

# To cure or create people: different or similar reproductive routes?

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## Abstract

The objective was to analyze the understanding of nursing and medical students of practical situations in the field of human reproduction and family planning in the context of a eugenicist theoretical framework. Qualitative, descriptive and exploratory research was conducted from September to December 2015, through interviews with ten students in the field of health. After thematic content analysis, two categories were constructed. One discussed advantages, such as the cure of genetic diseases, and the need to expand the regulation and supervision and care of the mother/child dyad. The other described practical and ideological dilemmas on the nature of the individual, family, biological and social reproduction of human beings, discussing historical limits for the socialization of benefits through the pursuit of physical and mental perfection. It was concluded that knowledge of eugenics was weak and that the expansion of debates on the subject in the academic, scientific, professional and/or social areas is required.

**Keywords:** Reproduction. Family planning (public health). Eugenics. Bioethics. Students, nursing. Students, medical.

## Resumo

### Curar ou criar pessoas: caminhos reprodutivos distintos ou similares?

Trata-se de pesquisa qualitativa, descritiva e exploratória, realizada entre setembro e dezembro de 2015, mediante entrevistas com dez estudantes de enfermagem e medicina com o objetivo de analisar sua compreensão sobre situações práticas no campo da reprodução humana e planejamento familiar à luz de referencial teórico eugenista. Após análise de conteúdo, na modalidade temática, foram estabelecidas duas categorias. Uma discutiu vantagens, como a cura de doenças genéticas, e a necessidade de se ampliar a regulação e fiscalização, e os cuidados ao binômio mãe/filho. Outra evidenciou dilemas práticos e ideológicos sobre a natureza do indivíduo, família e reprodução biológica e social dos seres humanos, explicitando limites históricos para se socializar benefícios em meio à busca pela perfeição física e mental. Concluiu-se que o conhecimento sobre eugenia foi incipiente e que é necessário ampliar debates sobre a temática nos meios acadêmico, científico, profissional e/ou social.

**Palavras-chave:** Reprodução. Planejamento familiar. Eugenia (Ciência). Bioética. Estudantes de enfermagem. Estudantes de medicina.

## Resumen

### Curar o crear personas: ¿caminos reproductivos distintos o similares?

Se trata de una investigación cualitativa, descriptiva y exploratoria, efectuada entre septiembre y diciembre de 2015, a través de entrevistas realizadas con diez estudiantes de enfermería con el objetivo de analizar su comprensión de ciertas situaciones prácticas en el campo de la reproducción humana y de la planificación familiar, a la luz de un marco teórico sobre eugenesia. Luego del análisis de contenido, en su modalidad temática, se establecieron dos categorías. Una de ellas abordó las ventajas, como la cura de las enfermedades genéticas y la necesidad de ampliar la regulación, la fiscalización y el cuidado de la díada madre/hijo. La otra evidenció los dilemas prácticos e ideológicos sobre la naturaleza del individuo, la familia y la reproducción biológica y social de los seres humanos, explicitando limitaciones históricas para la socialización de los beneficios en medio de la búsqueda de la perfección física y mental. Se concluyó que el conocimiento sobre la eugenesia era incipiente y que es necesario ampliar los debates sobre la temática en los medios académico, científico, profesional y/o social.

**Palabras clave:** Reproducción. Planificación familiar. Eugenesia. Bioética. Estudiantes de enfermería. Estudiantes de medicina.

Aprovação CEP-UEM CAAE 46239515.6.0000.0104

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Declaram não haver conflito de interesse.

The field of human reproduction has undergone significant advances in recent decades, which have encouraged and stimulated reflection on the subject. It is an area that covers a number of issues, which primarily have in common a concern for our offspring. This article is based on the presupposition that the eugenic ideals were maintained during the twentieth century and bring to the fore old and new dilemmas regarding human reproduction.

The term “eugenics”, from the Greek “*eugenes*”, which means “well-born”, was used in 1883 by the British scientist Francis Galton, who attributed it to the search for the improvement of the human race. Such a practice would guarantee the perpetuation of more talented beings, improving the hereditary characteristics of the population through the transformation of external influences<sup>1</sup>. Some studies<sup>2,3</sup> have highlighted different meanings and contradictions of eugenics since the last century, in relation to measures of positive and negative measures from this century and positive and negative eugenics in the 21<sup>st</sup> century.

As the possibilities of human intervention, change and knowledge in the area of biomedics becomes deeper, diverse situations arise that impel decisions and actions that seem to relativize eugenics. This assertion can be seen both in norms and legislation on the subject as well as in studies on family planning and even in news about interventions in the field of human reproduction. The Nacional de Demografia e Saúde da Criança e da Mulher (the National Demographic Survey of Children and Women’s Health), conducted by the Centro Brasileiro de Análise e Planejamento (the Brazilian Center for Analysis and Planning)<sup>4</sup> identified that socioeconomic context is one of the main factors responsible for a lack of knowledge among women about contraceptive methods, including reversible methods. The study found that the predominant pattern of contraception in Brazil is the contraceptive pill, often acquired without medical advice, followed by tubal ligation, with medical advice.

In December 2016, the UK<sup>5</sup> approved assisted reproductive technology that uses DNA from three people to prevent the transmission of genetic diseases – mainly mitochondrial, from mother to child – which cause brain damage, loss of muscle mass, cardiac arrest and blindness. After more than a year and a half of legal proceedings, the United Kingdom is the first country to legalize assisted reproduction with the genes of three people<sup>5</sup>.

In March 2015, a news report<sup>6</sup> stated that, for some diseases, the advancement of genetics had made gene therapy feasible, in other words, the insertion of a healthy gene into the DNA of a patient with certain mutations, especially diseases linked to the X-chromosome. Some primary immunodeficiencies are examples of suitable prospects for gene therapy, with good results for forms of severe combined immunodeficiency<sup>6</sup>.

In April 2015, it was reported in a national network that a child was generated by assisted human reproduction in order to cure her older sister, who was diagnosed at age five with thalassemia major, a severe genetic disease transmitted from two defective genes of the parents<sup>7</sup>. The sick child needed frequent blood transfusions, with bone marrow transplantation the only potential cure. The parents then decided to conceive a healthy child to be a possible donor, using assisted reproduction, selecting embryos considered normal and compatible for transplantation in the laboratory.

The parents were submitted to genetic tests to avoid serious diseases and, one year after birth, the transplant was performed. The parents considered this day to be emotional and a triumph for the eldest daughter who, two years later, is cured and free of complications. They also argued that this is the most important thing and that the youngest daughter was strong and contributed to the healing of her sister, fulfilling her mission. The doctors involved said that it would be unethical to choose embryos based on physical characteristics such as eye color and physique, but genetic counseling and embryo choice should be allowed to avoid disease. This was the first case of a genetically selected embryo helping to heal a sibling in South America<sup>7</sup>.

In September 2015, the Conselho Federal de Medicina (the Federal Council of Medicine) (CFM), in dealing with ethical norms for the use of assisted reproduction techniques, created restrictions for women over 50 years old, as well as for sperm donation after that age<sup>8</sup>. Undoubtedly, these facts refer to everyday cases involving eugenics practices understood as those aimed at the birth of physically and mentally healthy children<sup>3</sup>. Historically, eugenics concerns and practices have encompassed aspects of heredity and the environment that could interfere with birth conditions. They refer to the set of actions and methods applied to human reproduction, in the midst of opinions and ideologies present in this field that shape values and the vision of the world.

In view of this situation, it is important to consider the general understanding of the interface

between human reproduction, family planning and eugenics, considering the tireless search for human physical and mental perfection. The aim of this article was to analyze the understanding of nursing students of practical situations in the field of human reproduction and family planning in the light of theoretical reference eugenics.

## Method

A qualitative research with a descriptive and exploratory cross-sectional design was carried out in a public hospital in the northwest of Paraná, which was inaugurated in 1988 and certified as a teaching hospital in 2004. The survey took place in the gynecology and obstetrics care unit, which opened in 1993. The unit offers care and professional training in gynecology and obstetrics, human reproduction, urogynecology, infanto-puberal gynecology, lower genital tract pathology, mastology, ultrasonography and high-risk pregnancies. In addition to a multidisciplinary team, the sector receives students from the medical residency course and undergraduate courses in medicine and nursing, among others.

The study was conducted between September and December 2015 with nursing and medical students who met the following criteria: be a student of the respective undergraduate courses, in curricular activity in the unit, agree to participate, and present physical and mental conditions for the same. The exclusion criteria were: not agreeing to participate or not being physically or mentally fit to respond. To ensure the confidentiality of the data the participants were identified with the letter A (academic), the initial letter of the course (N or M) and the serial number of the interview.

After the acceptance of the participants, the interview schedule and location were agreed upon and a free and informed consent form was signed. The interviews were guided by a script composed of open questions that followed the presentation of the five facts cited<sup>4-7</sup>, transformed into clinical cases, previously chosen as sensitizers on the subject. It is considered that the selected cases represent real situations in the area of assisted reproduction and family planning, with different motivations and results. Once the interviews were recorded and transcribed, thematic content analysis<sup>9</sup> was performed, establishing two categories: “*the advancement of science and technology [to] treat this [is] wonderful*” and “*the advance of science and*

*technology [to] create an individual.*” The research was approved by the Institutional Research Ethics Committee and complied with CNS Resolution 466/2012.

## Results and discussion

Seven students from the 4<sup>th</sup> year of nursing, aged between 20 and 23 years, and three students from the 6<sup>th</sup> year of medicine, two male and one female, aged between 22 and 25 years old, took part in the study. The research data, organized into the following categories, reveal the themes that interrelate practices and ideas, as can be seen in the selected discourses.

### *The advancement of science and technology [to] treat this [is] wonderful*

Science and technology occupy an increasingly large space in the field of health, modifying standards and provoking new discussions about the values of professionals of the area. Scientific research and technological innovations lead to deeper reflections on reality and encompass social, religious, political, economic and environmental dimensions that are directly or indirectly related to each other. The data revealed the students’ opinions about these “*technological advances and their great importance for the future*” (AM1), emphasizing the need to explore what is new and to intensify research, so that benefits overcome the ill effects:

*“I think these situations occur very frequently and with the advancement of science and technology, they tend to appear more often, justifying the intensification of research, so that it can offer information based on these cases. (...) so that the benefits of this genetic alteration are greater than the harm”* (AE1).

The most relevant benefit cited was to avoid or treat genetic diseases, improving the expectation and quality of life of individuals. The idea of quality of life<sup>10</sup> appeared frequently in the data, converging with the opinion that, *at present, we can observe the resumption of the eugenic discourse with the addition of new approaches, based on propositions related to discourses about a better quality of life for people with some type of disability*<sup>11</sup>.

In general, the prevailing opinion was that there are no ethical or moral problems in using technology to avoid disease, as opposed to cases

where, for example, genetic characteristics were altered for aesthetic reasons, a view that was corroborated by other studies<sup>3,12</sup>. In other words, genetic interventions for therapeutic purposes, corresponding to negative eugenics, are more morally acceptable than those based on positive or improvement eugenics<sup>12</sup>. Considering reproductive technologies as emerging possibilities, there was criticism of the complete production of a new being in the laboratory:

*"I am in favor of treating a disease that at first would be intractable through gene therapy. I'm not in favor of creating something in the lab, like, 'Oh, I want a baby free from all this and with that gene', I'm against that. But if we have a gestation study, a genetic examination that can identify early if that child will have a mutation that will lead to damage in the future and we can treat it, wow, that would be wonderful, a miracle; in this case, I would be in favor, for sure."* (AM3).

Gene therapy *in vivo* was widely accepted as an important promise of early treatment, emphasizing that such manipulation would not have negative consequences for the baby after birth: *"I think it would be a good option for the future...I don't see ethical problems, because it will not interfere after the person is born, it will interfere before and will result in healthy people, and will avoid genetic diseases"* (AM1). There was serious concern about the control of practices and lack of legal protection – the creation of a monitoring body was suggested *"in order to avoid cases of eugenics"* (AM2) or to limit *"illegal trade in these practices, which may lead to harm"* (AE2).

Even without detailing the types of harm, such uneasiness cannot be treated lightly considering other illicit activities linked to therapeutic possibilities, such as organ trafficking. Research in the field of genetics can invariably be misused, as can any science, such as atomic science<sup>13</sup>. In this effort to treat diseases and comply with laws, a lack of knowledge – about the norms, rights and duties involved, and the effects of the technologies themselves – has motivated the expansion of debates in society:

*"We don't know, in removing or changing that gene, if it will really be possible to suppress the disease. It may be that if you take it out, despite having removed the illness, you may have interfered with another organic function of the patient to which you did not know it was related. Although well*

*developed, we still do not have a good perspective, or adequate knowledge about all the repercussions that genetic modification could cause in the patient"* (AM2);

*"I think these are situations that are at the margins of society, they are not discussed, but they are of great importance for the future. I think they have to be debated"* (AM1).

In terms of the mother-child binomial, the ideal maternal age for reproduction was one of the most frequently mentioned themes. Historically, this aspect has already been understood by nursing as a risk factor related to women. In 1935, ratified by the opinion of medical hygienists, the best age for procreation was considered to be from 18 to 25 years for women and from 20 to 30 years for men, guaranteeing that parents had the satisfactory bodily development to perform their reproductive functions.

Based on statistics with averages that are not always pertinent to particular cases, this limit was accepted by the Civil Code. In 1979, procreation outside the age group between 20 and 30 years was already characterized as a high-risk situation<sup>10</sup>, while these limits are currently increasing, possibly influenced, in the opinion of the interviewees, by techno-scientific advances and improvements in the health system in general. *"I think that the doctor who specializes and defends human reproduction is right, because if the woman is 51, 52 years old and still wants to get pregnant, I believe she is entitled, yes; it can't be restricted. Perhaps an upper limit, a higher limit, such as 55 years, would be more appropriate. For a 53-year-old woman who wants to try assisted reproduction, I would tell her to go to court to obtain the right"* (AM1).

There was, however, great concern about the frustration of women about the chances of failure in assisted reproduction and the high costs of the procedures, with adoption even being suggested as an alternative:

*"Due to a greater chance that assisted reproduction at this age is not as successful, these women end up being exposed to failed attempts, and at this point I agree with restrictions. For a 53-year-old woman who intends to attempt assisted reproduction, I would try to explain to her the reason for the refusal, try to offer as much information as possible regarding the risk of assisted reproduction at this age and, mainly, the question of the percentage of success"* (AE1);



*"I would advise her to think about what is best for her and the child, because if she is 53 years old, I think she has spent a little bit of time, and a lot of money, on reproduction. And there are other methods: adoption, for example"* (AE3).

One participant referred to the ceiling as being 40 years of age (AE7). Another believed a limit was not required (AE4). Still another emphasized the use of alternative techniques due to physiological and reproductive difficulties, regardless of the woman's age, such as egg donation, *in vitro* fertilization and hormone replacement (AM2). Special conditions were cited, such as the possibility of eclampsia or preeclampsia (AE6) or the fact that menopause comes earlier than before, which could lead to risks at more advanced ages (AE7).

There were few references to babies, with the possibility of more than one fetus resulting from *in vitro* fertilization (AM7) being highlighted, as well as the occurrence of side effects resulting from genetic alterations, taking care to avoid latrogenesis (AM2). In this sense, the data showed the importance of technology, as long as individuals/families are also monitored to manage the impact of this on their life. With due caveats, it can be inferred that care is not concentrated on the result of the application of the reproductive technologies themselves, but on the whole process triggered by their use.

It may be considered that the focus was on the cure of genetic diseases - not necessarily to produce a certain profile of individual, but to improve their quality of life. The high cost of the treatments, the conditions of access and the use of judicialization were also highlighted by the participants. One participant highlighted the possible reduction in the demand for care in health services, indirectly referring to the concept of health care networks: *"I think it would be good because it would also reduce the number of people in basic care, reduce the number of people going to hospitals, and the number of healthy children without diseases would be greater"* (AE6). Producing different views and perceptions, from the individual to the collective level, the cases presented mobilized the interviewees most in terms of the benefits and the need for research and advances in ethical and legal regulations.

### ***The advance of science and technology [to] create an individual***

Even if the cases presented are real and feasible, and can be reproduced daily in different

contexts, they are not limited to the practical world of techniques and laws. Rather, they reinforce and/or are motivated by historically constructed ideals amid the techno-scientific development of this field of knowledge. If, on the one hand, it would be relevant to avoid or treat genetic diseases with a view to quality of life, on the other hand, human nature itself is being questioned. Not so much in relation to the ideal profile of being a physically and mentally perfect human, through the actions of negative or positive eugenics<sup>3</sup>, but as regards the very constitutive nature of the human being, its form and origin:

*"[About] the procedure for selecting healthy embryos, while it is very good to be able to choose to remove diseases and everything else, and it will be great for the life expectancy of the person, it goes against nature as it is no longer natural to have or expect a child, but to create one. It's very strange, it's against nature."* (AE2);

*"From three people? If it were two people I would be in favor, because if I had the financial conditions and opportunities I would want to make sure my son was born healthy; but three people I think not, I am against it. Because when there are three, I cannot explain it, but we cannot change nature so much; I think everything has a course, if it's to be two, I do not want it to be three...man is not God, we cannot change things that much. Of course, it's wonderful to make sure your child is born without a disease, but I think it violates people's rights, it violates a very important right, I do not know which one, but I think it violates it, and I do not want mine violated"* (AE3).

The idea of "creating an individual" in a non-traditional form involving three people generated conflicts among the participants, even though they considered the birth of a healthy baby to be wonderful. Without knowing exactly how or what right was being violated, this technological innovation gave rise to the feeling that something conflicts with the notion of what is correct.

The repeated expression "playing God" was an explicit critique of the new reproductive paths and the need for advances in knowledge and regulation in the name of safety: *"Because playing God here is not the proper situation, a little more knowledge is needed, control of how this procedure will be performed, this embryo selection, before it becomes a conventional practice, a routine practice"* (AM2).

While the medical students prioritized the physiological, clinical, or genetic aspects involved in

the interventions before they became routine, the nursing students, even though they did not know for sure “what” or “how”, had contrasting opinions: *“I am against it, because I think that in the matter of avoiding diseases it is positive, even if there is a lot of research that disagrees with it; but the fact that it involves three people, this ends up altering the genetics of the individual a lot and does not respect the lineage, or heredity”* (AE1). The nature of the human being and the capacity of creating himself are themes that have been approached in literature, mainly in the field of bioethics<sup>12,15</sup>. Habits and customs were also problematized, such as the relation between parents and children and the concept of family. Generating a child from the three-person combination revealed some concerns:

*“It’s very controversial, because this third person is going to be ... the child being born will have her DNA too. She will be responsible for the child as well. I do not know ... it’s very strange. I am against it, because it is very controversial ... because if two people do it, the way they have always done it and the baby is born, and can be born with disease, it is a risk, but one that everyone faces”* (AE4);

*“I am personally against it because I think there would always be the doubt in the person’s head, looking at the child, ‘what does she have of me, what does she have of the other person?’”* (AE5).

Focusing on heredity as a guideline for family composition, these views differed from the earlier suggestion of adoption as an alternative to naturally born children in case of reproductive difficulties. Characteristics such as heredity and/or the affective bond come close to what some authors have discussed as dilemmas involving the biologization and geneticization of kinship in new reproductive technologies, considering the human nature created in the laboratory<sup>16</sup>. That is, to introduce and explain the mutability of concepts increases the impact of new technologies, which contribute to new meanings of concepts such as family, maternity, paternity, ties of kinship and other aspects related to the biological and social constitution of women and men.

In another sense, but in the same debate as what is “natural” or genetically modified, the association pointed out by a participant between the occurrence of chronic diseases and what authors have denominated as “contemporary genomania” or “neurogenetic determinism” stands out<sup>17</sup>. *“The only culpability for certain diseases is in the gene,*

*and yet many chronic diseases are mainly the result of environmental factors which are genetically reflected.”* (AE7). Concern has been expressed that in the near future there will be no need to change living habits for the prevention or treatment of diseases – it will be enough to modify the genes “responsible” for them.

Researchers highlight the concept of genetic-environmental interaction in the genesis of anomalies, that is, the existence of a predisposing genetic factor associated with a triggering environmental factor<sup>18,19</sup>. Excluding exaggerations, the data analyzed also referred to this fact, reiterating the idea that the responsibility for health or disease cannot be attributed exclusively to the use of already available biotechnologies, but in its interaction with the attitudes and habits of the individuals themselves.

In terms of differences, the case of the child created to save her sister caused controversy. Some considered it unethical to create another child *“only to avoid or treat complications of other individuals, as if she were a medicine”* (AE1) or *“for the purpose of helping others and not for the desire to have a child”* (AE2). Others agreed that *“if it is to save a life, if it has a higher purpose, there would be no problem”* (AM1), with the proviso that the rights of the child could at no time be infringed and that in the future there could be several implications for those involved.

On the other hand, and following the same line of reasoning about family composition, in the case of multiparity in the context of socioeconomic difficulties, the tone of the speeches prioritized the creation and education of children to the detriment of the reproductive rights of women. The importance of the support and education of children in the present and future was emphasized, being described as the “quality of the creation of children”, it being the responsibility of the professionals to provide sustained orientation from the predominant perspective of the restriction of natality in the discussion of possibilities:

*“I think that because of the socioeconomic conditions, it would be bad for her to have more children, so from this point, contraceptive methods should be proposed and she should adhere to these methods so as not to have another pregnancy”* (AE6);

*“I think I would try to talk to her and reflect on her situation, whether she if she had children later she*

would be able to care for them. Because she already has four and her income is too low to take care of this many children. Then I would ask her to reflect on what the education, the sustenance of these children would be like" (AE5).

In addition to socioeconomic difficulties, a lack of education was pointed out as the main cause of multiparity. Suggested behavior was that "we will provide guidance first, and then know what other action to take" (AE7). In fact, a recent study<sup>20</sup> showed that, among several factors, multiparity could be related to interruptions of schooling, since, of 464 participants, 1.3% were functionally illiterate, 47.9% had up to an elementary education and only 2.4% entered higher education. However, other authors<sup>21</sup> elaborate concepts about reproductive rights, inferring how important it is to recognize reproductive choice as a universal human right, and that laws that limit access to reproductive health services by individuals oppose and violate the human rights imposed by international conventions.

Sexual and reproductive rights indicate two different and complementary features<sup>22</sup>. On the one hand, the field of individual freedom and self-determination, with free exercise of sexuality and human reproduction, without discrimination, coercion or violence, guarantees the fundamental right of the power of decision in the control of fecundity. These are rights of self-determination, privacy, intimacy, freedom and individual autonomy in which non-interference by the state, non-discrimination, non-coercion and non-violence are demanded. On the other hand, there is a need for public policies that ensure sexual and reproductive health, in which the right to information, safe, available and accessible means and resources, as well as access to scientific progress and sex education, are essential. Revealing the tendency of the interviewees with regard to the first factor, the following statements presented two distinct positions:

*"In case 3, what I would recommend for this patient, given her obstetric history - that she has already had three previous cesareans, has four children, and is married - and if she has a stable relationship, I would suggest a tubal ligation, given these factors" (AM2);*

*"It's more complicated here. Well, she's less than 30 years old ... I think I'd try as hard as I could to guide her. Since she has no knowledge of contraceptive methods, I'd have to spend a lot of time with this person, to accompany her closely. I do not know in*

*what environment this could happen, if it was in the emergency room there is no follow-up care, if it is in the BHU [basic health unit] we can stay close to the patient. If I were a BHU doctor, I would try to stay close to this woman to explain the question of contraceptive methods. I would not perform a tubal ligation on a woman like that, there's no reason for birth control to involve a ligation. I would really advise trying this closer monitoring, to see if what she really wants is being done. It's basically that" (AM3).*

Overall, multiparity was still permeated by the concept of family planning as the exclusive alternative to limiting children: "I think it is important, the outlook is very good for the future because family control, family planning is important, even more so today when no one wants to have many children" (AM1). Advantages of family planning were considered: the spacing and limitation of pregnancies according to the desire of the individuals; retardation of pregnancy in young women; the reduction of gestational risks and maternal and infant mortality, among others. However, it was considered that, although the policy is ideally advocated and guided by the Ministry of Health, it still does not correspond to the reality experienced by the family health teams in Brazil<sup>23</sup>.

It was also found that the interaction between human reproduction, family planning and eugenics was strongly influenced by economic aspects. In the previous discussion, due to the lack of economic conditions, family planning had a restrictive character, ratifying the long-standing posture of health professionals. However, the limited access to new technologies due to high costs was verified, despite the defense that only universality can make these into something positive: "these things are very expensive, and not everyone has access to them" (AE4).

Recently, in a study presented at a scientific conference, Quister stated that *science today seeks the perfection of being, but, of course, the economic aspects that inevitably exist in any sphere of the human condition promote or restrain this will to improve*<sup>24</sup>. In this case, the concern and desire of the interviewees to share the benefits of science appear legitimate. As the same author said: *As is the case today, not everyone will have access to the benefits of modernity. We believe, as reality shows us, that the economic process is part of any modernization, and, as such, will be an exclusionary element for a large part of the population to the "products" of this new market, which is already a reality*<sup>25</sup>.

This context, so clearly described and shared by the participants of our research, explains, for example, the frequency of terms such as “injustice” in relation to those who do not have the same possibilities, and “indignation”, because those who have access to assisted reproduction would be more likely to have a “normal” or “perfect” child through genetic manipulation:

*“Because we always want the best, (...) only it would be good if everyone had access, because this type of treatment is not something that every class that will be able to have. If we are to have this, I want everyone to have it, because I do not want my son to be born with [a disease] while someone who is better off is able to remove it” (AE3);*

*“And will people who have normal children, without assisted reproduction, have a defective child? Why does the person who has a child with assisted reproduction have a greater right to have a normal child? It’s ridiculous, it’s crazy, at the very least it’s crazy.” (AE7).*

When faced with this indignation, the concept of eugenics is reaffirmed as a concern for the health and constitution of future generations, and the fact that all use of scientific means and knowledge so that a child is born physically and mentally healthy, or perfect, is eugenic action<sup>3,14</sup>. Thus, the data reveal eugenic desires and concerns that appeared in the discourses, although they were often not understood as such in the midst of the debate on several issues that seem distinct, but in fact comprise the same phenomenon of the reproduction of human life.

Two main postures were observed: one of great opposition to genetic manipulation for phenotypic changes, in the sense of achieving certain characteristics or, in an extreme manner, creating a new individual; and another of the defense of manipulation to remove genetic diseases. These resemble the arguments of supporters of liberal or social eugenics, who seek to anticipate and prevent disease and eliminate congenital defects, and thereby perfect the human species<sup>26</sup>.

It is not a case of arguing for or against eugenics. However, attention must be paid to the discourses that reiterate that the breakdown of the *undesirable genetic legacy is a condition that is realistically possible (...)* [especially for the purpose of] *the ascension* [of the human being and his] *mastery of nature ...* [and that] *we are capable of the greatest technological prowess at the same time as we keep the spirit small in relation*

*to the human being. Our ambition for money and power can delay the process that allows people the freedom to choose, where possible, to improve themselves or their children through the advances of biogenetics*<sup>27</sup>.

Contexts in which this alleged freedom of choice for betterment ratified the understanding that the differences between men, women, children and the elderly made some better or more deserving have in the past generated many atrocities and misunderstandings. In capitalist societies, especially in conditions of extreme social inequalities, this perception inevitably passes through economic factors, whether in established relations of power or through access to technologies. One discourse, in particular, alerted to the fact that:

*“All this manipulation of the body and the issue of disease, when you want to remove the genes that are of no value to us, is a form of manipulation. This is kind of pathological, I think we have to take the genes of perfection from the head of the human being (...). We have noticed that technology manipulates people a lot, you have to be very careful that it does not change, so that you think you are manipulating, but in fact you’re often being manipulated by a false idea of perfection” (AE7).*

The advancement of genetic technologies is seen as a promise of a cure of disease (genetic engineering used for therapeutic purposes), but the clear possibilities for racial and genetic discrimination are worrying (genetic engineering used for eugenic selection)<sup>28</sup>. The greatest fear of the participants was based on the very possibility of intervention and genetic manipulation present in the cases, more on “how” than “what” is done with the technologies, despite ignorance about eugenics and the previous history of the practice.

Caution is therefore necessary, as, now the initial fears have been overcome and precisely because of a lack of knowledge of a history filled with so many advances, yet permeated by misunderstandings and contradictions, the way is open to countless actions and interpretations. Actions focused primarily on benefits, whose positive or negative results, individual or collective, will only become explicit after many decades or centuries. And because it is the current state of the art in the field of reproductive science, this observation is not limited to the interviewees, but considers the aspects analyzed so far on the subject in contemporary times.



Therefore, in the face of genetic engineering, the possibility of creating human beings generates uncertainty, fear, opposition, injustice, cost, access, genomania, and other factors. When discussing family planning, attention is focused on the need to educate, limit and guide quality of life, especially that of children, repeating the position taken by health professionals and the like for decades<sup>14</sup>. Aspects of the same phenomenon that, in essence, carry and nourish eugenic ideas and practices.

Today's nursing students expressed doubts and opposition when faced with what science has produced for nearly a century. In 1934, an article published in the *Revista Brasileira de Enfermagem* (the Brazilian Journal of Nursing) recognized the need to establish the then new scientific approach of the time, eugenics, in the certainty that there is evidently no solution to social ills outside the laws of biology<sup>28</sup>. It was in the 1920s and 1930s that genetic science took its first steps and, faced with the explicit defense of eugenics, nursing endorsed this ideology.

Since the turn of the century, when technoreproductive science presented its potential, in the not explicit, but inevitably present, context of defending eugenics, the posture of nursing was to assimilate doubts about the procedure. Yet the fact is that advances in technoscience, even with theoretical and legal uncertainties, allow us to create individuals. What society will do with this technology is certainly part of the debate, intensified by the very gaze of science, producing knowledge about the dialectical movement of this historical construction.

## Final considerations

Within the limits of the investigation, it was concluded that contemporary biotechnologies allow different interventions and approaches on the issue of having children, presenting alternative approaches to the traditional way to the act of generating life. This ranges from the manner in which fertilization occurs to the quantity and profile of the individuals involved, as well as the result of the reproductive efforts, such as the type(s) of child (ren) generated and the purpose of this generation. Dilemmas are exchanged between the practical and ideological field, concerning the very nature of the individual, the family and the biological and social reproduction of human life.

Reflecting on the cases presented generated doubts, uncertainties and anxieties among students, specifically regarding the profile of the individuals involved, whether male or female, and the result of assisted reproduction, explaining contexts that arise from social inequalities and contradictions. If society improves the cure and prevention of genetic diseases, it also carries with it historical and ideological limits to making these benefits socially available. Current knowledge of eugenics was found to be negligible, corroborating data cited in another study<sup>14</sup> as this theme does not circulate explicitly in the present day and is sparsely promoted in academic, scientific, professional and/or social environments. It is suggested that the debate is widened to include it more forcefully in the formative processes in health.

*Supported by the Institutional Scholarships in Scientific Initiation Program of the Fundação Araucária, Paraná.*

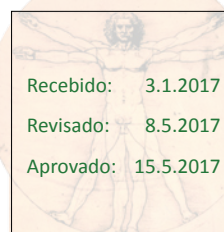
## Referências

1. Conti PHB. Melhoramento genético: uma aproximação desde a perspectiva bioética e jurídica. *Rev Sorbi*. 2015;3(1):30-46.
2. Mai LD. Boletim de eugenia (1929-1931): um estudo sobre forças educativas no Brasil [dissertação]. Maringá: Universidade Estadual de Maringá; 1999.
3. Mai LD, Angerami ELS. Eugenia negativa e positiva: significados e contradições. *Rev Latino-Am Enferm*. 2006;14(2):251-8.
4. Brasil. Ministério da Saúde. Pesquisa nacional de demografia e saúde da criança e da mulher: PNDS 2006: dimensões do processo reprodutivo e da saúde da criança. [Internet]. Brasília: Ministério da Saúde; 2009 [acesso 10 mar 2015]. Disponível: <http://bit.ly/2quLKEz>
5. Fernandes E. Parlamento Britânico aprova reprodução assistida com DNA de três pessoas. [Internet]. 16 dez 2016 [acesso 3 jan 2017]. Disponível: <https://glo.bo/2pVv59P>
6. Pimentel I. Doenças raras ainda representam desafio para saúde pública. *Portal Brasil*. [Internet]. 2 mar 2015 [acesso 17 mar 2015]. Disponível: <http://bit.ly/2pMWlpr>
7. Rede Globo. Menina nasce para tentar curar irmã de doença grave. [Internet]. 5 abr 2015 [acesso 23 maio 2015]. Disponível: <https://glo.bo/1yiC4MQ>
8. Brasil. Conselho Federal de Medicina. Resolução nº 2.121, de 24 de setembro de 2015. Adota as normas éticas para a utilização das técnicas de reprodução assistida – sempre em defesa do

- aperfeiçoamento das práticas e da observância aos princípios éticos e bioéticos que ajudarão a trazer maior segurança e eficácia a tratamentos e procedimentos médicos – tornando-se o dispositivo deontológico a ser seguido pelos médicos brasileiros. *Diário Oficial da União*. Brasília; 24 set 2015 [acesso 30 set 2016]. Seção 1. p. 117. Disponível: <http://bit.ly/1NW9tTQ>
9. Bardin L. *Análise de conteúdo*. Lisboa: Edições 70; 2011.
  10. Rosa MSO, Richter AMH, Bercini RR. Como proteger a criança de 0 a 24 meses contra a infecção. *Rev Bras Enferm*. 1979;32(3):271-95.
  11. Silva MDP. *Marcas eugênicas na educação de surdos no século XIX [dissertação]*. Campinas: Universidade Estadual de Campinas; 2015. p. 14.
  12. Cacique DB. Delineando fronteiras: reflexão sobre os limites éticos para a aplicação de tecnologias genéticas. *Rev. bioét. (Impr.)*. 2012;20(1):60-70.
  13. Quister ES. *A biotecnologia, o direito e suas manifestações no cinema: considerações a partir dos textos: eugenia negativa e positiva: significados e contradições; O admirável Projeto Genoma Humano e filmografias do gênero*. Anais do XVII Congresso de Ciências da Comunicação na Região Sul. Curitiba: Intercom Sul; 2016.
  14. Mai LD. *Análise da produção do conhecimento em eugenia na Revista Brasileira de Enfermagem (REBEn), 1932 a 2002 [tese]*. Ribeirão Preto: Universidade de São Paulo; 2004.
  15. Meurer QN. *A eugenia: um estudo a partir do contraponto entre a teoria bioconservadora de Jürgen Habermas e a teoria liberal de Ronald Dworkin [dissertação]*. Caxias do Sul: Universidade de Caxias do Sul; 2015.
  16. Luna N. *Natureza humana criada em laboratório: biologização e genetização do parentesco nas novas tecnologias reprodutivas*. *Hist Ciênc Saúde-Manguinhos*. 2005;12(2):395-417.
  17. Rose SA. *A perturbadora ascensão do determinismo neurogenético*. *Ciênc Hoje*. 1997;21(126):18-27.
  18. Abrahão AR. *A integração da genética na prática clínica do enfermeiro*. *Acta Paul Enferm*. 2000;13(N. Esp. pt. 1):203-6.
  19. Abrahão AR, Gomes AA, Santos M. *Gestantes de risco para anomalias fetais atendidas no CAENF, Setor de Medicina Fetal (Unifesp) em 1998*. *Acta Paul Enferm*. 2000;13(N. Esp. pt. 2):205-8.
  20. Moura LNB, Gomes KRO, Sousa CRO, Maranhão TA. *Multiparidade entre adolescentes e jovens e fatores de risco em Teresina/Piauí*. *Adolesc Saúde*. 2014;11(3):51-62.
  21. Mattar LD. *Reconhecimento jurídico dos direitos sexuais: uma análise comparativa com os direitos reprodutivos*. *Sur Rev Int Direitos Human*. 2008;5(8):60-83.
  22. Corrêa S, Ávila MB. *Direitos sexuais e reprodutivos: pauta global e percursos brasileiros*. In: Berquó E, organizadora. *Sexo e vida: panorama da saúde reprodutiva no Brasil*. Campinas: Unicamp; 2003. p. 17-78.
  23. Moura LNB, Gomes KRO. *Planejamento familiar: uso dos serviços de saúde por jovens com experiência de gravidez*. *Ciênc Saúde Coletiva*. 2014;19(3):853-63.
  24. Quister ES. *Op. cit.* p. 3.
  25. Quister ES. *Op. cit.* p. 10.
  26. Estanqueiro ASM. *As novas possibilidades de transformação dos homens por via tecnológica: reflexões éticas, sociais e políticas em Habermas, Jonas e Hotttois [tese]*. Évora: Universidade de Évora; 2013.
  27. Quister ES. *Op. cit.* p. 6, 8, 10.
  28. Lopes LR. *A Eugenia*. *Annaes Enferm*. 1934;2(3):25.

#### Participation of the authors

Both the authors participated in the elaboration of the article and the carrying out of the research.



## Annex

### General data collection instrument

#### Identification of participants

##### 1) Identification of professionals:

Date: \_\_\_/\_\_\_/\_\_\_ Nº of interview: \_\_\_\_\_

Name (initials): \_\_\_\_\_ Age: \_\_\_\_\_ Gender: ( ) M ( ) F

Profession: \_\_\_\_\_ Time spent working in sector: \_\_\_\_\_

##### 2) Identification of students:

Date: \_\_\_/\_\_\_/\_\_\_ Nº of interview: \_\_\_\_\_

Name (initials): \_\_\_\_\_ Age: \_\_\_\_\_ Gender: ( ) M ( ) F Course: \_\_\_\_\_

Course year: \_\_\_\_\_

#### OPEN QUESTIONS

\* Initially, the following cases will be presented for reading, in print and separately, with questions to be answered.

**Case 1:** A news report dated April 9, 2015 says that the Conselho Federal de Medicina ((the Federal Council of Medicine) CFM) has restricted the assisted reproduction of women over 50 and sperm donation after that age. There was previously no age limit. However, a specialist in human reproduction advocates the flexibility of age limits for human reproduction (source: G1 - "FCM restricts assisted reproduction for women over 50." Available at <https://glo.bo/2q3cjg4>)

Questions: What would you say about this? How would you deal with a 53-year-old woman who intended to try assisted reproduction?

**Case 2:** On February 3, 2015, the British House of Commons published a new technique of assisted human reproduction. Developed by researchers in Newcastle, it uses the DNA of three people in assisted reproduction in order to avoid the transmission of genetic diseases, especially for cases of mitochondrial diseases which pass from mother to child and can cause brain damage, loss of muscle mass, cardiac arrest and blindness. The idea was analyzed by MPs, 382 of whom voted in favor and 128 of whom voted against. If legislation, which will now pass to the House of Lords, is approved, the United Kingdom will be the first country to legalize assisted reproduction with genes from three people (source: Época Negócios, Inspiration to Innovate – "British Parliament approves assisted reproduction with three people". Available at <https://glo.bo/2pVv59P>).

Questions: Are you in favor of or against this situation? Why?

**Case 3:** According to studies on family planning, socioeconomic context is one of the main factors that contribute to a lack of knowledge about contraceptive methods, including reversible methods. Such studies have found that the predominant pattern of contraception in Brazil is the contraceptive pill, often acquired without medical advice, followed by tubal ligation, performed with medical advice (source: case prepared by the authors of the research project).

Question: What would your approach be for a woman under the age of 30, married, with a monthly income less than one minimum wage, who does not know if she wants to have more children in the future and does not have any knowledge about contraceptive methods?

**Case 4:** A news report published on March 2, 2015 dealt with gene therapy and was entitled "Rare diseases still pose a challenge to public health." It says that for some diseases, the advancement of genetics has already allowed gene therapy, in which the "healthy" gene is inserted into the DNA of a patient with certain mutations, especially when dealing with diseases linked to the X chromosome. One pediatrician stated that some primary immunodeficiencies represent good prospects for gene therapy, with successful results for some forms of severe combined immunodeficiency (source: Portal Brasil – "Rare diseases represent a challenge for public health". Available at <http://bit.ly/2pMWlpr>).

Questions: What do you think of the possibility of guaranteeing the birth of healthy individuals, free of disease linked to the transmission of characters through genetic research and gene therapy?

**Case 5:** A report broadcast on a national network on April 6, 2015 told the story of a child generated from assisted human reproduction to cure her older sister, who was diagnosed at age 5 with thalassemia major, a severe genetic disease transmitted from two “defective” genes from parents. The sick child needed frequent transfusions for a long time, and, according to doctors, could only be saved by a bone marrow transplant. The parents decided to have another healthy child so that she could be the potential marrow donor. For this, they used an assisted reproduction clinic, where embryos considered normal were selected in the laboratory and generated through *in vitro* fertilization, so that the conceived child was compatible with the older sister for bone marrow transplantation. The parents were subjected to genetic testing in order to avoid serious diseases. One year after the birth of the child, bone marrow transplantation was performed. The parents said that the day of the transplant was very emotional, and it was an achievement for the eldest daughter. Two years after the transplantation, the girl who had been suffering from thalassemia major is well and there is no evidence of complications, meaning she is cured, and her parents say nothing is more important. They also reported that the youngest daughter was strong and helped to heal the older sister, thus completing her mission. Doctors involved in the case reported that while it would be unethical to choose embryos based on physical characteristics such as eye color and physique, genetic counseling and the choice of embryos are allowed “in order to avoid disease”. This was the first case of a genetically selected embryo being used to help heal a sibling in South America (source: *Fantástico* – “Girl born to try and cure her sister of serious disease”. Available at <https://glo.bo/1yiC4MQ>).

Questions: Do you agree with the doctor interviewed? Have you ever heard of genetic counseling? What do you think of this procedure when dealing with the selection of healthy embryos?

\* After reading each case and answering the specific questions, the following general questions will be asked:

1. What do you think of these situations today?
2. What is the responsibility of health professionals when dealing with these cases? Comment
3. Have you ever heard of eugenics? Can you say what it is?
4. Do you think there is a relationship between eugenics and the cases cited? Comment
5. Did your undergraduate course offer knowledge of and stimulate the debate about the interrelationship between human reproduction, family planning and eugenics? Comment.