

IS GENETIC INFORMATION FAMILY PROPERTY? EXPANDING ON THE ARGUMENT OF CONFIDENTIALITY BREACH AND DUTY TO INFORM PERSONS AT RISK

¿LA INFORMACIÓN GENÉTICA ES DE PROPIEDAD FAMILIAR? AMPLIANDO
EL ARGUMENTO DE LA RUPTURA DE LA CONFIDENCIALIDAD Y EN EL DEBER
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A INFORMAÇÃO GENÉTICA É DE PROPRIEDADE FAMILIAR? AMPLIANDO O
ARGUMENTO DA QUEBRA DA CONFIDENCIALIDADE E O DEVER DE INFORMAR
PESSOAS EM SITUAÇÃO DE RISCO

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ABSTRACT

A current trend in bioethics considers genetic information as family property. This paper uses a logical approach to critically examine Matthew Liao's proposal on the familial nature of genetic information as grounds for the duty to share it with relatives and for breach of confidentiality by the geneticist. The authors expand on the topic by examining the relationship between the arguments of probability and the familial nature of genetic information, as well as the concept of harm in the context of genetic risk. Lastly, they examine the concept of harm in relation to the type of situations w the potential recipient of the information is not the person directly affected by the risk.

KEYWORDS: genetic information, familiarity, duty to inform, breach of confidentiality, privacy rights, genetic counseling, harm, genetic risk. (Source: DeCS, Bireme).

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RESUMEN

Considerar la información genética como una propiedad familiar es una tendencia actual en Bioética. El artículo examina con un método crítico, desde un enfoque lógico conceptual la propuesta de Matthew Liao, que sugiere como justificación de la obligación de compartir información entre familiares y para la ruptura de la confidencialidad, la naturaleza familiar de la información genética. Se amplía el tema mediante la relación entre los argumentos de la probabilidad y naturaleza familiar de la información genética y analiza el concepto de daño en el contexto del riesgo genético. Por último examina del concepto de daño en relación con el tipo de situaciones en que el posible receptor de la información no es la persona directamente afectada por el riesgo.

PALABRAS CLAVE: información genética, deber de informar, ruptura de la confidencialidad, derecho a la privacidad, asesoramiento genético, daño, riesgo genético. (Fuente: DeCS, Bireme).

RESUMO

Considerar a informação genética como uma propriedade familiar é uma tendência atual em Bioética. O artigo examina com um método crítico, a partir de um enfoque lógico conceitual, a proposta de Matthew Liao, que sugere como justificativa a obrigação de compartilhar informação entre familiares e para a quebra da confidencialidade, a natureza familiar da informação genética. Amplia-se o tema mediante a relação entre os argumentos da probabilidade e a natureza familiar da informação genética, e analisa o conceito de dano no contexto do risco genético. Por último, examina o conceito de dano referente ao tipo de situações no qual o possível receptor da informação não é a pessoa diretamente afetada pelo risco.

PALAVRAS-CHAVE: informação genética, dever de informar, ruptura da confidencialidade, direito à privacidade, assessoramento genético, dano, risco genético. (Fonte: DeCS, Bireme).

THE DUTY TO INFORM: AN ONGOING DEBATE

In an article in the *Journal of Medical Ethics*, Matthew Liao (1) commented on the familial nature of genetic information as grounds for the duty to share it with relatives and family members, and for breach of confidentiality by the health professional. He uses two case histories to illustrate his argument. The first concerns two sisters, one of whom (Anna) learns her two-year-old son has Duchenne muscular dystrophy. The dilemma posed by this situation is whether Anna has a duty to inform her sister (Betty), given that she knows Betty would use pre-implantation diagnostics or would not have a child at all if she learned the baby could be affected by the disease. The second case concerns a pregnancy that is already under way. In this instance, the pregnant woman, Heather, is known to potentially be carrying a child who eventually might be affected by Huntington's disease in later life. This risk is derived from the fact that Heather's father-in-law, Fred, has been diagnosed with the disease. Fred is not willing to disclose this information to his son, Gary, nor is Gary, Heather's husband, prepared to receive it. In fact, Gary has stated explicitly that he does not want to be informed about any genetic predisposition. Should health personnel inform Heather, given that she would consider aborting her child if she knew it to be affected by the disease?

In general, these case histories pose the following questions: "Is there a duty to inform one's relatives about one's own genetic condition?" (duty to inform); "Are health personnel duty-bound to warn relatives who are at risk of genetic conditions?" (breach of confidentiality). Some scholars base an affirmative answer to these questions on the familial nature of such information: 1) The fact that genetic information is shared among

relatives presumably is sufficient reason for committing anyone to disclose it to family members, considering the potential harm possibly caused by failure to inform them. 2) Similarly, confidentiality is superseded by potential harm to others on the grounds that others share the genetic information of the concerned individual. Position one is assumed, for instance, by Knoppers(2).² Analogous arguments are advanced by Parker & Lucassen (3) and Pullman & Hodgkinson (4), among others. Likewise, potential harm also is thought to override confidentiality duties on the basis of the familial nature of genetic information. For instance, Sandroff, R (5) and Alistair Kent (6)³ insist the health professional should ignore the concerned person's right to privacy whenever breach of confidentiality can prevent harm. Both the arguments cited are based on one assumption and one principle: the assumption that genetic information is familial and the principle of avoiding harm. As a contribution to the debate and in line with Liao's paper, we further expand on the question of information being "familial" and, as an additional point on the issue, we also consider the concept of "harm" in relation to the type of case histories presented in Liao's argument, which can

2 "In short, *the very nature of genetic information, as both individual and universal*, now mandates its treatment as familial. [...] at present, the acceptance of the principle of mutuality in the sharing of information in families (and hopefully one day in whole communities at risk) serves to reinforce the notion that we are literally our brothers' keeper" (p. 86).

3 "The familial nature of this type of genetic information also obliges the professional to define where he or she stands in relation to the maintenance of individual confidentiality or the decision to override it in pursuit of the greater good (or perhaps the lesser harm). Again, the view from the standpoint of families at risk is that, in the case of severe genetic disease *where there is a potentially avoidable harm*, professionals ought to be willing to override the wishes of individuals and make the information available" (p. 17).

be viewed as constituting a specific typology within the general category of genetic counseling. In this paper, we use the critical method and a logical and conceptual approach to assess the problem in question.

GENETIC “EXCEPTIONALISM” AND THE FAMILIAL NATURE OF GENETIC INFORMATION

Proponents of a general duty to inform and broader conditions for breach of confidentiality in the case of genetic information base their arguments on the exceptionality of this kind of information with respect to other types of biomedical data, as well as its familial nature. While both characteristics are clearly linked, they should be kept separate. We first address the issue of genetic exceptionalism, then focus on the question of the familial nature of genetic information.

So-called “genetic exceptionalism” is roughly based on two facts: 1) information *inheritance*: by being transmitted from one generation to the next, the DNA sequence constitutes a sort of commonly shared heritage among members of the same family; 2) information *expression*: the causal mechanism leading from genes to protein expression, and finally to phenotype, is characterized by a unique (irreversible) direction in which “information” is transmitted from genes to proteins and to the organism (the so-called “central dogma of molecular biology” advanced by Francis Crick in his groundbreaking paper in 1958) (7).

A great deal of literature has been produced on the philosophical distinction between genetic and other kinds of biological information, as well as on the causal mechanisms underlying these distinctions (8-14). Genetic exceptionalism is contested especially by biology

scholars in the development of systems theories. This school of thought advances the so-called “parity” thesis, whereby genetic phenomena are considered on a par with other kinds of biological phenomena that lead to the development of the organism (such as cell-to-cell signaling systems). (15-17) Genetic exceptionalism generally is denied on the grounds that both DNA and non-genetic components are necessary causes for the development of the organism and the performance of normal biological functions.

On an ethical basis, Juth (18)⁴ and others (19-22) also put genetic information on a par with other biological data normally used in clinical settings on the grounds that commonly advanced criteria for distinguishing between the two (intimate and personal information, predictive of future health conditions, transmittable to offspring, revealing about other relatives) are indeed shared by both genetic and other kinds of biomedical information. One of the two authors of this paper elaborates extensively on this topic;⁵ however, it suffices here to say the reason

4 According to Juth, these characteristics do not *ethically* single out genetic information from other kinds of biomedical data, not even jointly (2005: p. 32). Rather, the question for Juth is why a possible distinction between genetic and other kinds of clinical information should imply there is a morally relevant difference (i.e., that genetic information always and in principle should be treated differently from other information).

5 Osimani, B. (2010). Poster presentation. EIPE Conference: Causalities in the Biomedical and Social Sciences. Rotterdam, 6-8 October 2010. We reject genetic exceptionalism for two main reasons: 1) although genetic mechanisms can be considered as causes of the organism’s development that are just as necessary as other biological mechanisms, they possess the added property of being transmitted from one generation to the next with fixed patterns of inheritance; 2) the causal mechanism underlying the correspondence between genotype and phenotype can be considered as a kind of “linear order causality” (which somewhat

why exceptionalism is neither necessary nor sufficient for qualifying genetic information as “familial” is simply because the two concepts do not involve each other. Moreover, as it stands, the concept of “familiarity” is too vague and needs further explication.

Furthermore, genetic exceptionalism in the sense of the genotype-phenotype correlation is totally irrelevant to make the information “familial” in that this phenomenon does not regard the transmission of information from one family member to another, but its “expression”; i.e., the development of the individual organism on the basis of the inherited genome. In fact, Liao cites authors who are against genetic exceptionalism, but are ready to accept that genetic but not other biomedical information (such as one’s cholesterol level) is “familial”(23).

LIAO’S MODEL

Liao does not elaborate on genetic exceptionalism; rather, he addresses the familial status of genetic information as a means to evaluate the relevance of this sort of information for predictive purposes.

By relating the two parameters of inheritance pattern and disease “penetrance” and presenting them as binary variables, Liao constructs the following typology:

1. Strong inheritance pattern & high penetrance;

justifies much of the talk about “information,” “code” and “language”). The concept of “linear order causality” is fleshed out and consists of adding a linear order component to the manipulative theory of causality (Author, 2010). Manipulative concepts of causality applied to the analysis of genetic causality can be found in Waters, K. (2007) Causes That Make a Difference. *The Journal of Philosophy* (CIV), 11: 551-579.

2. Strong inheritance pattern & low penetrance;
3. Weak inheritance pattern & high penetrance;
4. Weak inheritance pattern & low penetrance.⁶

Liao asserts that most of the cases should be categorized as instances of the weak inheritance pattern (3 & 4). In fact, he believes the genome is inherited only in part from individual to individual, with only monozygotic twins sharing the complete genome. As far as penetrance is concerned, Mendelian diseases (as with Huntington’s disease) are obviously considered of high penetrance, since the genetic mutation leads to disease occurrence in practically 100% of the cases (in the long run). However, also in this case, Liao notes Mendelian diseases account for only a minority of the cases in the population of genetic conditioned diseases. Therefore, the most common case is type 4.

Liao parallels the figures provided in his case studies with standard threshold measures established by legal norms related to the regulation of imminent risk or serious harm. In doing so, he comes to the conclusion that the probabilities associated with genetic risk barely reach the threshold normally required in these cases (1).⁷ Liao’s argument against the duty to inform and breach confidentiality is based, therefore, on the low clinical relevance of the information (as derived from the relatively low probability of occurrence of the disease predicted solely on the basis of genetic information), rather than on its failure to stand out from other kinds of biomedical information.

6 Liao uses a different terminology, which we change for the sake of consistency with our account.

7 p. 309.

In the following section, we would like to expand on this and provide further elements for reflection.

FAMILIARITY AS A PROPERTY OF GENETIC INFORMATION AND AS A TYPE OF RELATIONSHIP BETWEEN INDIVIDUALS

Both proponents and detractors of the duty to inform and breach confidentiality concentrate on the goods at stake. Proponents generally appeal to possible (existential) harm and, therefore, focus on physical and psychological health, as well as on a broadly understood right to autonomy. Detractors, instead, are concerned with the violation of privacy rights (24, 25, 26). Generally, however, two meanings of the notion of familiarity are often confused, as opposed to being clearly distinguished. On one hand, there is familiarity as a relationship among individuals, where the *relationship itself* should trigger particular moral-legal rights and duties. On the other, familiarity is seen as a property of genetic information: in this case, it is the *peculiarity of the information* that should activate special rights and duties.

This confusion is clear in the following common arguments:

1. Genetic information is “familial”. Therefore, it must be shared with family members (duty to inform);
2. Genetic information is “familial” and, therefore, it is not strictly personal. Consequently, privacy and autonomy rights are weakened (duty to inform and breach confidentiality).

It is clear that “familiarity” as a property of genetic information comes together with the fact there is a familiar relationship linking the individuals. Nevertheless, these

are two distinct notions of familiarity: one is an *attribute of a kind of information*; the other, a *type of relationship* among human beings. Thus, arguments should clearly distinguish which notion of “familiarity” the duty to inform and breach confidentiality should be grounded on. And, even if it is claimed they are grounded on both, then this should be made explicit.

Liao’s paper achieves some progress in this sense. By distinguishing between strong and weak genetic relation, he implicitly admits the concept of familiarity is not a categorical one, but instead it comes in degrees. This idea may also help to better analyze the familial nature of genetic information.

The proportion of shared genome among family members varies with the strength of their kinship bond: for monozygotic twins, this proportion is 1/1; for parent to offspring, it is 1/2; for uncle to nephew, 1/4, etc. This means that familiarity, in a technical-genetic sense, can be modeled as a logarithmic function of the kinship relation and, therefore, it characterizes genetic information of immediate relatives much more than people linked by a loose kinship relation, and exponentially so. The association between familial relationship and proportion of shared genome rapidly decreases with the increase in inheritance passages: even if grandfather and son are considered strict relatives in a common sense notion of familiarity, they are only loosely so in genetic terms, in that they share only a low percentage of the genomic heritage (25%). By modeling “familiarity” as a logarithmic function, which exponentially decreases with looseness of kinship, we intend to give an idea of the behaviour of this property and thereby provide a basis for determining *to what extent* the information at hand is really familial.

These considerations obviously only marginally concern the argument that grounds special rights and duties not in the special nature of genetic information, but in the special nature of familial bonds. Moreover, a relationship can be more or less familial, but not only for genetic reasons. We could say the concept of “familiarity” can be applied to different kinship relations, but with a greater or lesser degree of “stereotypicality” (27).⁸ So, for instance, in a strict genetic sense, the relationship between father and son is much more stereotypically familial than the relationship between great-uncle and nephew. For some relationships, it might be difficult to say whether they are familial or not. However, there are many more criteria beyond the proportion of shared genome that should be taken into account to evaluate the degree of familiarity *of a relationship*; these concern the affective, social, economic and cultural domains. This renders the notion of familiarity as related to the relationship among individuals much vaguer and complex in comparison to the precise logarithmic function associated with the notion of familiarity in terms of genetic information (27).⁹

8 Putnam says any concept can be represented by the elements belonging to its class of reference in a more or less faithful way. For instance, among the individuals belonging to the class of birds, there are some, such as robins, who more *stereotypically* represent the notion of a bird than others, such as penguins.

9 Bell and Bennett point out the distinction between “individual” vs. “familial” in terms of genetic information cannot be solved by drawing on scientific criteria; instead, it should be based on social and political considerations (Bell, D.; Bennett, B. (2001); 160). This is so only if familiarity is considered as a type of relationship between individuals; however, the same does not hold true in relation to familiarity as a property of genetic information. Moreover, scientific criteria are the only necessary and sufficient parameters for estimating the probability of harm. These elements clearly must be separate and distinct. Here, we will not consider, in contrast, the relevant distinction between the duty to share existing information that is already available vs. the duty to obtain (and disclose) infor-

Therefore, when talking about familiarity as grounds for the duty to inform and for legitimating breach of confidentiality, it should be understood without a doubt that it refers to two very different notions: the technical-genetic notion pertaining to genetic information; and a common sense notion of familiarity (which regards acquaintance, existential bonds, affective links and shared physical, cultural and educational environment, as well as related social and legal duties and rights). It also should be clear that they both come in degrees and, more importantly, the criteria for measuring them are different.

These considerations call into question the link between the antecedent and the consequent in the arguments presented at the beginning of this section. First of all, according to what has been said, one cannot declare a given piece of information is familial in a categorical fashion, but rather that it is more or less so. Furthermore it should be made clear whether the duty to inform (or to breach confidentiality) should be grounded on the familiarity of the relationship between individuals, or on the familiarity of the information. And, it is important to keep in mind that familiarity of a relationship also comes in degrees and is measured not only with reference to strict genetic criteria, but also according to anthropological, social, cultural and legal ones.

PROBABILITY IS NOT EVERYTHING: THE CONCEPT OF HARM IN GENETIC RISK CONTEXTS AND ITS ROLE IN ESTABLISHING PROBABILITY THRESHOLDS

Both the duty to inform and to breach confidentiality have been based not only on the familial nature of genetic

information that is not already available. Sommerville, A.; V. English (1999), Genetic privacy: orthodoxy or oxymoron? *Journal of Medical Ethics*, 25 (2): 148-149.

information, but also on additional factors related to the main purpose of disclosing the information; i.e., the possibility of preventing harm. Lucassen and Parker (29), for instance, present a list of the various criteria that must be met to breach the fiduciary relationship legitimately. “Firstly, there will need to be an assessment of the seriousness of the harm itself. Secondly, there will need to be an assessment of the likelihood of the harm occurring. Finally, there will need to be an assessment of the availability of effective interventions, or other options.”⁽¹²⁾¹⁰ Therefore, in considering the legitimacy to breach the right to confidentiality and/or to enforce the duty to inform one’s relatives, one should consider, in addition to the “familiarity” of the relationship and/or the information, the probability of harm occurring, its severity, and the possibility to prevent it. In line with standard legal approaches to risk, all these parameters are interrelated: *the more severe the expected harm, the lower the probability threshold for privacy breach.*

HARM FROM FAILURE TO INFORM WHEN THE ADDRESSEE IS NOT THE INDIVIDUAL THE INFORMATION IS ABOUT

Apart from being an ethical postulate covering all possible domains of human action, the principle of avoiding harm to others is acknowledged with a special emphasis in medical praxis, given its risky implications. With the Hippocratic oath, the principle “*primum non nocere*” is established as a binding mandate for any doctor, together with the principles of justice, beneficence, and autonomy (Faden and Beauchamp)(30). However, as unproblematically as this principle is accepted in medical ethics and deontology, so the criteria for deciding

¹⁰ p. 93.

how to implement it in a context of conflicting values and goods are fiercely debated. Feinberg (31) notes the term “harm” has a large area of vagueness; this makes its correct use problematic, especially in the context of non-standard (borderline) cases. Therefore, he urges a refined analysis of this concept, “since vagueness cannot be tolerated in a concept that has to be applied to such important normative issues” (14),¹¹ addressing the entire spectrum of the issues related to the question of harm in the health context would exceed the scope of this contribution. Our main concern, here, is to underscore the relevance of a distinction between cases where the person who may receive the information is not the same person the information is about and cases where the informed person is the same person affected by the genetic risk. The former are the type of events instantiated in Liao’s analysis.¹²

Here, the critical element we would like to stress concerns the very causal inference connecting harm and failure to disclose information, and the way this link can guide where the probability threshold is set.

The classical approach to identifying harm – and the responsible agent – compares the condition of individual

¹¹ p. 65.

¹² The examples adopted by Liao follow a well-established topic in the ethical literature on genetic counseling. See among others: Bennett, R. (2001) Antenatal genetic testing and the right to remain in ignorance. *Theoretical Medicine*; 22 461-71; Hayry, Matti & Takala, Tuija, (2001) Genetic Information, Rights, and Autonomy, *Theoretical Medicine and Bioethics*, 22 (5): 403-414; Parker M, Lucassen A. (2003) Concern for families and individuals in clinical genetics. *J Med Ethics* 2003; 29: 70; Gilbar, Roy (2007) Communicating genetic information in the family: the familial relationship as the forgotten factor. *Journal of Medical Ethics*; 33 (7): 390-393.

X before it happened (at time t_0) and after it occurred (at time t_1), as a result of Y's action (31).¹³ Alternatively, the condition of X is counterfactually compared to its possible condition, at the same time t_0 , if individual Y had not acted (for instance, by considering this omission as a failure to benefit someone who needed help). In any case, the notion of harm cannot do without a comparative element (contextual or temporal). From this standpoint, the notion of harm is strictly related to a *status quo ante* and a *status quo post* or to a counterfactual condition. How does this notion of harm relate to the idea that information would have prevented it? The most straightforward way to see this connection is to consider information as a means to avoid harm by making the potentially concerned individual aware of it. This can be considered as a warning act (32). In this respect, lack of warning can be considered as a cause of harm, because a warning would have put the individual at risk in a position to prevent (or at least minimize) harm. However, the cases presented at the outset of this paper conceal the following difficulties:

1) In cases where genetic information is used for family planning, the individual affected by the genetic risk is

13 According to Feinberg J. (1987; 102): "To be harmed is to be put in a worse condition than one would otherwise be in (to be "worse off"). This standard notion of harm does not obviously apply to cases where there is no possibility to compare a *status quo ante* and a *status quo post*, simply because there is no change/worsening of the condition (as in the case of congenital diseases). In order to apply the concept of harm to these cases as well, Buchanan et al. draw on a utilitarian paradigm and compare the lives of different individuals to rank them on a preference scale (Buchanan, A., D. Brock, N. Daniels, D. Wikler (2000) *From Chance to Choice*. Cambridge: Cambridge University Press: 234-235).

not the same individual in whose interest the duty to inform and to breach confidentiality are enforced (18).¹⁴ This urges an examination of the concept of harm in a genetic context, according to which it is clearly distinguished between cases where harm directly concerns the individual in whose interest privacy rights are violated and information duties are enforced versus cases where it only indirectly does so by damaging someone else.

14 As Juth puts it: "However, without therapy, *we are not avoiding the harm to the child with the gene for Huntington's disease, we are avoiding the child with the gene for Huntington's disease.*" (p. 325). Yet, Juth specifies that we are still avoiding harm that would have happened otherwise, although we are not avoiding harm to an existing person (personal communication). The philosophical debate has looked extensively at the possibility of damaging not-yet existing subjects. For instance, Parfit (1976) has given a positive answer to this question by advancing the "person-affecting view principle" ("Right, Interest and Possible People," in Kuhse, H. and P. Singer (eds.) *Bioethics: Anthology*. Blakwell, Oxford, 2006: 109); or "It will be worse if [specific] people [who would exist no matter what we choose to do] are affected for the worse" (*Reasons and Persons*, Oxford University Press, Oxford 1986, p. 370). According to Parfit, any theory with a person-affecting approach must imply that it makes some difference to the morality of an act whether the same people or different people would have existed if we had acted otherwise. This debate is very important to our actual ability to evaluate the act morally and will depend on whether the same people or different people would have existed had we act otherwise. Instead, other authors (such as David Heyd) maintain ethical questions can be settled only with regard to existing individuals and not to future ones. Furthermore, Heyd says relevant relationships concern only the "here and now" ("The Intractability of the Non-identity Problem," in Roberts, M. and D. Wasserman (eds.) *Harming Future Persons: Ethics, Genetics and the Non-identity Problem*. Springer, Dordrecht, 2009: 3). However, it is not the focus of this paper to concentrate on the possibility of damaging not-yet existing subjects, but rather to consider that the information that should prevent harm is not given to the person at risk (be he/she a future or actual person).

2) There is no point of reference for assessing *ante/post* difference (the future Betty's son or current Heather's son). Unless the harm is thought to regard the potential mother or the potential family of the individual who might be affected by a genetic risk. There is no *quo ante* condition of the individual. Potential harm cannot be measured or identified in this condition.

The precautionary principle, (33) which urges deferring the scientific decision, controlling it in proportion to the seriousness of the risk, does not apply in all cases. As is well known, the precautionary principle outlines the need for a cautious attitude, which is understood as anticipating the preventive risk facing the epistemological uncertainty of medical knowledge. The precautionary principle only corresponds broadly to an attitude of prudence, which intends to avoid abstentionism on the one hand and technoscientific interventionism on the other. This principle promotes only those interventions insofar as risky actions in humans are assessed and controlled. The aim of the physician's actions should be to optimize the risk; that is, to control the damage in proportion to the benefits obtainable for the protection of life and people's health.

Among the conditions for applicability (33)¹⁵ of the precautionary principle there is the possibility of serious and irreversible damage and the fact that precautionary measures (such as breach of confidentiality) are justified only when the damage is severe and irreversible. However, as we show in the context of genetic damage, this principle has difficulties in terms of its applicability. This is because it is impossible to refer, in the cases described above, to damage in relation to a newly conceived human being.

¹⁵ p. 347.

These facts characterize prenatal genetic counseling uniquely and represent a specific paradigm with respect to the standard legal framework used to determine responsibility in health matters. This calls for a specific definition of harm in this context. The tight spot in this paradigm is that the individual potentially affected by the harm the information should avoid is not the same individual in whose interest confidentiality should be breached and the duty to inform should be enforced. These formal objections reinforce the ethical concern in the sense that, because the only way to avoid harm is to eliminate the concerned individual, there is some confusion in calling this practice "preventive".

Among the various types of prenatal diagnosis, prenatal genetic diagnosis is the one that poses the most ethical problems (34); some are related to the possibilities for breaching confidentiality, others are linked to the physician's duty to warn others of possible damage. However, the problematic nature of prenatal diagnosis is rooted in the fact that genetic diseases have few possibilities for healing and, consequently, selective induction of abortion in the case of an unfavorable diagnosis is common. Sometimes, the link to abortion, in the event of an unfavorable outcome of the diagnosis, is through programs arranged by the local health authority and is understood as a way to "prevent" genetic disease.

This "preventive" practice problematizes the purpose of medicine. Is the aim to cure or to eliminate the sick person? It must be remembered that in France, until 1885, the way to eliminate rabies (hydrophobia) was by suffocating the patient between two mattresses or causing death by exsanguination of all four limbs (35). The discoveries of Pasteur are proof that those who liberated humanity from rabies were not those who had

suffocated, bled or burned patients in their homes, but rather those who attack the disease while respecting the patient.

It is important to make another substantial objection to the practice of “preventing” genetic diseases by eliminating individuals with genetic defects. The objection is that we cannot speak of “genetic diseases” as a being, since they are not entities that can be avoided; rather, we must speak of human beings who are sick. We refer here to individuals in the scholastic and descriptive sense of the term: *individuum est indivisum in se, et quodlibet alio ente divisum*.¹⁶ *Individuum* in this case means a member of the human family. In other words, genetic diseases exist because there are human beings; that is, persons who are ill. Therefore, the only way to “prevent” becomes precisely to “prevent” humans with a genetic disease from being born. This position ignores the clear biologically and rationally demonstrable evidence that the embryo or fetus is a human subject (36, 37) and enjoys full human dignity and the full right to life afforded to every human being.

Today, in the context of the medicalization of all phases of existence, recognition of the value of man as such must be subtracted from a purely clinical and functional assessment. It is important to note that the source of responsibility towards other human beings is not simply the frailty, weakness or vulnerability of humans (these traits are not values in themselves), but their mere existence.

16 In this regard, St. Thomas Aquinas in *De veritate* says that: “*Sicut ens dicitur unum in quantum est indivisum in se ita dicitur aliquid in quantum est ab aliis divisum.*” [So, a being is said to be “one”, insofar as it is undivided in itself and we say it is “something” because it is separate from others and distinguished from others] in *De Veritate*. qu. 1 art. 1 corpus.

No pathology should obfuscate this constitutive relational dynamic, which is the same that has allowed us to exist, a dynamic that speaks of our original dependence and our human finitude (38).

CONCLUSIONS

What bearing does probability have in this argument? Probability is used in these contexts as a measure of the uncertainty about the occurrence of harm. Furthermore, according to the legal principle of proportionality, in order to allow for a violation of privacy, it is important to consider that the more severe the expected harm, the less the probability of its occurrence.

This boils down to the following questions. If probability is a measure of how likely it is the disease will occur, is it still legitimate to link this measure to the duty to inform (or to breach confidentiality) when the disease will not directly affect the person in whose interest the duty is enforced (or the breach of confidentiality is legitimized)? Even when considering the parents and the family as harmed, questions would be no easier. Whose harm should the probability threshold be connected to: the parents’ or the child’s? Should it be an average of both? And, why connect the probability of a disease occurring in individual X to the harm concerning individual Y? There is no easy answer here.

Nevertheless, taking into consideration these questions, however, when we speak of familiarity of genetic information we are referring implicitly to two very different concepts: the technical notion related to genetic information and the common sense notion of familiarity. It is important, in this regard, know how to operate distinctions in the field of genetic counseling.

The technical concept, which can be modeled as a logarithmic function, decreases exponentially with a decreasing bond of kinship. At the same time, the notion of familiarity linked to the relationship between individuals is far more vague and complex compared to the logarithmic function associated with the more technical term. It should be noted that both meanings are expressed in degrees and there should be a difference in the measurement of both, if necessary.

In genetic counseling, to use the term “familiarity of genetic information” for breach of confidentiality it must be clear whether the duty to inform should be based on the familiarity of the relationship between individuals or the familiarity of information. In genetic counseling, it is important to consider that familiarity cannot be measured only in relation to genetic criteria, but also with respect to anthropological and social criteria. The contribution from this paper is limited to insisting on the distinction between a common-sense and a technical notion of familiarity as relates to genetic information and showing the complex link between expected harm and the probability threshold required to breach privacy rights. The proposed distinction between a technical and a common sense notion of genetic information is considered as a first step towards an analytical clarification of this term.

Furthermore, in the context of the medicalization of life, it is important to reconsider the fallacy of “preventing genetic diseases” to prevent harm. Appealing to the precautionary principle is not useful in all cases, because harm or damage is not always identifiable. It is not possible to consider “prevention” in the context of eliminating human individuals with genetic disorders. In this case, the use of family genetic information turns

against a member of the human family. It is an event that challenges us and puts a strain on the purpose of genetic medicine.

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