Is Genetic Counseling a Form of Eugenics?

Asesoramiento genético: ¿una práctica que estimula la eugenesia?

Assessoria genética: uma prática que estimula a eugenia?

Ricardo Miguel Luque Bernal, MSc, PhD (c)[*1];

Roberto José Buitrago Bejarano, MSc[1]

Received: August 9th, 2017 / **Accepted:** October 5th, 2017
Doi: http://dx.doi.org/10.12804/revistas.urosario.edu.co/revsalud/a.6475
To cite this article: Luque Bernal, l RM, Buitrago Bejarano RJ. Is Genetic Counseling a Form of Eugenics? *Rev Cienc Salud.* 2018;16(1):10-26. Doi: http://dx.doi.org/10.12804/revistas.urosario.edu.co/revsalud/a.6475

Abstract

Introduction: Genetic counseling can be practiced under four scenarios: preconception, preimplantation, prenatal, and postnatal (which is similar to preconception). Some authors argue that it should be considered a form of eugenics. The aim of this article is to present different views expressed in the literature regarding the relation between genetic counseling and eugenics. *Materials and methods*: A search of articles was conducted in several academic databases using the MeSH/DeCS terms bioethics, medical genetics, genetic counseling, and eugenics. Articles were included if they discussed eugenics or genetic screening. Articles were excluded if they provided a technical description of procedures. The selection was made after examining titles, abstracts, and full texts. *Results*: Fifty-seven articles were selected for analysis. In preconception counseling, the "reproductive beneficence principle" can be based on eugenic practices of the early twentieth century. In pre-implantation consultation, the genetic selection of embryos can be considered eugenic when it is used to change the natural course of reproduction or used for non-medical purposes. Prenatal diagnosis, when linked to abortion as a response to congenital malformations, can be considered negative eugenics. *Conclusion*: At present, eugenics can be defined in multiple ways. By some definitions, genetic counseling can be framed as a eugenic practice. However, the design of health policies and the interests of society may influence the autonomy of individuals. The possibility of generating a genetic selection of individuals, on the other hand, can be constituted as positive eugenics.

Keywords: Genetic counseling, eugenics, medical genetics, bioethics, screening.

Resumen

Introducción: el asesoramiento genético es una práctica que puede enmarcarse en cuatro escenarios: preconcepcional, preimplantación, prenatal y posnatal (similar al preconcepcional). Para algunos autores este tipo de práctica se considera eugenesia. El objetivo del presente artículo es exponer los

1 School of Medicine and Health Sciences, Universidad del Rosario.
* Corresponding author: ricardo.luque@urosario.edu.co

distintos puntos de vista, descritos en la literatura, sobre la relación del asesoramiento genético con la eugenesia. *Materiales y métodos*: se buscaron artículos en bases de datos académicas con los términos MeSH/DeCS bioética, genética médica, asesoramiento genético y eugenesia. Se incluyeron artículos que hablaran sobre eugenesia o sobre cribaje genético; se excluyeron artículos con la descripción técnica de procedimientos. La selección se realizó por título, resumen y texto completo. *Resultados*: se seleccionaron 57 artículos para el análisis. En el asesoramiento preconcepcional, el "principio de beneficencia procreativa" se considera que parte de posturas similares a las prácticas eugenésicas de principios del siglo xx. En la consulta preimplantación, la selección genética de embriones puede considerarse eugenesia cuando se usa para alterar el curso natural de la procreación o para fines no médicos. El diagnóstico prenatal, cuando se vincula con el aborto por malformaciones congénitas, puede considerarse eugenesia negativa. *Conclusión*: en la actualidad, la eugenesia abarca múltiples definiciones. Según la definición escogida, el asesoramiento genético puede enmarcarse como una práctica eugenésica. Sin embargo, el diseño de políticas de salud y el interés de la sociedad puede influir en la autonomía de los individuos. Por otro lado, la posibilidad de generar una selección genética de individuos puede constituirse como eugenesia positiva.

Palabras clave: asesoramiento genético, eugenesia, genética médica, bioética, cribado, tamización.

Resumo

Introdução: a assessoria genética é uma prática que pode enquadrar-se em quatro cenários: pré-concepcional, pré-implantação, pré-natal e pós-natal (similar o pré-concepcional). Para alguns autores este tipo de prática considera-se eugenia. O objetivo do presente artigo é expor os distintos pontos de vista, descritos na literatura, sobre a relação da assessoria genética com a eugenia. *Materiais e métodos*: buscaram-se artigos em bases de dados acadêmicas com os termos eSH/DeCS bioética, genética médica, assessoria genética e eugenia. Incluíram-se artigos que falaram sobre eugenia ou sobre rastreio genético; excluíram-se artigos com a descrição técnica de procedimentos. A seleção se realizou por título, resumo e texto completo. *Resultados*: selecionaram-se 57 artigos para a análise. Na assessoria pré-concepcional, o "princípio d beneficência procriativa" se considera que parte de posturas similares às práticas eugénicas de começos do século xx. Na consulta pré-implantação, a seleção genética de embriões pode considerar-se eugenia quando se usa para alterar o curso natural da procriação ou para fins não médicos. O diagnóstico pré-natal, quando se vincula com o aborto por malformações congénitas, pode considerar-se eugenia negativa. *Conclussão*: na atualidade, a eugenia abarca múltiplas definições. Segundo a definição escolhida, a assessoria genética pode enquadrar-se como uma prática eugénica. No entanto, o desenho de políticas de saúde e o interesse da sociedade pode influir na autonomia dos indivíduos pode constituir-se como eugenia positiva.

Palavras-chave: assessoria genética, eugenia, genética médica, bioética, rastreio, tamisação.

Introduction

Genetics has been one of the areas most closely studied by bioethicists since its inception as a science. This is because it can potentially have direct effects on one of the elements that constitute the essence of the human person: his or her genes. Medical genetics focuses on studying, diagnosing, and treating diseases that result from inherited factors and providing counseling services to patients and their relatives. Genetic counseling emerged in the United States in the second half of the 20th century to provide patients with

information about reproductive risks related to genetic diseases. It is currently defined as the process that helps patients and their relatives understand and adapt to the medical, psychological, and social implications of the genetic component of these diseases. This includes the following elements: 1) knowing the possibilities for occurrence or recurrence of genetic diseases based on interpretations of family and medical history; 2) education on the genetic inheritance of patients and their possible diagnoses; and 3) counseling to assist in informed decision-making and adaptation to risk. Both medical genetics and genetic counseling have benefited from the development of diagnostic testing and potential therapies deriving from the Human Genome Project and the development of genomics (1-5).

Genetic counseling has usually taken one of two deontological approaches. In *nondirective counseling*, patients receive information in the clearest and most impartial form possible so that it is they who make their own reproductive decisions. This form is closest to the biomedical model and defends the autonomy of the patient as a fundamental value. In *directive counseling*, on the other hand, the counselor communicates his or her perceptions to patients, and advises them about the best path to follow. The central focus of the first form of genetic counseling is informed decision-making by patients regarding their pathology, while the second form of counseling seeks to maximize their psychological well-being. Nondirective counseling prevails in most countries, where it closely complies with counselors' deontological codes. In some countries such as China, Chile, and Mexico, on the other hand, directive counseling is also accepted and promoted (6-9).

Genetic counseling is applied in the context of four different circumstances that patients may find themselves in. First, a couple or their family members may have inherited disorders when they seek counseling. In this case, a couple may be referred by a healthcare provider or seek counseling based on their own concerns about the risk of having children with inheritable diseases. This is called preconception counseling. In a second scenario, a couple seeks counseling when they have decided to have a child using assisted reproductive technology (ART). This is called preimplantation counseling. The third scenario entails prenatal counseling provided during pregnancy. The fourth scenario applies when a couple whose child has a congenital disease wants to know of the risk of having another child affected by the same disorder. This fourth scenario is called postnatal counseling, and it is very similar to preconception counseling in the way it is carried out and in terms of the possible eugenic consequences (10-14).

Due to the effect of genetic counseling on the reproductive decisions of clients, some authors have said that it should be considered a form of eugenics. To respond to this suggestion, an operative definition of eugenics should be established, because the term has a wide range of meanings and interpretations. Etymologically, the word's components mean "good birth." The concept of eugenics was first introduced by Sir Francis Galton at the end of the 19th century. Galton believed that the species could be improved using technological means for controlled reproduction. The evolution of this line of thought led different political movements to commit some of the worst atrocities ever recorded, and the politically-influenced use of eugenics was virtually proscribed by the second half of the 20th century. Now, however,

two different views of eugenics have developed: a political perspective and a purely biological one. Politically, eugenics can be practiced from a liberal or an authoritarian standpoint. Under liberal eugenics, people autonomously choose the genetic characteristics of individuals, while under authoritarian eugenics it is the State that determines who should or should not be born. Biological eugenics can also take two forms: negative eugenics, in which it is sought to avoid the birth of people with undesirable genetic characteristics or traits. Aborting an individual with Patau Syndrome (trisomy 13) is an example of negative eugenics. In positive eugenics, on the other hand, people actively pursue the selection of genetic traits considered to be desirable, for example by using assisted reproductive technology to select an embryo that does not share a defective gene with its parents. To some authors, only the positive and the authoritarian approaches described above can really be considered forms of eugenics, while our species has engaged in the other two kinds of practices for time immemorial (15-21).

There is controversy over whether medical genetics and genetic counseling constitute eugenic practices. Some authors maintain that medical genetics and genetic counseling are a form of eugenics, or implicitly include elements of it. Others, however, maintain that scientific consultations regarding genetics do not truly constitute eugenics since eugenics necessarily implies a political component (15, 21-24).

This study seeks to describe the different points of view in the literature about the relationship between genetic counseling and eugenics, as well as the possible social implications of this relationship.

Materials and methods

Searches were conducted in several databases including Pubmed, Ebsco, ScienceDirect, Scielo, OVID, Social Science Journal, and Wiley Online Library. The following MeSH terms were used: bioethics, medical genetics (genetics, medical) genetic counseling, and eugenics.

Articles published in 1990-2017 were selected if their topic was eugenic practices as a bioethical dilemma in the context of genetic counseling or a medical consultation regarding genetics. Articles were eliminated if they focused exclusively on a technical description of genetic counseling or of consultations regarding medical genetics.

An initial screening was based on article titles. The articles selected were subsequently filtered a second time based on the content of their abstracts, and a final selection was made after the entire document was read.

Results

The initial search produced 470 articles, 59 of which were eventually determined to meet the criteria. The description of results is based on the findings from these 59 articles, which led to dividing the analysis into a description of three scenarios of genetic consultation and counseling: preconception counseling, preimplantation counseling, and prenatal

counseling. Postnatal counseling was not specifically mentioned, due to its conceptual similarity to preconception counseling. Thus, the description of preconception counseling can be extrapolated to postnatal counseling.

Preconception Counseling

Preconception counseling provides prospective information and support to future parents, allowing them to take measures during pregnancy that will optimize the health of both mother and fetus. There are two approaches for couples with elevated genetic risk. One approach focuses on prevention, and the primary objective of this approach is to provide information and take measures to avoid the birth of children with genetic disorders. The second approach is more common and focuses on autonomy. Under this approach, providers seek to help potential parents make informed decisions. Moral justifications for the first approach focus on the prevention of suffering and the reduction of socioeconomic costs, while the second approach is justified by the desirability of reproductive autonomy (25).

In this context, patients are faced with two possible decisions. If the probability of a genetic disease is not elevated, i.e. if such risk is considered equal to that of the general population, then patients have the same options as any other person wanting to reproduce. If, on the other hand, there is increased risk for the presence of a genetic disorder, then the mother should decide whether she wants to reproduce. If she does not want to reproduce, the couple can use family planning methods such as vasectomy, tubal ligation, hormonal methods or others, or they may opt for adoption. If patients opt for pregnancy, they must decide between using assisted reproductive technologies or assuming the risks and accepting the possible consequences of taking no special action (26).

Several factors may generate bioethical tension during preconceptual genetic counseling. One factor to consider is the act of consultation itself, which indicates that the parents seek to decrease the risk that their child will suffer from a condition leading to disability. The Principle of Procreative Beneficence (PPB) argues that it is the moral obligation of parents to seek that their children be born in the most beneficial way possible and that this moral principle takes precedence over reproductive autonomy. To those who take this position, it is morally objectionable to decline preconception counseling because doing so may expose offspring to preventable risks (11, 27-29).

Authors use three arguments to add nuance to the Principle of Procreative Beneficence and accommodate its application to the principle of autonomy. The first of these arguments is based on what is called the minimum threshold perspective. In such cases, future parents believe that they have sufficient moral justification to select offspring who will be able to live dignified lives, over others who would not have that opportunity. The second argument is based on the idea of harm prevention. In these cases, future parents would be morally justified to select offspring based on their lesser suffering, avoiding the birth of offspring with limited prospects for quality of life. The third argument is that of satisfaction, in which future parents have sufficient reasons to believe that some offspring would have a more satisfying life than others (27, 30-34).

Many arguments have been used to attack Savulescu's proposal for a moral obligation based on the PPB. The first problem with the principle is that it assumes that a disability is something inherently bad, based on the premise that the lives of people with disabilities are of lesser value than the lives of people without them. A 1998 study on a deaf population published by Middleton in 1998, however, reported that 55% of subjects felt that genetic counseling was more harmful than beneficial; 46% felt that the use of genetic testing devalued deaf people and 29% wanted to have deaf children, illustrating that category "disability" is more socially-constructed than absolute (35-36).

The second criticism sees the use of the PPB as a eugenic mechanism under which parents are effectively obligated to have offspring with a genetic profile that guarantees their well-being. This implies their obligation to avoid, for example, discrimination against their offspring based on phenotype, harking back to elements of the old eugenics such as racism. Other authors go even further, questioning the very justification for the PPB because it is based on a fragile concept of impersonal harm, which is not a justifiable moral argument (37-39).

Preimplantation Counseling

Assisted reproductive technologies have been developed thanks to various technical-scientific advances that use artificial methods to achieve fertilization and the subsequent implantation of a developing embryo. In principle, these technologies were developed to help couples with problems of fertility. In practice, however, their use was quickly extended to fertile couples seeking to improve their chances of having healthy children (40).

The technologies include a wide variety of procedures, some of them relatively simple, such as scheduled intercourse and artificial insemination. In the former, the sexual relations of a couple are scheduled to follow ovarian hyperstimulation by artificial means. In artificial insemination, previously prepared or selected spermatozoa are deposited in the uterine cavity without the couple having sexual contact. The professionals who carry out these two assisted reproductive technologies have little to do with the characteristics of the embryo. In fact, their participation is limited to facilitating the process of fertilization. On the other hand, the process may include the selection of masculine gametes: homologous if they come from the same couple or heterologous if they come from a male who is not part of the couple (40-42).

Other assisted reproductive technologies are more complex and involve the selection of gametes and embryonic characteristics. This is the case for *in vitro* fertilization. With this technique, ova are removed from the uterine tubes after hormonal stimulation. These ova are then fertilized by spermatozoa using one of two strategies. In the first strategy, multiple spermatozoa are placed near the ovum in a culture medium with the hope that fertilization will take place. In the second strategy, an intracytoplasmic sperm injection is performed to produce fertilization. In either case, the resulting embryo is implanted in the uterus. The use of homologous gametes is indicated for *in vitro* fertilization when the couple is not able to have sexual relations for any reason (postmortem insemination, congenital or acquired anatomical alterations), when they want to preserve ova for fertilization with sperm at a later time, when there have been changes to the spermogram or changes to cervical mucous,

in the case of infertility for endocrinological, ovarian, or immunological reasons, or when there is unexplained infertility. The use of heterologous gametes is indicated when there is a total or nearly total absence of spermatozoa or in the case of genetic disorders (when the preimplantation genetic diagnosis is not accepted), in the case of diseases transmitted from mother to daughter such as HIV, when blood groups are incompatible, or when there is RH with previous exposure (previous isoimmunization), and in the case of single women or lesbians wanting to have children (43-45).

When patients decide to use an assisted reproductive technique, they must personally decide on one of the following options based on their individual circumstances and the results of their genetic counseling. They may opt for a selection of homologous gametes, avoiding the use of gametes with undesirable genetic characteristics. Alternatively, they may avoid risk by using a selection of heterologous gametes from a previously selected donor. On the other hand, they may use an embryo of their own or a donated embryo selected because it does not present any undesirable characteristics (46, 47).

When eugenic goals are suggested, assisted reproduction may give rise to several ethical dilemmas. The dilemmas begin when technological means first devised for the treatment of infertility are used for the prevention of genetic diseases with the selection of embryos using criteria other than health. The ethical questions that most resemble eugenic problems are those related to preimplantation genetic diagnosis (48, 49).

Preimplantation genetic diagnosis involves carrying out a series of studies on the genetic material of an embryo to obtain information about its genetic characteristics. This technique has been used primarily for selecting embryos when preconception screening has detected high probabilities of a hereditary disease. It becomes a dilemma, however, when it is used in selecting embryos for reasons unrelated to disease prevention, such as for sex selection. At the same time, it should be remembered that there are valid medical reasons for the sex selection of embryos in the case of sex-specific diseases (40, 50-53).

These technologies are also subject to even more complex ethical problems when they are used for preimplantation genetic diagnosis to select embryos that have genetic characteristics specific to a gene complex known as human leukocyte antigen (HLA), which is in a small region of chromosome 6. In this case, preimplantation diagnosis is not limited to searching the embryo for genes possessing mutations but also for an identical genetic load in the HLA genes. HLA genes are fundamental for the selection of transplant donors because two individuals are incompatible unless they coincide. This makes it possible for a couple whose child has a malignant neoplasm to select a genetically corresponding embryo and be able to carry out a procedure called an "allogeneic transplant" using hematopoietic stem cells, increasing the chances of the procedure's success. This practice gives rise to different ethical problems, but there is consensus over one of them: it is problematic to produce an individual not as an end in itself, but as a means of medically protecting the life of another individual. Although this can't be considered a eugenic practice, and although there is no intention of generating a "genetically improved" individual, say some authors, it does give rise to several ethical questions (53-56).

The selection of embryos for medical reasons based on a preimplantation genetic diagnosis (PGD) is considered a eugenic practice by some, based on both its goals and its results. First, it is the selection of embryos as a method for preventing genetic diseases, justifying this intervention by its utility in fulfilling two goals. One goal is to avoid the consequences for both the child and the parents of having a child with a genetic disease. This can be justified by the reproductive beneficence principal described above. A second goal is to reduce healthcare costs arising from genetic diseases. In terms of results, PGD has been shown to influence the genetic makeup of humans conceived through *in vitro* fertilization with the subsequent selection of embryos. Studies carried out on couples with problems of infertility have shown that PGD reduces the frequency of aneuploidy in couples with at high risk for this condition, increasing the probability of carrying a pregnancy to term. It has also diminished the probability of monogenic disorders such as Sanjad-Sakati syndrome, Canavan disease, cystic fibrosis, Tay-Sachs disease, Duchenne muscular dystrophy, and others. Because the arguments that support both the goals and results of PGD can coerce patients in their reproductive decisions, some authors consider them eugenic practices (27, 57-69).

Despite the possible advantages described above, Hansen et al. published an article in 2002 that showed that 8.8% of people conceived by means of intracytoplasmic sperm injection suffered from major congenital birth defects, while only 4.4% of those conceived naturally suffered from such defects, a statistically significant finding. Another study published in 2012 by Sagot et al. provided evidence of a similar situation for people conceived by means of intrauterine insemination. A study published by Liebaers et al. in 2010 did not show increased risk for major congenital birth defects but did show increased risk for perinatal death, particularly in multiple pregnancies. Although PGD diminishes the risk of having a child affected by a genetic disease when the parents are at high risk of having such a child, babies born as a result of assisted reproductive technology also have a higher probability of being born with major birth defects than those conceived naturally (70-73).

Sex selection for social rather than medical reasons is another practice associated with ART that can affect the genetic composition of the population, particularly in China where the ratio of men to women is 1.2 to 1. The Ethics Committee of the American Society for Reproductive Medicine discourages the use of assisted reproductive technologies for sex selection unrelated to any medical reason. In 2001, however, Zaid Kilani published an article defending sex selection as unlikely to affect the sex ratio of the population and as an expression of family autonomy, including over cultural factors and particularly religion. Marcus Pembrey, on the other hand, argued in 2002 against sex selection, saying that to permit this practice in the United Kingdom would be a slippery slope, because arguments based on the autonomy of couples and cultural factors would eventually lead to legitimizing the selection of more complex genetic traits such as skin color, height, or intelligence (52, 74-76).

Prenatal Counseling

Prenatal genetic counseling is a common component of prenatal care during pregnancy. It is a means of learning and informing parents if a gestating fetus has genetic diseases or major congenital birth defects. Information is provided to the mother regarding the severity of

any disease and the possibilities for treatment. The genetic risk of the parents is evaluated, and the most appropriate diagnostic procedures are determined. One great challenge is to communicate knowledge about the relatively new biomedical field of clinical genetics to the parents in the context of pregnancy, and to explain the differences between a screening and a diagnostic examination. The genetic consultation allows mothers to decide whether to continue their pregnancies to term (24, 26, 77).

The main diagnostic test for determining genetic disorders is called amniocentesis. In this procedure, amniotic liquid is extracted from the uterine cavity using a needle and syringe. The risk of spontaneous abortion resulting from this procedure is .5%. Other invasive diagnostic tests also present a risk of ending the pregnancy. Such tests include chorionic villus biopsy, in which a segment of the placenta is extracted for study, as well as cordocentesis, the extraction of blood from the umbilical cord using a needle. In both cases the risk of ending the pregnancy is from .5 to 2% (24, 77).

In prenatal genetic counseling, a pregnant woman may be faced with the information that her child suffers from a genetic or congenital disorder, and because most such medical conditions do not yet have solutions, parents may be confronted with the choice of whether or not to abort the pregnancy. Several authors assert that when parents abort a pregnancy based on the results of prenatal genetic counseling, they may be engaging in negative eugenics because they are impeding the birth of people with certain physical or genetic traits. In a 2010 discussion of eugenic abortion in Spain, Carmen González maintained that prenatal diagnosis is in fact a form of quality control with respect to human beings because it effectively suggests aborting a pregnancy if the fetus does not meet expected standards. Because there are not yet medical solutions to the problems diagnosed, medical practitioners focus on eliminating "diseased human beings [who are] carriers of their diseases" (19, 78-80).

The development of State programs for prenatal diagnosis as strategies for public health is also controversial. In a work on the ethical aspects of genetic medicine written for the World Health Organization, Wertz et al. define eugenics as "a coercive policy intended to further a reproductive goal rather than the rights, freedoms, and choices of the individual." In other words, it is argued that the term *eugenics* refers to actions that affect the reproductive decisions of the population when they are applied globally, but when genetic medicine and genetic counseling are applied to individuals, they cannot be considered eugenics. If this argument is correct, however, then public health measures intended to prevent genetic disease would be considered eugenics, and that would include birth control programs extended to the general public in countries where therapeutic abortion is permitted (81, 82).

Because prenatal genetic counseling suggests the possibility of therapeutic abortion, some authors have compared it to the program known as *Aktion T4* implemented in Nazi Germany to systematically exterminate disabled people. But the same authors acknowledge that genetic counseling is not State policy and imposes no obligations on parents. Prenatal diagnosis has few or no benefits to the fetus, because even though treatments exist for some diseases, the risks of those treatments are high in comparison to their possible benefits;

and where doctors do implement these treatments, they do so at the risk of violating the principle of non-maleficence. Peter Singer, on the other hand, says that people who compare therapeutic abortion to the eugenic practices of the Nazis are ignoring the contextual circumstances of the two practices. While there was no freedom to decline this kind of treatment under National Socialism, in the case of abortion in response to prenatal diagnosis parents are not forced to abort their embryos and there is no intention to systematically eliminate disabled people. In addition, Miller et al. published a 2000 study on the theoretical cost to the state of Michigan if it were to suspend the availability of therapeutic abortion in the case of genetic anomalies. They found that the average cost would be $74 million in that state and in the entire United States it would be $2 billion (82-85).

Discussion

Genetic counseling has been developing and becoming more complex; its practice has been spreading geographically, and it is now being made available to new population groups. In the beginning it was used exclusively by high-income and highly-educated white people in English-speaking countries. In addition, the sophistication of biomedical and biotechnological testing has been slowly increasing, so that genetic counseling now has great potential to predict possible genetic diseases. This predictive potential is significant because genetic counseling focuses to a great extent on the reproductive decisions of patients, and thanks to biotechnological advances they now have the chance to learn about the genome and make such decisions with the help of professional consultation. Today's debate is whether this should be considered eugenics, and if so, just how bad that is, going beyond the negative connotations that eugenics acquired due to the nature of its application in the first half of the twentieth century (86-89).

In a 2008 article, Stephen Wilkinson referred to the controversial use of the term *eugenics* in cases of preimplantation genetic diagnosis and neonatal screening. He points out that several authors propose that the term be applied exclusively to authoritarian and positive practices, and that liberal and negative practices cannot really be called eugenic. In his book *The Politics of Life Itself*, Nikolas Rose asserts that genetics has surrendered its early-20th-century eugenic pretensions and undergone a process of philosophical liberalization, granting fundamental weight to the concept of autonomy. In addition, early wishes to modify the genetic composition of populations were transformed by the molecularization of genetics, resulting in a search for the molecular bases of diseases focused on the individual rather than on the social group. He also asserts that because biotechnological advances work on a probabilistic rather than a deterministic model, they do not shape the destiny of individuals, but rather provide opportunities to prevent certain pathologies and the hope that they can do so. The WHO agrees with Rose; it does not consider genetic counseling a eugenic practice, because it is not carried out as State policy (19, 21, 90).

In 2007, Jyotsna Agnihotri Gupta classified eugenics into two categories, one private and the other public. The former can be used to describe the decisions of a couple to engage in

a genetic diagnosis while the latter refers to policies carried out by a State to perform tests and genetic consultations among population groups. She subsequently indicates that despite considering the decision of the couple to be autonomous, in fact every choice that is made is structured by a wide range of factors including the information to which the couple has access, their religious beliefs, and their cultural values, all of them considered social constructs. Gupta also states that although couples may technically make their own decisions, the State has ways to implement policies using coercive mechanisms that influence people to make reproductive decisions, and these coercive mechanisms amount to eugenics. These realities can contradict the concept of autonomy after a couple receives genetic consultation and counseling because individual perceptions are founded on a genetic discourse that reflects the social perceptions of what is considered "normal" or "acceptable." At the end of the day, autonomous decisions by couples are the moral interpretations of people immersed in a society undergoing a process of geneticization (82, 84, 91-93).

The development of prenatal and preconception screening as components of public health programs has progressed to the extent that testing has become more generalized and more accessible. Newly-developed primary prevention strategies include the administration of folic acid to reduce the incidence of neural tube defects and preconception screening tests among Ashkenazi Jews. Publicly-sponsored screening programs for the prevention of genetic disorders has begun to be implemented in some Western countries. In New Zealand, for example, a program for pregnant women was established in 2010 consisting of a kind of ultrasound called nuchal translucency screening. When combined with a blood test known as "double marker," it increases the probability of detecting fetuses with Down syndrome. Some groups have accused this program of promoting eugenics, while its defenders argue that because participation is optional, the autonomy of couples is respected. Another example is Virginia Miller's 2000 cost-benefit analysis of elective abortion programs in which she and her colleagues discuss the economic benefits of therapeutic abortion, illustrating how ethical discussions have impacts beyond individual cases, affecting public health and social composition (83, 94-95).

Conclusion

There is no doubt that under certain circumstances, the availability of genetic counseling leads some to argue that couples should make reproductive decisions favoring particular genetic characteristics.

Whether or not genetic counseling is considered a form of eugenics will depend on the definition of the latter term. If eugenics is considered an attempt to "improve" the genetic load of individuals by avoiding the birth of individuals with an undesirable genetic load, or to promote the birth of individuals with a genetic load considered favorable, then the association between genetic consultation and eugenics is obvious. If a political component is required, on the other hand, and eugenics is seen as a way for the State to impose a particular genetic ideal, disregarding the interests and autonomy of individuals with respect to their

reproductive decisions, then the question of whether genetic counseling can be considered a eugenic practice becomes more complex. For these reasons, nondirective counseling was conceived based on the idea of separating clinical genetics from the eugenic practices of the early 20th century. From its beginning, this kind of counseling sought to respect the autonomy of patients. Nevertheless, the question would be whether presenting potential parents with reproductive scenarios replete with calculated risks, and requiring decisions when those parents often lack the information and criteria necessary to carry out a critical analysis constitutes autonomy. Can parents in such a situation make an autonomous decision, or is this but a disguised form of medical paternalism —to put it in as positive a light as possible— or of eugenics, to be blunt about it? In addition, the moral neutrality of the consultation can be questioned, since no human being can ever claim to act with total objectivity. Directive counseling, on the other hand, focuses more on the empathetic relationship between the counselor and the patient regarding the information provided, and *a priori* rejects the objectivity and neutrality of the counselor. With this orientation, it implicitly favors the reaching of decisions through the interaction between counselor and patient, making patient autonomy secondary at best.

Thus, although genetic counseling can potentially affect the genetic load of the offspring of patients by means of the mechanisms described above, it is less clear whether it can affect the genetic load of a population group, let alone how this can affect society. Whether or not genetic counseling should be considered a eugenic practice depends on the subjective connotation that each reader or author applies to the concept of eugenics.

Disclaimer

This research and the manuscript were produced by the authors, who declare that they have no conflict of interest that would risk the validity of the results presented here.

References

1. Nussbaum RL, Mcinnes RR, Thompson MW, Thompson JS, Williard HF. Genética en medicina. 7th ed. Barcelona: Elsevier; 2008.
2. Oduncu FS. The role of non-directiveness in genetic counseling. Med Health Care Philos. 2002;5(1):53-63.
3. Resta R, Biesecker BB, Bennett RL, Blum S, Hahn SE, Strecker MN, et al. A new definition of genetic counseling: National Society of Genetic Counselors' Task Force report. J Genet Couns. 2006;15:77-83.
4. Santos Alcántara MJ. Aspectos bioéticos del consejo genético en la era del proyecto del genoma humano. Acta Bioeth. 2004;10(2):191-200.
5. Santos y Vargas L. Valuación bioética del proyecto "genoma humano." Acta Bioeth. 2002;8(1):111-23.

6. Raz AE, Atar M. Nondirectiveness and its lay interpretations: the effect of counseling style, ethnicity and culture on attitudes towards genetic counseling among Jewish and bedouin respondents in Israel. J Genet Couns. 2003;12(4):313-32.
7. Häyry M, Takala T. Genetic information, rights, and autonomy. Theor Med Bioeth. 2001;22(5):403-14.
8. Cirión AE. El consejo genético y sus implicaciones jurídicas. Comares: Alborotes; 2001.
9. Biesecker BB. Goals of genetic counseling. Clin Genet. 2001;60:323-30.
10. Casabona CMR, Casabona-Romeo C. Los genes y sus leyes. El derecho ante el genoma humano. Bilbao-Granada: Comares; 2002.
11. Wille MC, Weitz B, Kerper P, Frazier S. Advances in preconception counseling. J Perinat Neonatal Nurs. 2004;18(1):28-40.
12. Scott R. Choosing between possible lives: legal and ethical issues in preimplantation genetic diagnosis. Oxf J Leg Stud. 2006;26(1):153-78.
13. Garber AP, Hixon HE. Prenatal genetic counseling. Clin Perinatol. 1990;17(4):749-59.
14. Casabona-Romeo C. Los genes y sus leyes. El derecho ante el genoma humano. Bilbao-Granada: Comares; 2002.
15. Camps V. ¿Qué hay de malo en la eugenesia? Isegoría [Online]. 2002;27(27):55-71. Available at: http://isegoria.revistas.csic.es/index.php/isegoria/article/view/554/555
16. Waller JC. Ideas of heredity, reproduction and eugenics in Britain, 1800-1875. Stud Hist Philos Sci Part C Stud Hist Philos Biol Biomed Sci. 2001;32(3):457-89.
17. Galton F. Hereditary talent and character. Macmillan's Magazine. 1865;12:157-66.
18. Gems D. Politically correct eugenics. Theor Med Bioeth. 1999;20:201-13.
19. Wilkinson S. "Eugenics talk" and the language of bioethics. J Med Ethics. 2008;34(6):467-71.
20. Ekberg M. The old Eugenics and the new genetics compared. Soc Hist Med. 2007;20(3):581-93.
21. Rose N. Políticas de la vida. Biomedicina, poder y subjetividad en el siglo XXI. La Plata: Unipe; 2012.
22. Conti PHB. El consejo genético como procedimiento eugenésico: una reflexión en relación con los principios bioéticos y los derechos fundamentales. Rev Bioética y Derecho. 2015;(33):44-56.
23. González-Melado F, Di Prieto ML. Noninvasive prenatal genetic diagnosis: a bioethical reflection on the use of noninvasive prenatal diagnosis from the analysis of nucleic acids present in maternal peripheral blood. Cuad Bioét.2011;1(1):49-75.
24. Grimm T, Zerres K. Genetic counseling and prenatal diagnosis. En: Vogel and Motulsky's human genetics: problems and approaches. Berlin: Springer-Verlag; 2010. p. 845-66.
25. De Wert GMWR, Dondorp WJ, Knoppers BM. Preconception care and genetic risk: ethical issues. J Community Genet. 2012;3(3):221-8.
26. Casabona-Romeo C. Hacía una nueva medicina: consejo genético. Granada: Editorial Comares; 2013.
27. Savulescu J, Kahane G. The moral obligation to create children with the best chance of the best life. Bioethics. 2009;23(5):274-90.
28. Savulescu J. In defence of procreative beneficence. J Med Ethics. 2007;33(5):284-8.

29. Green RM. Parental autonomy and obligation not to harm one´s child genetically. J Law, Med Ethics. 1997;25(1):5-15.
30. Douglas T, Devolder K. Procreative altruism: beyond individualism in reproductive selection. J Med Philos (United Kingdom). 2013;38(4):400-19.
31. Robertson JA. Children of choice: freedom and the new reproductive technologies. New Jersey: Princeton University Press; 1996.
32. Shiffrin SV. Wrongful life, procreative responsibility, and the significance of harm. Leg Theory. 1999;5(2):117-48.
33. Harman E. Can we harm and benefit in creating? Philos Perspect. 2004;18(1):89-113.
34. Parker M. The best possible child. J Med Ethics. 2007;33(5):279-83.
35. Michie S, Marteau T. The choice to have a disable child. Am J Hum Genet. 1999;65:1204-7.
36. Middleton A, Hewison J, Mueller RF. Attitudes of deaf adults toward genetic testing for hereditary deafness. Am J Hum Genet. 1998;63(4):1175-80.
37. Sparrow R. Procreative beneficence, obligation, and eugenics. Life Sci Soc Policy. 2007;3(3):43.
38. Sparrow R. A not-so-new eugenics. Harris and Savulescu on human enhancement. Hastings Cent Rep. 2011;41(1):32-42.
39. Bennett R. The fallacy of the principle of procreative beneficence. Bioethics. 2009;23(5):265-73.
40. Rowe PJ, Griffin PD. Current practices and controversies in assisted reproduction. Geneva: World Health Organization; 2002.
41. Barros Delgadillo JC, Martínez Barrios E, Moreno Aburto C, Godines Enríquez MS, Manzur Navarrete F, Sánchez Solís V, et al. Inseminación intrauterina versus coito programado en ciclos de hiperestimulación ovárica controlada. Ginecol Obstet Mex. 2008;76(1):18-31.
42. Ramos-Alvarado AM, Delgado-Rosas A G-D la T. Inseminación artificial intrauterina y comparación de resultados referentes al tiempo posterior a la inducción de ovulación. Rev Méxicana Reprod. 2012;4(4):164-9.
43. Van-Voorhis BJ. In vitro fertilization. N Engl J Med. 2014;356(4):379-86.
44. Kably Ambe A, Salazar Lopez Ortiz C, Serviere Zaragoza C, Velazquez Cornejo G, Perez Peña E, Santos Haliscack R, et al. Consenso Nacional Mexicano de Reproducción Asistida. Ginecol Obstet Mex. 2012;80(9):581-90.
45. Bernal Crespo JS. Reproducción asistida y filiación. Tres casos. Opin Juridica. 2013;12:135-50.
46. Bredenoord A, Dondorp W, Pennings G, Die-Smulders C De, Smeets B, Wert G De. Preimplantation genetic diagnosis for mitochondrial DNA disorders: ethical guidance for clinical practice. Eur J Hum Genet. 2009;17(12):1550-9.
47. King D. Preimplantation genetic diagnosis and the “new” eugenics. J Med Ethics. 1999;25:176-82.
48. Borenstein J. The wisdom of caution: genetic enhancement and future children. Sci Eng Ethics. 2009;15(4):517-30.
49. McConnell T. Genetic enhancement, human nature, and rights. J Med Philos. 2010;35(4):415-28.

50. Ravitski V, Fiester A, Caplan A. The Penn Center guide to bioethics. New York: Springer Publishing Company; 2009.

51. Williams C, Wainwright SP. Preimplantation genetic diagnosis in clinical practice. Preimplantation Genet Diagnosis Clin Pract. 2014;39:165-74.

52. Pembrey M. Social sex selection by preimplantation genetic diagnosis. Reprod Biomed Online. 2002;4(2):157-9.

53. Baruch S, Kaufman D, Hudson KL. Genetic testing of embryos: practices and perspectives of US in vitro fertilization clinics. Fertil Steril. 2008;89(5):1053-8.

54. Kasper D, Fauci A, Hauser S, Dongo D, Jamerson L, Loscalzo J, editors. Harrison's principles of internal medicine. 19th ed. New York: McGraw-Hill Education; 2015.

55. Devolder K. Preimplantation HLA typing: having children to save our loved ones. J Med Ethics. 2005;31(10):582-6.

56. Walters L. Genetics and bioethics: How our thinking has changed since 1969. Theor Med Bioeth. 2012;33:83-95.

57. King D. Preimplantation genetic diagnosis and the "new" eugenics. J Med Ethics. 1999;25:176-82.

58. Botkin JR. Ethical issues and practical problems in preimplantation genetic diagnosis. 1998;26(1):17-28

59. Kaufert PA. Health policy and the new genetics. Soc Sci Med. 2000;51(6):821-9.

60. Shakespeare T. Choices and Rights: Eugenics, genetics and disability equality. Disabil Soc. 1998;13(5):665-81.

61. Gianaroli L, Magli C, Ferraretti A, Tabanelli C, Trengia V, Farfalli V, Cavallini G. The beneficial effects of preimplantation genetic diagnosis for aneuploidy support extensive clinical application. Reprod Biomed Online. 2005;10(5):633-40.

62. Gianaroli L, Magli MC, Ferraretti AP, Tabanelli C, Trombetta C, Boudjema E. The role of preimplantation diagnosis for aneuploidies. Reprod Biomed Online. 2002;4(Suppl 3):31-6.

63. Hellani A, Aqueel A, Jaroudi K, Ozand P, Coskun S. Pregnancy after preimplantation genetic diagnosis for Sanjad-Sakati syndrome. Prenat Diagn. 2004;24(4):302-6.

64. Yaron Y, Schwartz T, Mey-Raz N, Amit A, Lessing JB, Malcov M. Preimplantation genetic diagnosis of canavan disease. Fetal Diagn Ther. 2005;20(5):465-8.

65. Handyside A, Lesko J, Tarín J, Winston R, Hughes M. Birth of a normal girl after in vitro fertilization and preimplantation diagnosis testing for cystic fibrosis. N Engl J Med. 1992;327(13):905-9.

66. Biazotti MCS, Pinto Junior W, Albuquerque MCRM de, Fujihara LS, Suganuma CH, Reigota RB, et al. Preimplantation genetic diagnosis for cystic fibrosis: a case report. Einstein (São Paulo). 2015;13(1):110-3.

67. Gibbons WE, Gitlin SA, Lanzendorf SE, Kaufmann RA, Slotnick RN, Hodgen GD. Preimplantation genetic diagnosis for Tay-Sachs disease: successful pregnancy after pre-embryo biopsy and gene amplification by polymerase chain reaction. Fertil Steril. 1995;63(4):723-8.

68. Ray PF, Vekemans M, Munnich a. Single cell multiplex PCR amplification of five dystrophin gene exons combined with gender determination. Mol Hum Reprod. 2001;7(5):489-94.

69. Shakespeare T. Choices and rights: eugenics, genetics and disability equality. Disabil Soc. 1998;13(5):665-81.

70. Hansen M, Kurinczuk J, Bower C, Webb S. The risk of major birth defects after intracytoplasmic sperm injection and in vitro fertilization. N Engl J Med. 2002;346(10):725-30.

71. Sagot P, Bechoua S, Ferdynus C, Facy A, Flamm X, Gouyon JB, et al. Similarly increased congenital anomaly rates after intrauterine insemination and IVF technologies: a retrospective cohort study. Hum Reprod. 2012;27(3):902-9.

72. Liebaers I, Desmyttere S, Verpoest W, De Rycke M, Staessen C, Sermon K, et al. Report on a consecutive series of 581 children born after blastomere biopsy for preimplantation genetic diagnosis. Hum Reprod. 2010;25(1):275-82.

73. López Moratalla N, Huerta Zepeda A, Bueno López D. Riesgos para la salud de los nacidos por las técnicas de fecundación asistida. La punta de un iceberg. Cuad Bioética XXIII. 2012;2:467-527.

74. Savulescu J, Dahl E. Sex selection and preimplantation diagnosis: a response to the Ethics Committee of the American Society of Reproductive Medicine. Hum Reprod. 2000;15(9):1879-80.

75. Medicine T Ethics Committe of the American Society of Reproductive. Sex selection and preimplantation genetic diagnosis. Fertil Steril. 1999;72(4):595-8.

76. Kilani Z, Hassan LH. Sex selection and preimplantation genetic diagnosis at The Farah Hospital. Reprod Biomed Online. 2001;4(1):68-70.

77. Hunt LM, De Voogd KB, Castañeda H. The routine and the traumatic in prenatal genetic diagnosis: Does clinical information inform patient decision-making? Patient Educ Couns. 2005;56(3):302-12.

78. Remennick L. The quest for the perfect baby: why do Israeli women seek prenatal genetic testing? Sociol Heal Illn. 2006;28(1):21-53.

79. DE F, Fenner DEW. Negative eugenics and ethical decisions. J Med Humanit. 1996;17(1):17-30.

80. González Marsal C. El aborto eugenésico en España. Revsita Sociológica Pensam Crítico. 2010;4(2):259-69.

81. Wertz DC, Fletcher JC, Berg K. Review of ethical issues in medical genetics. Geneva: World Health Organization; 2003.

82. Gupta JA. Private and public eugenics: genetic testing and screening in India. J Bioeth Inq. 2007;4(3):217-28.

83. Scully JL. Disability and genetics in the era of genomic medicine. Nat Rev Genet. 2008;9:797-802.

84. Gates EA. Ethical considerations in prenatal diagnosis. West J Med. 1993;159(3):391-5.

85. Singer P. De compras por el supermercado genético. Isegoría. 2002;27:19-40.

86. Miller VL, Ransom SB, Ayoub MA, Krivchenia EL, Evans MI. Fiscal impact of a potential legislative ban on second trimester elective terminations for prenatally diagnosed abnormalities. Am J Med Genet. 2000;91(5):359-62.

87. Hodgson J, Weil J. Commentary: how individual and profession-level factors influence discussion of disability in prenatal genetic counseling. J Genet Couns. 2012;21:24-6.

88. Turnbull D. Genetic counselling: ethical mediation of eugenic futures? Futures. 2000;32(9):853-65.

89. Lei T, Fu F, Li R, Wang D, Wang R, Jing X, et al. Whole-exome sequencing for prenatal diagnosis of fetuses with congenital anomalies of the kidney and urinary tract. Nephrol Dial Transplant. 2017;1:1-11.

90. Gaille M, Viot G. Prenatal diagnosis as a tool and support for eugenics: myth or reality in contemporary French society? Med Heal Care Philos. 2013;16(1):83-91.

91. Lewis LJ. Models of genetic counseling and their effects on multicultural genetic counseling. J Genet Couns. 2002;11:193-212.

92. Have HAMJ. Genetics and culture: the geneticization thesis. Med Health Care Philos. 2001;4(3):295-304.

93. Pampols T. Los cribados genéticos de población como herramientas de salud pública. En: Casabona-Romeo CM, editor. Hacia una nueva medicina: consejo genético. Bilbao-Granada: Comares; 2013. p. 21-47.

94. Gross SJ, Pletcher BA, Monaghan KG. Carrier screening in individuals of Ashkenazi Jewish descent. Genet Med. 2008;10(1):54-6.

95. Cole R, Jones G. Testing times: do new prenatal tests signal the end of Down syndrome? N Z Med J. 2013;126(1370):1-7.