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Lay Constructions of Genetic Risk. A Case-study of the Polish Society of Huntington's Disease

Abstract: This article explores the lay constructions of genetic risk, the right not to know and the obligation to do a genetic test, know the risk and share genetic information with others. The study was carried out on 27 members of the Polish Society of Huntington's Disease. I describe their understanding of bioethics and their arguments for and against the right not to know. I argue that lay perceptions of the risk, rights and obligations mentioned above are shaped not only by the type of genetic disease involved but also depend on the social group to which it poses a threat and/or costs. Consequently, such obligations are framed toward: future generations, family members, society, the State and oneself. I also argue that genetics is turning families into bioethicists who, as lay experts, become one of the key players in the biomedicalization of society and bioethicization of genetic discourse.

Keywords: genetic risk, lay experts, right not to know, responsibility, the Polish Society of Huntington's Disease.

The links between sociology and biology can be traced back to the origins of that scientific discipline, when its founding-fathers emphasized the importance of biology for organization of society and human behaviour (Szczepański 1969; Szczurkiewicz 1969; Piątkowski and Skrzypek 2012). And while sometimes biology served only as a useful metaphor for describing social phenomena, when Durkheim and Spencer referred to society as an organism, frequently those links were more straightforward, as it was in the case of racial theories of de Gobineau, Galton, Pearson, Woltmann, Rosenberg, Chamberlain or Gumpłowicz, who emphasized the importance of physiological and anatomical features, for the human individual and social life. Those links are further exemplified by such biological concepts of deviant and criminal behaviours as Lombroso's theory of 'born criminals', Sheldon's theory of body types or Jacob's and Witkin's extra Y chromosome theory. All these theories contributed to the nature-nurture debate and gave birth to the eugenic movement. Also, modern sociobiology stresses biological, i.e. genetic basis of personality traits and behaviours. Thus, it is worth to emphasize the importance of biology for sociology (Mazur 1978), and although nowadays it has shifted its point of reference from 'biology' to 'medicine' (Piątkowski and Skrzypek 2012) still there can be observed an increased integration of knowledge on the social and biomedical, i.e. genetic factors determining human health.

On the other hand, as constant proliferation of genetic knowledge and application of new genetic technologies transcend their original formulations, sociologists emphasize social implications of genetics (Conrad and Gabe 1999; Nelkin and Tancredi 1989). Consequently, as genetics is one of the dominant paradigms of modern science, it becomes an important theme of sociological research (Conrad and Gabe 1999; Clarke and Tisdechurst 2006; Kerr 2004; Lock and Nguyen 2010). Thus, the most common topics related to new genetics studied by sociologists are: a new way in which health and disease are understood (Stemsey 2006) and a new way of understanding and experiencing pregnancy/parenthood (Lippman 1991; Rapp 2000; Rothman 1993) and the influence it has on transformation of social relations, including family and kinship (Atkinson, Parsons and Featherstone 2001; Featherstone, Atkinson, Bharadwaj and Clarke 2006; Finkler 2001; Konrad 2003; Sachs 2004). Moreover, as genetic risk becomes highly individualized (Boenink 2011; Hunt, Castañeda and De Voogd 2006; Svendsen 2006) sociologists focus their attention on the way genetics influences medical ethics and patient rights (Rhodes 1998; Shaw 1987; Takala 1999). All in all, the constant proliferation of genetic knowledge and the application of genetic technologies provoke claims of a geneticization of society (Lippman 1991).

The reason reasons being so, is that by providing new knowledge on a genetic basis of many diseases, personality traits and human behaviours genetics promotes a “new molecular ontology of life” (Rose 2007a) which stresses the molecular basis of human existence and relies on a neo-ontological concept of disease in a context of genetic reductionism. Consequently, individuals are framed in somatic terms (Rose 2007a; 2007b; Novas and Rose 2000). Moreover, such a “molecularization of life” also provokes a shift in the social perception of the risk which becomes highly individualized and is located on the genetic level (Braun 2007). As medicine promotes the idea that the genetic risk can be anticipated and managed, there can be observed a growing concern over “biosecurity,” which is exemplified by the widespread application of genetic testing—which now has become an important part of the reproductive process (Arribas-Ayllon, Sarangi and Clarke 2011; Buchbinder and Timmermans 2011; De Zordo 2012; Hallowell 1999; Hanoch, Miron-Shatz and Himmelstein 2010; Hunt, Castañeda and De Voogd 2006; Lippman 1991; Rapp 2000; Rothman 1993; Rapp, Heath and Taussig 2001). Furthermore, as DNA reveals the secrets of (family) life, genetic risk is now framed as a public concern and becomes a concern of not only geneticists, bioethicists and other health professionals (Ettorre 1999; Falk, Dugan, O’Riordan, et. al. 2003) but also of laypersons, including the families of affected individuals (Domaradzki 2013; Finkler 2001; Hallowell 1999; Hunt, Castañeda and De Voogd 2006; Parsons and Atkinson 1992; Rapp 2000; Rothman 1993). Consequently, as lay knowledge gains greater legitimacy, it is now perceived as an alternative system of knowledge, if not even of expertise (Collins and Evans 2002; Evans and Plows 2007; Irwin 2001; Kerr and Cunningham-Burley 1998; Kerr, Cunningham-Burley and Amos 1998; Prior 2003; Lindsay and Vrijhoef 2009).

It should not surprise, since at least from Freidson’s study on the lay referral system, sociologists focused their interest on the lay understanding of health and ill-

ness (Lawton 2003; Pawluch, Cain and Gillett 2000; Skrzypek 2011). Consequently, personal health beliefs are now perceived as an important factor that shape one's illness experience and health behaviours. Not only do they influence whether one defines him/herself as sick and looks for a confirmation of self-diagnosis in the doctor's office, but may be a reason why patient ignores early symptoms of disease. Nevertheless, while in Polish sociology there are many studies focusing on lay understanding of health and illness fewer attention has been paid to lay constructions of genetics (Domaradzki 2013).

Hence, my aim is to describe lay constructions of genetic risk and their influence on one's right not to know. I explore the understanding of bioethics of the members of the Polish Society of Huntington's Disease¹ and describe their arguments for and against the right not to know. While doing so, I try to answer the following questions: How do progress in genetic knowledge and development of new genetic technologies influence perception of the risk? What factors influence social perception of genetic risk? How does genetic discourse transforms one's right not to know? Does genetic testing become a moral imperative? Does genetic discourse enable new forms of surveillance and social control? At the same time I argue that the constant proliferation of genetic discourse is blurring the distinction between the private and the public dimension of genetic information. Moreover, an increasing participation of laypersons, including family members of affected individuals, in bioethical and political debate on genetic testing and the patient right (not) to know, is turning families into bioethicists who are engaged in everyday decision-making about testing, patient's responsibilities and morality (Arribas-Ayllon, Sarangi and Clarke 2011; Boenink 2011; De Zordo 2012; Domaradzki 2013; Finkler 2001; Featherstone, Atkinson, Bharadwaj and Clarke 2006; Hallowell 1999; Hanoch, Miron-Shatz and Himmelstein 2010; Hunt, Castañeda and De Voogd 2006; Kerr and Cunningham-Burley 1998; Kerr, Cunningham-Burley and Amos 1998; Konrad 2003; Rothman 1993). I also argue that while the genetic condition in question may play a role in shaping lay perceptions of the genetic risk, rights and obligations, such accounts also depend on the social group to which a disease poses a threat and/or costs. In conclusion, I stress the importance of identifying lay people as lay-experts.

¹ Huntington disease (HD) is a rare, neurodegenerative genetic disorder of the brain caused by mutation in the HTT gene located on the short arm of chromosome 4. The gene mutation was identified in 1993 and since then predictive testing for HD is now available. HD is inherited as an autosomal dominant trait, which means that a child of affected parent has a 50% risk of developing the disease. HD cannot be cured and it can only be treated palliatively. Consequently, death usually occurs 15–17 years after the onset of the disease and is usually caused by secondary illness, mainly aspirational pneumonia and suffocation or suicides. HD prevalence is estimated to reach 4–8 persons per 100 000. What is significant is that in contrast to many other genetic disorders HD is characterized by late onset of symptoms which usually begin at the age of 35–40, although about 10 per cent of cases refer to juvenile variant of HD. The most characteristic symptoms of HD are progressive involuntary movements of the body, abnormal gait and loss of motor skills. It also includes cognitive and affective decline and such behavioural disturbances as: problems with concentration, planning and problem solving, memory loss, decreased communication skills, mood changes and emotional lability, depression, suicidal ideation, aggression and antisocial behaviours (Dubas-Ślemp et al. 2012).

Ethical and Legal Aspects of Genetic Testing

As recent advancement in genetic knowledge and development of new genetic technologies allow identification of genetic basis of many diseases, it also offers individuals effective means of knowing and managing the genetic risk. Moreover, as medicine emphasizes individual character of risk it frames genetic testing as an integral part of reproductive process and disease prevention (Hallowell 1999; Rhodes 1998; Rothman 1993; Siemińska 2010). The reason being so is that genetic testing² enables detection of new diseases, description and better prevention of those already known and thus allows people to make conscious and responsible life choices regarding education, professional career, reproduction and marriage. Consequently, most bioethical and legal codes stress patient's right to genetic information which is now said to be a source of empowerment and autonomy.

At the same time, genetic testing rise many concerns over its ethical, legal and psychosocial implications.³ Among the most commonly expressed fears related to genetic testing is that it brings a spectre of social stigma and can become a source of genetic discrimination as individuals may be denied health insurance, employment, education and money loans (Nelkin and Tancredi 1989). It is also argued that such testing opens 'backdoor to eugenics' and reinforces negative social image of the disabled. Especially, that it poses questions regarding legal status of the foetus and accessibility of abortion and preimplantation genetic diagnosis (Frączek, Jabłońska and Pawlikowski 2013). Yet another problems are related to genetic screening and biobanking (Pawlikowski, Sak and Marczewski 2009).

For all these reasons most international bioethical and legal codes emphasize that genetic testing should be purely voluntary and free of external pressure and that all decisions regarding doing the test, accepting its results and family planning should be taken by a person her/himself in accordance with one's beliefs, goals and values. Additionally, it is strongly recommended that in most genetic testing situations such procedure should be accompanied by genetic counselling (Kapelańska-Pręgowska 2011) which should be guided by such ethical principles as: truthfulness, autonomy, privacy, nondirectivness, confidentiality, beneficence, nonmaleficence, equity and justice (Chadwick et al. 1999; Kapelańska-Pręgowska 2011). For the same reason, while

² Genetic testing is a type of medical test that allows to identify changes in chromosomes, genes, or proteins and helps to determine the risk of developing or passing on a genetic disease to future children or can confirm a suspected genetic condition in affected individual. The most common types of such testing are: 1. newborn screening, which are performed after the birth to identify genetic disease that can be treated early in life, for example phenylketonuria; 2. diagnostic testing which can confirm the existence of genetic condition in symptomatic individual; 3. predictive or presymptomatic testing which detect gene mutations in individuals with family history of late-onset disorders, such as Huntington disease or certain types of cancer; 4. carrier testing detects a gene mutation that may not influence one's health but can pose a risk to one's children, i.e. cystic fibrosis or fragile X syndrome; 5. prenatal testing are performed during a pregnancy, where there is increased risk for a certain condition in the fetus; 6. preimplantation genetic diagnosis (PGD) which allows testing of an embryo in order to select the unaffected one to be implanted during IVF; and 7. genetic screening which is offered to the general population or a specific group, for example newborns or some ethnic group (Kapelańska-Pręgowska 2011).

³ For that reason, with the Human Genome Project which aimed in sequencing entire human genome another project—the Ethical, Legal, and Social Implications (ELSI) program was founded in 1990.

medicine stresses one's right to genetic information it also recognizes complementary although opposite right—"the right not to know".⁴

At the same time it is important to note, that genetic testing is somehow different from other types of screening, as it provides information not only about the person who is at risk but also other family members, including (future) children. For that reason, some argue that genetic information is not a private matter and should be regarded not as a right but as an obligation or even a duty (Rhodes 1998; Shaw 1987; Siemińska 2010). They argue that while the "right not to know" may enhance a person's autonomy and privacy, it also poses a question about an individual's responsibilities toward others, who may be harmed by one's ignorance. And it especially problematic, as in many jurisdictions, including Poland, the legal status of genetic disclosure is still unclear. Nevertheless, while it is individual who controls dissemination of genetic information, it is widely acknowledged that that while each individual has a right not to know one's genetic status, such right is strictly related to the duty to inform others about any genetic risk. It is important, as there are persons at risk who are not willing to undergo the test, do not want to receive information about its result and/or disclose such information to others. Consequently, such 'problematic' patients create a tension between professional duty to respect the patient's autonomy and privacy and the physician's duty to prevent potential harm to at-risk relatives and may become a source of law suits on negligence and malpractice (Soniewicka 2013). It also initiates a bioethical debate whether bringing someone into existence may cause him/her harm (Chańska 2009; Savulescu and Kahane 2009). Such claims are then reflected in the legal context, with "wrongful conception" and "wrongful birth" lawsuits (Soniewicka 2013). All in all, it seems that as new genetic technologies allow people to know and manage the genetic risk, passing on "faulty" genes is perceived by many as actually selfish, immoral and irrational behaviour. This, in turn, may place the collective interests of the family, society or the State before those of the individual.

Thus, while decision to undergo genetic testing can only be made by the individual at risk, once a test is done and the results are known, however, some family-related ethical dilemmas are born: Does a person who is at risk of genetic disorder has the right not to know about one's risk status or is he/she obligated to undergo genetic testing? Should a carrier of a known genetic risk be obligated to inform his/her relatives about the risk? Is it morally acceptable for a person who is at risk of genetic disorder to get married and/or have children? Such question are of key importance, as the public dimension of genetic risk may influence individual's decisions whether to do a test, know the risk and share that information with others (Boenink 2011). While such decisions seem to be personal, in fact family members too may have a role in shaping these decisions. It seems that especially in group oriented cultures, such as the Polish one, families may be involved in this process. Consequently, individuals

⁴ The most important documents stressing such right are: the World Medical Association's *Declaration on the Rights of the Patient* (art. 7d), the *European Convention on Human Rights and Biomedicine* (art. 10 and the *Explanatory Report*), UNESCO's *Universal Declaration on the Human Genome and Human Rights* (art. 5c) and the WHO's *Review of Ethical Issues in Medical Genetics* (art. 10.2). In Polish law such right is guaranteed by the *Charter of Patient Rights* (art. 9.4) and *Physician and Dentist Professional Act* (art 31.3).

may well experience social pressure to make the right choices and be expected to place other's right to know above one's own right not to know.

Study Design

Recruitment, Data Collection and Analysis

The study was carried out among members of the Polish Society of Huntington's Disease. It included 27 family members of affected individuals, either parents, spouses, siblings or children of HD patients, who were interviewed via structured questionnaires, which consisted of five hypothetical case studies describing ethical dilemmas related to genetic testing. Respondents were approached at the conference, and those who agreed were invited to participate in the study. Out of thirty-two family members, five refused. Their refusals were motivated by an unwillingness to discuss personal and/or ethical issues. Each questionnaire was filled out individually by the respondents themselves.

The source of empirical data presented here is qualitative. A thematic analysis of interviews was carried out. A grounded theory approach was the basis for the analysis (Glaser and Strauss 1967). After all the interviews were collected, they were coded and analyzed according to the categories based on the arguments I identified for and against the right not to know. These categories were then refined to describe the lay constructions of genetic risk.

It also seems important to emphasize that while I refer to the subjects from the study as "laypeople" I am aware that as relatives of HD patients and members of the Polish Society of Huntington's Disease they possess an above average knowledge on genetics which brings them closer to medical experts. Nevertheless, such knowledge is still often but partial and fragmentary as they are "experts" only in the particular areas of genetics, mainly Huntington's disease which runs in their families. Moreover, their knowledge is somehow "filtrated" and translated into a lay dialect. Thus, while they have become lay experts on HD, they differ from "fully-fledged" medical experts, i.e. professionals. On the other hand, their active participation in the Polish Society of Huntington's Disease bring them closer to professionals. Finally, as they participate in scientific seminars and conferences, for sure they are influenced by genetic and bioethical discourse. Nevertheless, as active participants they may also reflexively influence scientific, bioethical and political discourse (Collins and Evans 2002; Evans and Plows 2007; Irwin 2001; Kerr and Cunningham-Burley 1998; Kerr, Cunningham-Burley and Amos 1998; Prior 2003; Lindsay and Vrijhoef 2009).

Sample Characteristics

The sample was in the majority female ($n = 17$). Twelve respondents were married and nine were single. Five others were widowed and one was divorced. Of those who declared having children, most had two and three ($n = 10$) or more ($n = 5$). Nine respondents were childless. The majority were middle aged or older and all the partici-

pants were white. Most of them lived either in big agglomerations with a population of over 500 thousand or in small towns with less than 10 thousand inhabitants. Most had completed their education at the level of high school (n = 9) or university (n = 14). Two persons had received medical training. The majority were employed as intellectual workers outside the home and reported an income of 3000 PLN (720 euros) or more per month. Of those reporting religious affiliation, twenty five were members of the Roman Catholic Church, and this group was split equally between those who defined themselves as “practicing believers” (n = 12) and “believers who do not practice” (n = 11). Religion was declared as either important for their life decisions and choices (n = 13) or as insignificant or irrelevant (n = 13).

Clinical Cases⁵

Each hypothetical case study was designed to reflect attitudes surrounding patients’ right not to know and obligation to undergo testing and/or disclosing information required for the protection of: distant others (1), family members (2), oneself (3), future generations (4) and the State (5). At the same time, I am aware that all the case studies presented raise a number of different bioethical issues for families, individuals and society, as one’s right not to know is inextricably linked to the obligation to inform others of one’s genetic risk. Nevertheless, it seemed appropriate to focus on particular dilemmas to illustrate and emphasize the individual’s specific obligations toward different segments of society. Thus, while each case study covers a consistent set of bioethical issues, the participants were encouraged to talk particularly on the indicated topics.

Case 1. Tom’s family has no history of Huntington’s disease. If researchers were to undertake a population study which would provide scientists with more adequate knowledge about the genetics of HD, should Tom volunteer and donate his cheek cells as research material? Even if it helps only in the distant future does he owe this to society? Does his fear of disturbing test results justify his refusal?

Case 2. Dick has been diagnosed with Marfan syndrome. His cousin Martha may also be affected. If she is positive, she has a 50 per cent chance of passing the disease on to her children. A genetic counselor informed Martha and her husband that the easiest way to know their risk would be a genetic linkage analysis. Martha’s uncle Henry agreed to have his blood tested. Martha has also asked Dick to participate, since as a carrier he is a source of vital information for the whole family. Does he have a moral obligation to participate in the study?

Case 3. Harry’s father died of HD and Harry himself found out that he has a 50 per cent risk of developing the disease in the near future. Although he may die young or pass on the disease to his future children, he has refused to be tested. As he is in love with Sylvia and together they want to start a family, does he have a right not to know about the risk?

⁵ The first four cases are drawn from Rhodes (1998) and the last one is by the author of the present paper.

Case 4. Hariette's sister had a daughter who died of Tay-Sachs disease after a brief and agonizing life. Although Hariette and her husband want to have children, they decided not to know whether she is a recessive carrier of the Tay-Sachs gene. Does Hariette have the right not to know and consequently risk passing the disease on to her child?

Case 5. Caroline's mother and elder sister both died of breast cancer. Caroline herself discovered a small lump in her breast. Even though she knows that early detection allows effective treatment which is refunded by the National Health Care System, Caroline is afraid that a positive result may lead to chemotherapy, (double) mastectomy and social stigma. Apart from her worries, she decided to undergo mammography which gave negative result. Nevertheless, as she belongs to a high risk group she was advised to undergo additional molecular testing for mutation of BRCA gene that might help to predict her risk of developing cancer in the future. Considering the fact that she belongs to a high risk group and given the high costs of late treatment for the State, should she do the test? Does her anxiety justify her refusal?

Results

Obligations Toward Society: Tom

As in modern times health has become a major imperative (Lupton 1997), individuals are increasingly expected to be personally responsible for its preservation. Although it seems that the current focus on genetic determinants of diseases may shift the responsibility for health from individuals, in fact it may also strengthen it. The reason for this being so is that, at least in some cases, individuals may influence their genes. For example, thanks to a special diet people can control the level of the enzyme phenylalanine hydroxylase (PAH) that causes phenylketonuria (PKU) and help their child to develop appropriately. Nevertheless, even in diseases where there is no such possibility, modern medicine promotes the idea that due to genetic technologies it is now possible to know and manage the risk. Moreover, as people are said to be genetically different from each other to a degree of less than 1 per cent, genetic discourse frames the individual as a mirror of a larger group. Consequently, people may feel external pressure to know and manage the genetic risk for the sake of others. For this reason family members from the study argued that all people, including the healthy ones, owe something to everyone and are obliged to participate in population studies which may lead to advances in the knowledge about genetic diseases and which might benefit future generations. Hence, on the most abstract level, respondents emphasized one's responsibility for "distant others," i.e. society at large. Twelve subjects referred to such an expectation in terms of "moral obligation" (8) or "duty" (4).

These opinions were justified by the belief that as social beings people have moral responsibilities toward others. Thus, while emphasizing altruistic motives, these respondents referred to the principles of genetic altruism and solidarity and believed that the personal right not to be tested ought to be subsumed for the sake of others.

For this reason they actively encouraged individuals to participate in population genetic studies, and while negative consequences of genetic testing, i.e. personal effort, psychological discomfort and physical pain were often mentioned, “the good of society” was said to exceed personal damages. A middle-aged male even argued that for the benefit of society genetic tests should be enforced on individuals:

In such cases tests should be done without a person's knowledge. (5)

Acting as bioethicists, respondents also took up the roles of psychologists and moral entrepreneurs, who explained human behaviors and preached what one should do. Many framed negative emotions, nervousness and fear as “irrational” or “weird” and argued that they do not justify one’s aversion toward the research. Some considered claims about personal costs as “rationalizations” for egoism. In contrast, in their accounts respondents also referred to “rationalism,” “courage” and “altruism.” Such attitudes reflect not only the group-oriented character of Polish culture but also the belief in people’s rationality. It also demonstrates the moral dimension of genetic discourse and the pressure that may be put on individuals who “ought to volunteer.” A wife of an HD patient urged people to overcome anxiety and act “rationally”:

Fear is not abstract to anybody, including the healthy. (...) he should overcome his fear and participate. (26).

Interestingly, even those who understood patients’ worries felt that obligations toward others do not interfere with one’s right to privacy and ignorance, as individuals do not have to know the results of their test. Hence, people were expected to provide their genes as a study material for the research without obtaining knowledge about their genetic make-up. Such attitudes were mainly driven by “the political economy of hope” (Novas 2006; Rose and Novas 2004). Respondents believed that people should have hope in modern technologies that may, in the future, enable management of a disease. Thus, it seems that their positionality as family members of individuals affected by HD has influenced their responses since they belong to the group that can benefit most from genetic testing. For this reason they were vitally interested in the mobilization of social resources for scientific research. Consequently, they argued that each individual is an important resource for biomedical research and that people’s involvement in science would speed up the race for the correct therapy and this, in turn, would offer new hope to those affected by genetic diseases and their families. Hence, as individuals were expected to donate their DNA for the research they were framed as a unique type of biocapital (Rose 2007b). Moreover, as moral entrepreneurs, respondents constructed a bioethical issue in such a way that it did not interfere with their collectively shared ideals and/or interests. By emphasizing the individual’s contribution to genetic research, a female pharmacy student believed in scientific progress and was waiting for a cure:

Without genetic material it is impossible to conduct scientific research and develop a drug. (8)

On the other hand, thirteen respondents claimed that neither knowledge nor testing could be enforced upon people and that individuals should be encouraged

and not coerced. Like many bioethicists (Takala 1999) they stressed the voluntary character of such research and that the information about one's genetic make-up is a private issue and should be protected. Nevertheless, while some referred to the idea of "genetic privacy," they were more concerned with personal liberty and one's right not to be tested than with the negative consequences of genetic testing. Hence, respondents rejected any moral dimension of genetic discourse, which by some was found as oppressive. A male intellectual worker compared population studies to blood donation, and rhetorically asked whether the latter should also be made mandatory:

If he is not at risk, it is only a matter of individual decision (...) For me participation in such studies is similar to the question: 'Does every person have a duty to donate blood or bone marrow?'. (6)

Frequently, respondents emphasized the negative effects genetic testing can have on a person's psychological condition and family life. Some of them argued that even for healthy individuals the decision to undergo testing is a very hard one to make and that testing itself is a stressful experience. Respondents believed that genetic tests force individuals to think about things they do not want to think about and may create a state of permanent anxiety and uncertainty. Others stated that ignorance is sometimes bliss, as a choice of not to be tested gives an individual a sense of security and enables an untroubled life. Moreover, they stressed that being tested for a particular disease does not mean that a person will not get information about other abnormalities and that such knowledge is a "terrible gift" and poses a threat to one's right to an open future, as one may feel trapped by genetic knowledge. A female student of medical informatics described all these worries:

[f]ear justifies his refusal. It is only his decision. He should not be forced. If his results turn out to be positive, he may experience a psychological breakdown. And his life may be devastated, too. (3)

To summarize, even on the most abstract level, when genetic risk was not presented as a real threat, but instead testing was framed as a scientific enterprise that might end up in the development of a therapy for future generations, many respondents constructed genetic information as information about "humanity." And while some expressed their concern about the moral dimension of genetic discourse, nevertheless they assumed that genetic testing can benefit the entire society and that it would be desirable that all people, including the healthy, would participate in such studies. Consequently, people were framed as a particular type of biocapital that can be used in biomedical research for the benefit of humankind.

Obligations Toward Family Members: Dick

When respondents assumed that the risk of a genetic disease affected also the family, individuals were expected to submit personal autonomy to the needs of others. In the case of Dick's dilemma of whether to participate in a genetic linkage study that might help to establish the risk to his cousin's children, only two respondents said that such decision was a personal choice and that in such a case a person had no obligations toward the family. In contrast, twenty respondents were more focused on the family

than on the individual. As the former was (re)defined as a “patient” who “has a right to know” and “should to be informed,” people were assigned responsibilities toward their kin. In general, respondents regarded the provision of information about the risk status of the relatives as one of the most important benefits of DNA-testing. Respondents’ altruistic motives were strengthened by two additional claims: first, that Dick, who is already diagnosed, has “nothing to lose;” and, second, that as he is the only family member who can provide genetic material necessary for the testing “he is the only hope” for his sister and, consequently, is morally obliged to agree to undergo testing. Such was the rationale of a female student of medical informatics:

As he is already diagnosed, the study will not influence his life. He has nothing to lose, and Martha who is trying to make conscious reproductive choices may benefit from his participation... (a)s in Martha’s family (...) there are very few males left (...) if it helps to establish a pattern of inheritance so that Martha could give birth to a healthy child, he has a moral obligation to participate. (3)

Nevertheless, also here family members stressed the voluntary character of testing and that people should neither be pressured by the family nor feel forced to participate. Hence, in order to protect a person’s autonomy, privacy and ignorance respondents took the role of negotiators who suggested possible solutions to satisfy both parties. A male middle-aged office worker argued that people ought to participate in the study without knowing its results:

[T]he study should be anonymous, i.e. the family should not be informed about the result and it should only aim to answer Martha’s question. (5)

Thus, again, the risk was framed as a collective entity and genetic information was pictured as information about “the family.” Consequently, throughout these accounts an individual self was constructed in relation to others—as an “interdependent” self (Hallowell 1999) because the needs of others were seen as an integral part of the self. Moreover, as family relations were constructed as “risky” (Featherstone, Atkinson, Bharadwaj and Clarke 2006) information about the risk was constructed as the property of the entire family (Sachs 2004), and individuals were said to be obliged to ensure that also their kin had access to this information.

Obligations Toward Oneself: Harry

The imperative of testing had the least application when only individual health was involved, as in Harry’s case. Although also here personal responsibility for preservation of one’s health and risk management were emphasized, respondents were more concerned about patient rights than “genetic purity.” Twelve respondents claimed that every individual is an autonomous person and decides for her/himself whether she/he wants to know. Those who rejected the testing imperative framed the genetic knowledge as “unbearable” and as a source of psychological distress, diminished self-esteem and broken identity. Some argued that information about a terminal disease may cause constant anxiety and uncertainty about the future and lead to anticipation of the symptoms of disease whilst still being asymptomatic and reinterpretation of future plans regarding education, marriage and professional career. Finkler (2001: 341)

referred to such persons as “perpetual patients.” Hence, while rejecting the common belief which fetishizes knowledge, respondents framed genetic information as “life breaking” and “depressive” and stressed the self-stigmatizing character of genetic diagnosis. A young physiotherapist with an HD family history argued that individuals with a genetic label may become over-concerned about their health, anticipate future disease and death and reframe their social roles, expectations and social relations:

[i]t may be better not to know about having a ‘faulty’ gene. Social functioning of people with genetic diagnosis is not easy, as it was in my case (...) It was, and still is, hard: constant fear of tomorrow. A person changes his/her entire lifestyle. I am happy that we have a child, but now I am constantly worrying that my baby has inherited the same ‘bad’ gene. (23)

Similarly, others rejected the vision of a predetermined life that stems from genetic diagnosis and argued that apart from a positive result one can still live a long and meaningful life. On the other hand, an unemployed widow with three children expressed an ambivalent attitude towards the risk and believed that it is precisely lack of knowledge that can create anxiety and may turn a person into a “worried-well”:

[i]t [ignorance] may be agonizing to him and he can seek symptoms. In the future he may worry that his children will develop the disease and may look for the signs of it. Ignorance is not good. (17)

At the same time, twenty respondents believed that an individual’s right to ignorance should be limited by the consequences that the diagnosis brings for others, especially the spouse and/or children. They argued that as health is written in one’s genes, the risk is a family matter and that persons are morally obliged to inform their partner who may be forced to take the role of caregiver and thus should be involved in the decision-making about marriage and having children. A low-paid widow with two children referred to her own experience:

If they plan to spend a life together he should undergo testing. His possible disease will influence her entire life, as she may become his caregiver (...) My husband had HD. But when we got married I did not know all those things I know now about it, and our daughter has inherited the gene. When she did the test (...) she experienced a deep shock, and for me it was even worse. It is very hard to live being conscious about a daughter’s disease. (...) they should know about it and take appropriate steps. (21)

All in all, although health increasingly becomes a matter of public concern, when only individual health is involved family members under the study stressed that both doing the test and having children are personal decisions. Nevertheless, they argued that if information about the risk influences others’ lives, especially that of one’s partner who can be burdened with the role of a future caregiver, one’s right not to know should be limited and people should be obliged to inform others about the risk.

Obligations Toward Future Generations: Hariette

Respondents from the study imposed the strongest obligations when future generations, i.e. planned and/or existing children, were involved. As the genetic risk was said to be written in blood, it carried a moral weight and constituted a basis of “genealogical ethics” (Konrad 2003) which places the interests of the family and offspring in

particular before those of an individual. As in Polish culture family is regarded as one of the most important values, children were defined as its most important component. They were constructed as precious, innocent and in need of protection (Lancy 2008). Consequently, the decision about having children was framed as a moral enterprise that ought to be rationally planned, and genetic technologies were defined as the “right” and “moral” means of reproduction. And while genetic screening destabilized parents’ hopes of having a healthy child, at the same time the rejection of biomedical achievements was framed as a form of “irrational” and “irresponsible” reproduction that jeopardizes children’s future (Chańska 2009; Savulescu and Kahane 2008). On the other hand, those who “do the right thing” were seen as “rational,” “responsible” and “caring” parents.

In the case of Hariette, who is afraid that a positive test result may influence her reproductive choices, over one half of respondents (15) stressed her responsibility towards future children who should be “protected” from suffering. They emphasized that parents are obliged to plan reproduction consciously and that its goal is not merely conceiving a child but the creation of one with the “best chances of the best life” and the assurance of their happiness, which was equated with health. Thus, while the use of genetic technologies was defined as a moral practice and a sign of “paternal maturity,” conceiving a child who is at risk of inheriting a terminal disease was defined as “morally wrong.” A Catholic widow with two children framed genetic tests as the most important means in assuring the child’s well-being and argued that parents have no moral right to “sentence” their child to suffering:

Hariette should do the test and plan her offspring consciously. She is not the only one who will bear the consequences of the risk. Early knowledge can save them [children] from physical and psychological suffering. She should use all possible scientific measures to make her daughter happy. (21)

Interestingly, even those who supported parental rights to ignorance and reproductive freedom constructed genetic technologies as an effective means for managing the risk. Thus, those who framed conceiving a diseased child as “traumatic” also suggested that in case of a “negative” scenario abortion would be a “solution.” And while respondents were aware that using genetic technologies would mean that a child would not come into existence, they believed it would prevent its suffering and/or premature death. By stressing parental responsibility to assure the child’s “quality of life,” they assumed that bringing someone into existence may cause him or her harm and that no life is better than a life with a terminal disease. For this reason, in their accounts they promoted “genetic enlightenment” which was said to make one’s dream of the perfect (healthy) newborn come true. A young, single male intellectual worker framed testing as a positive reproductive practice and an effective tool for the creation of healthy children:

If there is a chance of ‘protecting’ a child with PGD (...), she is obligated to try those procedures. (6)

On the other hand, twelve respondents believed that even when parents’ ignorance may endanger their child’s health, they have the right not to know about the risk. They stressed that it is parents who will bear the consequences of raising a diseased child

and if they are prepared for it, will love and accept the child the way it is born without moral remorse, so they may resign from doing the test. Such was the rationale of a retired widow with three children who emphasized the parental right to make their own reproductive choices:

The decision belongs to Hariette and her husband, as they will be responsible for the life of the conceived children. (22)

Love and respect for a future child was supported by the claim about the relativity and probability of the prognostic capability and accuracy of the tests of genetic risk which were said to be overestimated. Thus, while many professionals tend to imagine the “worst scenario,” this group of respondents resisted the “risk-medicine” and argued that the results of genetic tests cannot be expressed as a simple “yes” or “no” and cannot provide a “100 per cent guarantee.” Moreover, while questioning the reliability of the test some also believed in luck and argued that parents should “take their chance.” A middle-aged physiotherapist emphasized that apart from genetic diseases there are many other threats to a child and even if parents decide to adopt a child, they cannot be sure it will be healthy:

How can she be sure that an adopted child will be free of genetic encumbrance? (23)

Surprisingly, despite the religious character of Polish culture very few respondents were concerned about the eugenic character of genetic testing. Nevertheless, those who did argued that all people, including the diseased ones, deserved to live and should be respected. Some claimed that not bringing a child into existence could not be treated as avoiding harm and that a life with a terminal disease was better than no life at all, especially that the disease may not manifest itself for many years. Consequently, respondents reasoned, it is knowledge not ignorance that may lead to harm as the tests do not prevent the harming of children but prevent children from being born. A wife of an HD patient criticized the utopian vision of Huxley’s *Brave New World* and emphasized the “inhuman” potential of biotechnology:

We do not live in the world of genetic purity and do not have a duty to exclude genetic defects. It would be inhuman to demand such behaviors. (12)

All in all, this study suggests that individuals readily accept responsibility for the health of their children, who are the most valued members of the family. For this reason, many respondents stressed that parents are responsible for having put their children at risk and thus are morally obliged to avoid children’s suffering (Buchbinder and Timmermans 2011; Rothman 1993). The feeling of genetic responsibility meant that they were prepared to compromise their own needs to not to know the risks for the sake of future generations. Even those who acknowledged that having a positive test result would cause anxiety or might have negative implications for their reproductive choices stressed that responsible and caring parents ought to test themselves and protect the child.

Obligations Toward the State: Caroline

As health is framed as both a personal and a public issue (Lupton 1997), the biological dimension of human existence acquires a political meaning and the distinction between the private and the public dimension of citizenship becomes blurred. Consequently, a concept of “biological citizenship” emerges (Rose 2007a; Rose and Novas 2004). Like all kinds of citizenship, the one based on biology also offers individuals rewards and endows responsibility: whilst people have “the right to health,” healthcare and prevention, at the same time it is now their responsibility to take preventive actions and be well. Thus, testing is perceived not only in moral terms but in political and economic ones as well. In the case of Caroline who is afraid of her BRCA testing, many respondents argued that people should consider the economic and political dimension of their health decisions. They stressed that because the costs of healthcare for the State are skyrocketing responsible citizens are obliged to be aware of their health and ought to undertake preventive actions. Rose (2004) refers to such a form of citizenship as “informational” as it involves a specialized scientific and medical knowledge of one’s condition and an imperative of activity.

Only eight respondents said that even in the case of diseases that can be prevented and cured testing is a personal decision. This was justified by the claim that in such a case a person’s ignorance does not cause others’ harm and that a possible positive result may cause a psychological breakdown. Nevertheless, nineteen respondents referred to Caroline’s hesitation and fear as “irrational,” “unreasonable” or “cowardly.” Such moral judgments were supported by the concern over a person’s relatives who may experience “survivor guilt.” For this reason a young, unemployed male emphasized that as social beings, people should act “rationally” and should consider the opinions of significant others:

Caroline has the right [to ignorance]. Nevertheless, she should remember that she has big chances of being cured and returning to good health. She should also take into account the opinions of her relatives, for whom the loss of a loved one can be a painful experience which may cause compunction, as they did not prevent it. (24).

Additionally, respondents stressed the empowering character of genetic information and believed that even in the event of the worst scenario it is better to know than to live in constant uncertainty. They argued that although knowledge about the disease can paralyze and cause negative emotional and psychological reactions, ignorance, too, can be a source of constant fear, uncertainty, “serious mental problems” and can deprive individuals of autonomy.

Hence, despite moderate support for patient rights, most family members stressed one’s responsibility to undergo testing which was seen as a form of political commitment and individuals were framed as political projects. As “technologies of the self” (Foucault 1997; Taussig, Rapp and Heath 2008) genetic tests were perceived as an effective means that permit individuals to affect and transform their own bodies in order to attain a state of happiness and purity. Moreover, in contrast to genetic diseases that cannot be cured, in the case of cancer respondents framed genetic tests not only as “lifesaving technologies” and “technologies that increase one’s chances of sur-

vival” but also as a means of taking care of the State’s economy. For this reason, many framed fear and anxiety associated with testing as “irrational” and consciously putting the State to expenses as “irresponsible.” Nevertheless, political pressure was masked under the clichés of a “right to health” and “prevention.” Even though respondents framed testing as a “right” and stressed the positive dimension of prevention, they also spoke of it in terms of political responsibility and civic involvement. Additionally, a female student of pharmacy claimed that a person ought to keep faith and hope in the modern technologies that enable management of the disease. Thus, again, the political economy of hope was expected to structure and drive the actions of individuals, who were assigned responsibility for becoming active participants in the race for the cure:

[a]s she belongs to the group where the risk is much higher, she should undergo testing. This is what prevention is all about and every citizen has a right to it. The sooner she knows, the sooner she can undertake preventive actions as early and be cured. (8)

In sum, even in the case of a disease that seems to affect only an individual person one was expected to subordinate to the needs of the State their wish not to know and overcome their fears. Thus, these accounts reflect the interrelated processes of the biologization of politics and the politicization of biology, which turns *homo geneticus* into a *zoon genetikon*.

Conclusions

There is strong evidence that geneticization of medical discourse has a profound impact on individuals and society at large (Conrad and Gabe 1999; Clarke and Tishehurst 2006; Kerr 2004; Lock and Nguyen 2010). One of its consequences is that people are said to share their genes with others and, consequently, each person is now framed as a mirror of a larger group. For that reason, some argue that genetic risk is not merely a private matter but becomes a public concern (Rhodes 1998; Shaw 1987; Siemińska 2010). Moreover, as medical discourse promotes the idea that the risk can be anticipated, managed or even eliminated, genetic testing gains a moral status and becomes an important component of the ideology of healthism. It also strengthens the assumption that knowledge, like health itself, is not only a privilege but also an obligation. Consequently, some argue that a responsible individual should not only consult experts who can quantify the genetic risk and provide information about its management, but in order to protect others he/she should also take appropriate steps and “do the right thing.”

Similar observations have been made in this study. Where social relations were framed as “risky” (Featherstone, Atkinson, Bharadwaj and Clarke 2006), family members promoted the idea that information about the risk and disease itself are the property of the whole family (Sachs 2004), society and even the State. In particular, they constructed the entire family as a patient (Finkler 2001) who has the right to know. Moreover, by emphasizing the social, economic and political dimensions of genetic testing, respondents seemed to refashion the Western concept of citizenship to

include the human biological component, which, in turn, gained a political dimension (Rose 2007a; Rose and Novas 2004).

Thus, while genetic discourse is often presented as objective and politically neutral, there is evidence that, in fact, perceptions of genetic risk are value-laden (Douglas 1990) and that those values influence both professionals (Atkinson, Parsons and Featherstone 2001; Ettore 1999; Falk, Dugan, O’Riordan, et. al. 2003) and lay persons (Hanoch, Miron-Shatz and Himmelstein 2010; Hallowell 1999; Konrad 2003; Parsons and Clarke 1993; Rapp 2000; Rothman 1993). Consequently, as Boenink (2011) has demonstrated, individual decisions whether to do a genetic test, know the ensuing genetic risk and disclose such information to others may be shaped by relatives who are involved in the decision-making about testing and sharing information about that risk. Similarly, this study indicates that the perceptions of genetic risk are shaped not only by the type of disease in question but also by the social group to which it poses a threat and/or costs. Interestingly, respondents used the same rhetoric as scientific discourse does. They referred to such clichés as: rationality, (genetic) maturity, prudence, altruism, solidarity, responsibility for others, prevention and (self)control. And while the voluntary character of testing was often emphasized, different biopolitical rationalities were used to doubly stigmatize those who rejected the imperative of testing. Such individuals were labeled as “irrational” and “unreasonable” persons, but also “egoistic,” “uncaring” and “irresponsible” parents and “selfish” citizens.

These accounts also suggest that the self was framed in-relation to others as an “interdependent” self (Hallowell 1999). Consequently, while genetics may benefit individual’s health and autonomy, it may also pose a threat to patient rights. It is so because although people want to control genetic knowledge and its disclosure without any interference from health professionals, this study shows that individuals may be submitted to indirect and informal pressure from their families. Moreover, as such pressure is imposed on individuals not only by their families but also by science and the media, it may be difficult to resist. Consequently, genetic testing is framed as a moral practice, i.e. an act of purification, prudence, rationality, altruism and solidarity with others. Thus, the former political pressure to act responsibly is being replaced by an informal, cultural pressure which instils in society a new ethos of duty (Domaradzki 2013; Gibbon 2006; Hallowell 1999). This, in turn, may transform Western ideas on autonomy, responsibility and blame (Arribas-Ayllon, Srikant and Clarke 2011; Rapp, Heath and Taussig 2001). All in all, while genetics may increase personal autonomy and (reproductive) freedom, it may equally also create a pressure to know and manage the risk. As it constructs the entire family as the “patient,” it may impose on individuals a moral pressure to do the genetic test, know the risk, disclose the genetic information to others and make the “right” life choices regarding career, reproduction and marriage (De Zordo 2012; Hunt, Castañeda and De Voogd 2006; Featherstone, Atkinson, Bharadwaj and Clarke 2006; Finkler 2001; Rapp 2000; Rothman 1993). Moreover, by emphasizing the public dimension of the genetic risk, such obligations are framed toward: future generations, family members, society, the State and oneself. Thus, while medicine no longer aims

at “enhancing” the human race, but is more focused on the prevention of diseases, it still enables new forms of surveillance and social control (Nelkin and Tancredi 1989). Nevertheless, as modern biopower operates with a pseudo neutral “scientific” language which is not related by the public to power and control, it manages to mask its moral and political dimension, indeed, under clichés of the “right to health,” “autonomy,” “choice” and “responsibility” (Douglas 1990; Gibbon 2006; Lippman 1991; Tesh 1988). Furthermore, as it presents itself as acting for people’s good, many people do not see the coercive and hazardous dimension of genetic testing. On the contrary, as it is done in the name of health, it is seen as something natural and much sought after. Thus, medical control is achieved through normalization, i.e. the construction of idealized norms of conduct such as genetic testing.

Summing up, as genetics influences the way we think about the self, our bodies and social relations, it is turning families into bioethicists who, as lay experts, become one of the key players in the geneticization and biomedicalization of society and bioethicization of genetic discourse. As families actively promote genetic knowledge and technologies, the latter are framed as unique technologies of the self that enable effective (self)observation, (self)visualization, (self)management and (self)surveillance. Moreover, their active participation in patient associations, support groups and organizations, their involvement in genetic research, the dissemination of knowledge on genetic diseases, education campaigns, political actions, the collection of funds and their contribution to the creation of bioethical standards all demonstrate that lay persons are now active consumers and not passive recipients of genetic innovations. Finally, their positionality as family members of affected individuals and members of the Polish Society of Huntington’s Disease make them an important interest group who can benefit from genetic testing. For this reason they also become moral entrepreneurs who act as bioethicists, psychologists and moralists who stress one’s obligations, respectively, towards: future generations, family members, society, the State and oneself. Consequently, as their participation in policy discussions and the decision-making process about the new genetics and health increases, it seems reasonable to identify lay people as experts (Collins and Evans 2002; Evans and Plows 2007; Irwin 2001; Kerr and Cunningham-Burley 1998; Kerr, Cunningham-Burley and Amos 1998; Prior 2003; Lindsay and Vrijhoef 2009).

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