needs a specific analysis of the way in which genetic information affects people at the most individual level, family level and community level, while also at the professional and social level. Generally speaking, the genetic diagnosis brings about benefits to patients, enabling them to understand their disease, and pursue the adequate treatment. It can also be useful for other family members, in making decisions with regards to their own health and life.

Genetic information allows for multiple-level answers: the individual level (being concerned for his own health – an adult diagnosed with a genetic condition who considers family planning, must bear in mind the fact that future offspring can be highly exposed to genetic conditions), the community and society level (fear of discrimination and stigmatization, fear of possible implications in health insurance). According to the review pursued by Ellen Wright Clayton (2003), the most frequent fear expressed by people is that genetic information may be used in ways which can affect them (they can be refused the access to health insurance, they can be refused to work, to learn or loan). In a study conducted with regards to changing public attitude related to genetic testing in 2002 (which marks the hopeful launch of the „book of life” and expects to contribute to the understanding, prevention or cure of many diseases) up to 2010 (10 years since the discovery of the human genome), we find out that in 2010 the population was more interested in the personal genetic profile, and considers that knowing the genetic background of the disease will help people to live longer (43% in 2002, 64% in 2010, $p < 0,001$) and in order to prevent a disease, the population would like to know the risk of having that specific disease (52% in 2002, 53% in 2010, $p > 0,05$) (Henneman *et al.*, 2013).

Thus, genetic information can raise questions referring to personal and social responsibility, as well as personal choice vs. genetic determinism/fate, to the issues of health and disease, whose answers are determined by individual factors, family values, cultural and social beliefs.

2. The Oncogenetics as medical practice - social impact point of view

The oncologic diseases are conditions determined by multiple factors and by altering the cellular genome. These alterations are either inherited, or tumoral. Identifying the germinal (hereditary) mutations allows quantifying the risk of cancers as well as taking some prophylaxy measures which help in reducing the occurrence and mortality through cancer. The efficiency of oncogenetics was demonstrated in the Western world starting more than a decade ago, in terms of incidence and anticipation of cancer forms, especially of breast, ovary and colon cancer. It was estimated that 5-10% of cancer diseases are attributed to a very high auto-somatic inclination (Henriksson, Olsson and Kristoffersson, 2004).

In Romania, approximately 78000 individuals are diagnosed with cancer, as per the latest review of the National Cancer Research Institute – GLOBOCAN 2012. While in 5-10% of these patients the tumors are due to genetic inclinations, it means that approximately 3900-7800 of the total annual cases come from families with genetic exposure to cancer. These patients could benefit from oncogenetic testing and counseling.

The history of oncogenetics in Romania is very recent, due to the fact that a few years ago, there was no information whatsoever about mutations, polymorphisms or unclassified gene sequencing (Negură, Matei and Negură, 2010). Recent studies in Romania at the level of families which are prone to breast or ovary cancer allowed the identification of genetic mutations in 40% of those families (Negură *et al.*, 2010). Also, the implementation of the oncogenetic diagnosis allowed the local mutational spectre to be characterized and the treatment adapted to the analysed population (Negură *et al.*, 2011, 2012). The Program of personalized oncogenetic surveillance was implemented (Negură *et al.*, 2010) and the first Oncogenetics Department was founded in Romania. At present time, 50 families are analysed in HBOC and 12 families in this program.

3. Case Study

This patient (P1) is 46 years old and was diagnosed at 44 years old with rectal neoplasma (colon infiltrative adenocarcinoma cT2N2M0). He is still under treatment even at present time, this condition being very serious (hepatic and pulmonary metastasis). P1 addresses to the Oncogenetics Department from the University of Medicine and Pharmacy G.T. Popa of Iasi, in order to be advised by an oncogenetics counselor, at the request of the oncologist, due to his family history of colon cancer (a brother deceased at 39 years old, his father deceased at 67 years old) – Fig.1. P1 has another sister who is 35 years old, not married and lives in Italy. P1 doesn't know that his sister has health problems. P1's brother was diagnosed with colon cancer in Italy where he lived with his sister, and hid that he had the disease until the its last phase. Both the brother and the sister

belong to a religious cult (P1 doesn't want to reveal the religious practice of his kin) which prohibits medical interventions. After his brother dies, P1 looks through the medical documents of his brother and finds that he bore a mutation called KRAS (p.Gly12Val) which recommends an extensive genetic review. P1 thinks that due to his religious belief, his brother didn't share the health problems and the results of genetic testing. He also believes that not even his sister is worried with her present and future health.

P1 wants to enroll in the genetic testing program, being especially worried for his future children. He is married and has two children, one being 17 years old, and the other being 15 years old, and apparently perfectly healthy. He decided that the genetic test results be submitted only to him and his wife. He wants to not worry the children for their future health. He believes that this would be a great burden at their age. He doesn't know when, how, what he'll tell them about the colorectal cancer genes, so as to enable them to decide if they want to pursue genetic testing as well. „I have some more time to think”, P1 says. „I believe I'd feel guilty if I bear cancer genes which I could transfer to the children as well”. „I believe it would be difficult for them to think that they will have cancer because of me. But at the same time, they could see the doctor earlier than I did. Maybe I wouldn't have reached such a serious state or maybe I wouldn't have had cancer if I knew about my brother, his testing, prevention and all that”. The children only know about the oncologic condition of their father, being unaware of the extended family history.

Under the informed consent that P1 signs before the genetic testing, he agrees in writing to submit the information about the genetic testing only to his wife. P1 believes that he can tell them about the genes for colorectal cancer only when they're older. Given the serious state of the disease, it may be that his death happen before finding out the results to molecular testing, so that the talk to his children won't take place anymore. If the spouse decides not to tell the children that they could or could not bear the modified gene, the right to know and to benefit from information with regards to risks and to being prone to a condition which could be treated or prevented will again be violated.

The situation described above raises two questions:

- Should genetic information belong to the individual or to the family?
- Does P1 have the ethical obligation to tell his children that they could face colorectal cancer?

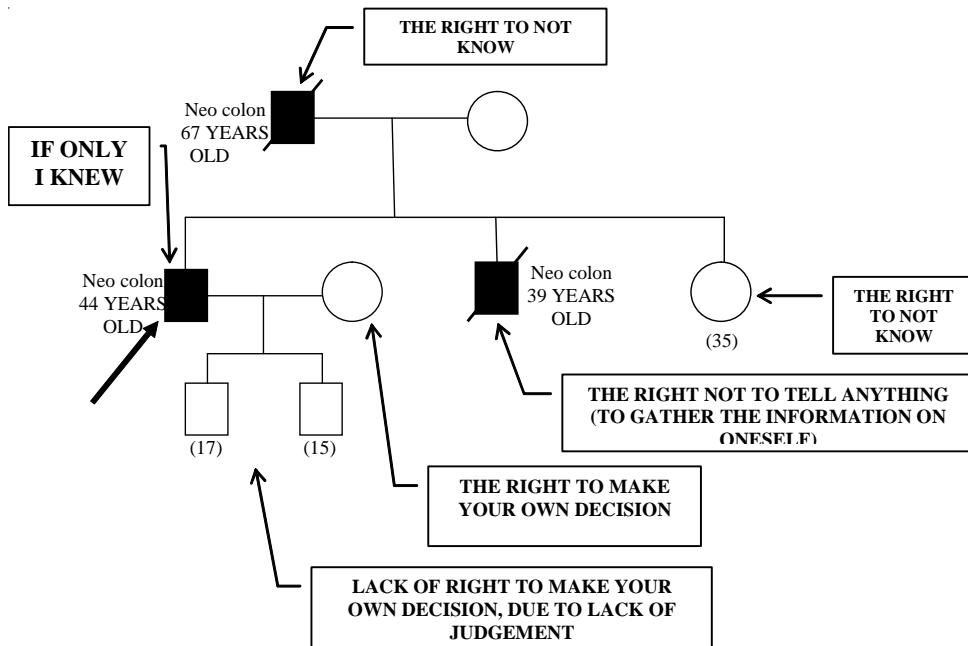


Figure 1. P1's pedigree

4. Discussions

Unlike other medical information, genetic information is more than individual information, it is information of extreme importance for the family. Due to these characteristics, revealing genetic information in the family structure raises problems of ethical origin. On one hand, this is about the private and confidential character of this information, whose unjustified revealing may affect the person. On the other hand, revealing information could be of significant benefit for other family members (informing them with regards to being prone to a disease such as is cancer) which can be detected at a very early stage). This is why there is the acceptance of “the right to know” (Etchegary and Fowler, 2008) and patients have the responsibility to reveal this information to relevant family members (Davey, Newson and O’Leary, 2006; Gilbar, 2007). Genetic testing affects the degree of awareness with regards to a disease or condition. It is also accompanied by fears in relation to the possibility of cancer, feelings of fury (towards those who might bear the disease) or guilt (with regards to transmitting these genes to the offspring), as well as in relation to the emotional reactions connected to the past or present experiences with those affected by cancer or whom we lost due

to this disease. All these aspects alter the quality of life and can also alter family relations. Right before genetic testing, there are some psychological aspects which influence the decision-making with regards to testing (fear of cancer, fear of death, fear of not being transformed after surgery, fear of being stigmatized, fear of not having access to health insurance or to different jobs) (Bowen *et al.*, 1999; Codori *et al.*, 1999). Genetic testing can begin with only one person, but can easily become a family problem (Foster, Eeles, Ardern-Jones, Moynihan, Watson, 2004).

The development of molecular medicine lead to genetic tests pursued for detecting genetic mutations involved in about over 1000 diseases (www.genetests.org). These tests aren't effected only on symptomatic patients in order to confirm the disease present, but also on asymptomatic persons, as an anticipatory action, which detects the possibility of a future condition. A positive genetic test doesn't necessarily show if the person will have the disease, nor does it predict the moment of the disease or the seriousness of the condition. However, the hereditary risk factor is of utmost importance, among all the risk factors for cancer. It indicates the possibility that the mutation be present with relatives of the person submitted to testing, who inherit some genetic material. Genetic testing involves both the tested person and his or her family (Jensen, Siegler, Winslade, 2010).

Among the ethical principles which connect to genetic testing, the most important ones are: respecting the autonomy, protecting privacy, protecting the genetic information and respecting the rights and equalities of the person. The respect for autonomy (respect for the person and the family, including by offering accurate, appropriate, undistorted information, and offering support for making personal decisions) is claimed by the majority of clinical situations. The informed consent is an expression of respecting the autonomy and includes talking to the patient about aims, benefits, risks and limits of genetic testing.

The confidentiality and privacy of genetic information refers to: who has the right to own the genetic information, who has access to this information, how it will be used and interpreted and how the individuals will be protected from the misuse of this type of information (David, Benga, Rusu, 2007). Personal genetic information raises difficult problems with regards to the legal and moral obligations of the professionals to reveal it to high-risk patients (Andrews, 1997). The arguments were keen on the patient's right to privacy and confidentiality, as opposed to the right of the family members to get relevant information for their health status. The risk of being stigmatized and discriminated imposes proper precautions both moral and legal (Wilson & Etchegary, 2010).

Just as in the case of any other medical information, also in case of genetic information, the confidentiality must be respected, the information being strictly private. The clinical doctor or the medical professional has the duty of informing the patient with regards to the family implications and the risks for other relatives exposed to that specific genetic condition. On the other hand, confidentiality prevents revealing genetic information to relatives (Knoppers, *et al.*, 1998). In clinical genetics, confidentiality raises important principle and practical problems, due to their implications in connection to the family.

The circumstances which can justify the act of disclosing genetic test results to close family members, without the prior agreement of the patient, include : the situation in which voluntary disclosure of genetic results was a failure, the case in which there could be serious irreversible or lethal damage for close relatives, that is, if they are not aware about the information and the disclosure of information prevents harm, the situation in which information is limited to the necessary information for the diagnosis and treatment of relatives, the situation in which there is no other reasonable way to avoid harm/prejudice (Schneider, 2012).

Genetic testing can offer information which allow patients to make choices and decide for their future. If P1 carries a modified gene involved in colorectal cancer, then, by informing his children when they turn 18 years old about the potentially high risk of colorectal cancer, they could choose to be genetically tested. In case when they are prone to a modified gene, they could choose in what concerns their lifestyle and health, they could be included in a oncogenetic surveillance program, in which they can be easily monitored in order to prevent the disease. Providing information could enable them to choose wisely in what concerns their future health. Based on the analyses of our case, we conclude about the importance of medical information with possible implications within the family environment and on biological relatives, P1 claiming that if he only knew about his brother's diagnosis, he would have associated that condition with his father's disease as well, and so he would have presented to the doctor's office way earlier and maybe would have been diagnosed at an early stage, or „maybe I wouldn't have had the disease in the first place”. Moreover, P1 is „disappointed and at the same time, angry” with the fact that even though his brother got the results to the extensive tests, he wasn't communicated the results by his brother. At the same time, it was his family's right not to disclose these results to other family members. Under these circumstances we can say that the principle of „un-harm” was violated, and P1 now knows the information which could have helped him somewhat late. We might ask ourselves if P1 has the right to use these results, given the confidentiality of the medical information of an individual, even after his death. Several studies (Davey, Newson, O'Leary, 2006; Gilbar, 2007; Etchegary and Fowler, 2008) demonstrated that refraining from disclosing genetic information is in fact a common human will to protect as much as possible your family members.

Thus, after genetically testing the father, the genetic information belongs to the father himself or to the entire family? Given that this information could influence the health state of other family members, such as children. According to Forrest *et al.* (2007) review, many of the published guidelines specifically claim that genetic information is relevant not only for the tested individual, but also for family members, due to inherited genes. Such information can have serious consequences in family planning and the health status of other relatives. Therefore, “the real patient” can be the “family”, and this fact would justify the act of disclosing genetic information to family members directly involved.

The information generated by genetic testing is of confidential nature, but the obligation for confidentiality is not absolute and there can be strong reasons to disclose it. It is recommended that the disclosure be done only when there is serious identifiable risk with other persons, and when disclosure may lead to anticipated avoidance of harm. In our case, relevant factors could include: the seriousness of the disease, the possibility to prevent and treat the condition, the predictability of the risks, P1's children's actions in case when they are informed about the risks. At the same time, we must take into account both the reasons for not informing P1 about the genetic risk (he doesn't know when, how, what to say, or the emotional burden due to the possibility of transmitting to the children a cancer gene), and the fact that P1 could transmit to the children some pieces of information which are of strong emotional impact but weren't requested by them.

Thus the professional geneticist could find himself in serious conflict between the absolute right of the patient to privacy and the absolute right of family members to disclose important information for the health status. Is it then the obligation of the professional geneticist to the individual (the principle of confidentiality) or to the extended family (the principle of no-harm)? One could take into account the implied agreement with regards to disclosing information to the family at risk. During counseling sessions, personal risk is evaluated in the context of family history supported by official paperwork. Thus, it is more than obvious that just as information from other family members is useful for a patient, at the same time personal information of a patient may be useful for the rest of the family members. Stol *et al.*, 2010, claims that the ethical dilemma from the point of view of the patients is seldom connected to the opposition between the right to confidentiality and the right to inform the relatives (Stol, Menko, Westerman, Janssens, 2010). They are preoccupied more by the dimensions of their ethical responsibility to warn family members in order to maintain the health status (Klitzman, Thorne, Williamson, Chung, Marder, 2007; Etchegary and Fowler, 2008) and in order to minimize side effects and negative results (Gaff *et al.*, 2007, Klitzman, Thorne, Williamson, Chung, Marder, 2007), such as being accused/blamed by others (Arribas-Ayllon, Sarangi, Clarke, 2008). At the same time, when disclosing genetic information to the affected biological relatives without being required, is there a principle of un-harm which is always respected? Isn't the right of a person to not know violated?

Sharing genetic information could connect people within a special moral relation, in this so called „genetic solidarity” which may take a higher stance compared to the self-determination of a person with regards to his genetic information (Johnston and Bradbury, 2008). However, P1's sister refuses genetic testing, claiming religious reasons. At the same time, she has the right to not know if she bears a modified gene for colorectal cancer. Her decision doesn't have consequences over others. But what if at some point she will have children? Torleiv Austad argues against the absolute right to not know: „A person who say „no” to important genetic information and at the same time is reluctant to disclosing information to his or her relatives, makes also a decision with regards to them” (Austad, 1996).

Conclusions

Genetic information, because it is both individual and familial, will always generate ethical conflicts between the duty of maintaining the confidentiality of information and the duty of warn the other family members who are directly involved. The decision to violate the rule of confidentiality is difficult and raises ethical dilemmas. The consequences of violating confidentiality by means of informing a biological relative with regards to the genetic risks must be compared to the benefits of disclosing information by taking medication or by altering one's lifestyle in order to prevent or to improve the condition. Thus, professional genetic counselors should make an effort to talk the patient into disclosing information for the others' sake, and the implicit agreement should be replaced with the explicit agreement, based on the ethical responsibility of each individual.

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