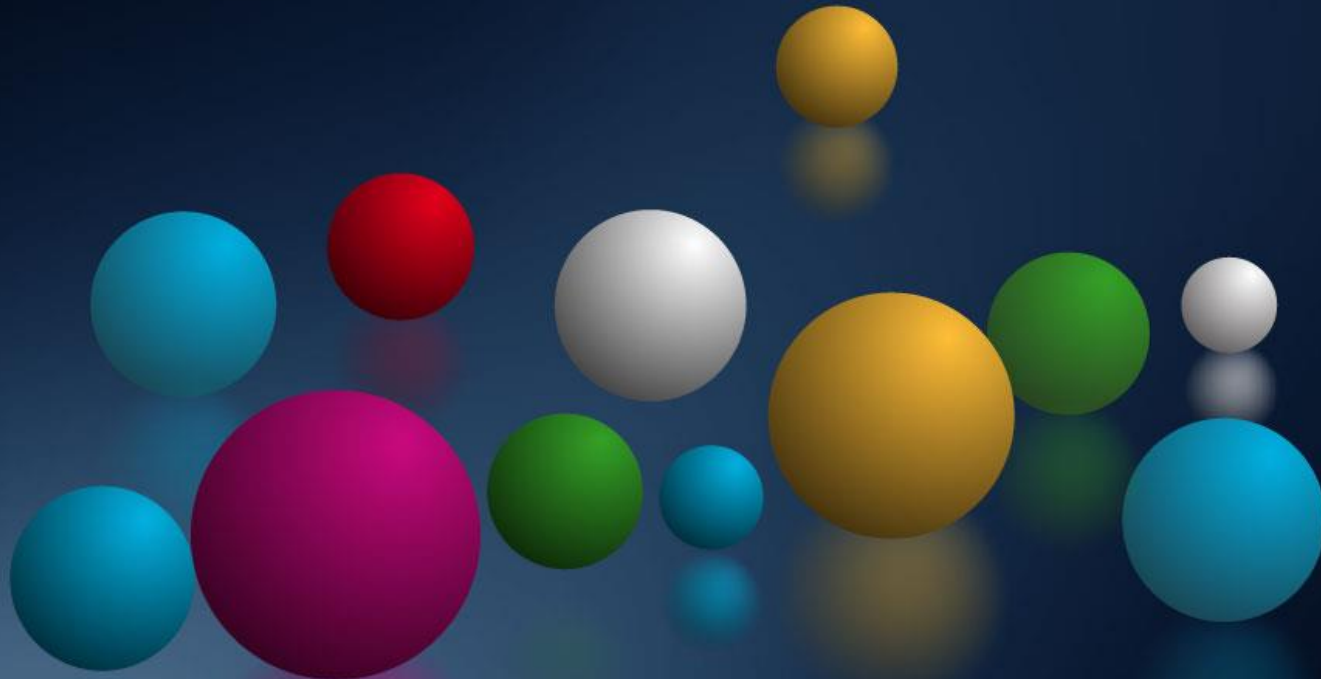


RESPECT FOR CONFIDENTIALITY IN GENETIC TESTING: RIGHT OR BURDEN?

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Importance of and reasons for oncogenetic testing

GLOBOCAN 2012 – aprox. **78.000** people are diagnosed with cancer each year in **Romania**, as shown in the latest review of the International Agency for Research on Cancer.

5-10% of the tumors in these patients are due to genetic predispositions.

aprox. **3.900 – 7.800** of the annual cases come from families with a genetic predisposition to cancer.

aprox. **3.900 – 7.800 people + their families** can benefit each year from genetic counselling and testing in order to prevent, diagnose as soon as possible and treat cancer.

THE PUBLIC ATTITUDE TOWARDS GENETIC TESTING

2002 = the hopeful launch of the „book of life“, with high expectations regarding the contributions of genetics to the understanding, prevention and treatment of many diseases.

Henneman et al.,
European Journal of
Human Genetics, 2013:
Study about changing the
public attitude towards
genetic testing from 2002
to 2010

2010 -10 years
since the
discovery of the
human genome

People were more interested in the personal genetic profile, considering that knowing the genetic background of the disease can help people live longer (43% 2002, 64% 2010, $p < 0,001$)

In order to prevent a disease, people would like to know the risk of having that specific disease (52% 2002, 53% 2010, $p > 0,05$)

The nature of genetic information

Genetic information – more than individual information, representing information relevant to the entire family

Disclosing genetic information to the family raises ethical dilemmas

the private and confidential nature of this information, on the one hand

its disclosure could have significant benefits for other family members, on the other hand

unjustified disclosing may affect the person



CASE STUDY

- male, 46 years old
- diagnosed at 44 with middle rectal neoplasma (infiltrative well differentiated colon adenocarcinoma cT2N2M0)
- currently under oncologic treatment focusing on palliative care, as the disease has had an aggressive evolution (hepatic and pulmonary metastasis)
- married, 2 children (17 and 15 years old, both male)
- a 35 year old sister, apparently healthy

Family cancer history

- Father – colo-rectal N. – died aged 69
- Brother – colo-rectal N. - died aged 39 (genetic testing in Italy, followed by recommendations for extensive genetic investigations)
- The patient seeks the Department of Oncogenetics at the recommendation of the oncologist.

- **The father** wasn't concerned about the disease, considering that it was something regarding one's fate
- **The brother was diagnosed in Italy and kept this – including the result of the genetic testing - a secret until the terminal stage of the disease.**
- **The sister isn't worried about the genetic risk of developing the disease, refusing any medical evaluation.**
- Both the brother and the sister are members of a religious cult (not explicitly named) which partially prohibits medical interventions – P12 believes that this is the reason why the brother had kept his health problems a secret, and also why the sister is not worried about her health.

How is P12 feeling? Disappointed, angry

Why? Had he known about his brother's disease, he would have associated it to the father's and he would have went to the doctor's sooner, the disease would have been diagnosed at an earlier stage or maybe he „would't even have developed the disease in the first place“.

P12:

- As a part of the informed consent he agreed to submit the results of the genetic testing only to his wife.
- He considers that he will tell his children later about the result of the genetic testing, though he doesn't know exactly when and how (given the advanced stage of the disease, it is possible for him to die before receiving the results, so that the discussion with the children might not be able to take place).

"I think I would feel very guilty if I carried the cancer gene which I could pass on to my children as well".

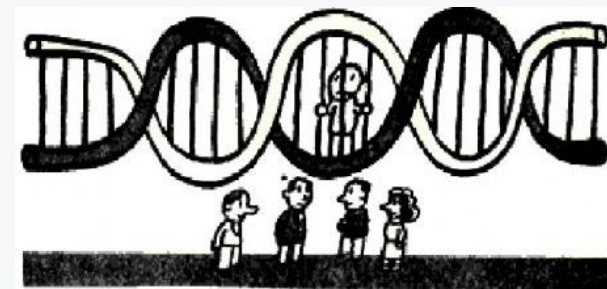
Studies (Davey et al., 2006, Gilbar, 2007, Etchegary & Fowler, 2008, Dupras, 2013) have repeatedly shown that holding back from disclosing genetic information is in fact a common human wish to protect the members of the family as much as possible.

- **The wife**

If the patient dies before talking to his children, and the wife decides not to disclose the results of the genetic testing of their father, there will be a violation of the children's right to know and to benefit from relevant medical information about the risks and predisposition for a condition that could be prevented or treated.

- **The children**

- By not being informed, they are deprived of the possibility to take decisions about their health and lifestyle.
- Does not disclosing genetic information with a significant emotional impact, if this information is not solicited, respect the principle of acting against bodily harm? Isn't the right not to know of a person violated?



THE RIGHT NOT TO KNOW

Neo colon (67)

IF ONLY I HAD KNOWN

Neo colon (44)

THE RIGHT NOT TO KNOW

Neo colon (39)

(35)

THE RIGHT NOT TO TELL

(17)

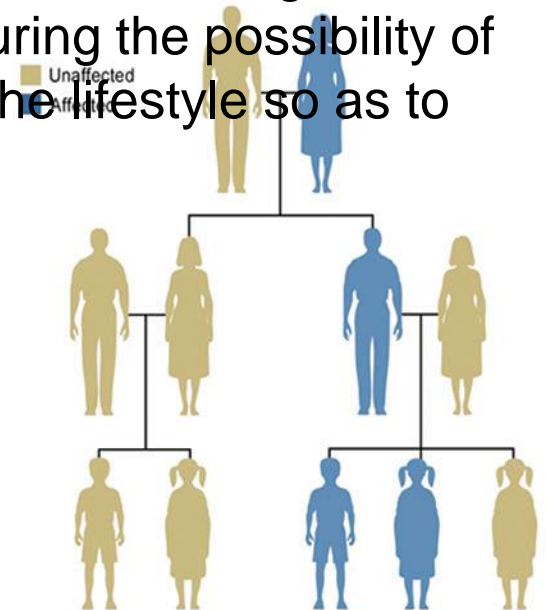
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THE RIGHT TO DECISIONAL AUTONOMY

**THE ABSENCE OF THE RIGHT TO DECIDE
THE RIGHT NOT TO KNOW?**

Conclusions

- Genetic information, concerning both the individual and the family, will continue to be a source of ethical conflicts between the duty to ensure the confidentiality of the information and the duty to warn the other members of the family that are directly concerned.
- It is important to weigh up the negative consequences of the violation of confidentiality by informing a biological relative about the genetic risk and the advantages of revealing this information and ensuring the possibility of following a treatment or adjusting the lifestyle so as to prevent or to cure the disease.



Professional genetic counselors should make an effort in convincing the patient into disclosing information for the benefit of others, and the implicit agreement should take the form of an explicit agreement based on the ethical responsibility of each individual.

