Blind Woman Pregnant and Ethical Conflicts: A Case Study

Lorita Marlena Freitag Pagliuca, PhD
Lecturer
Post graduate nursing program at the UFC, Researcher 1A level of CNPQ
Brazil

Rosilene Santos Baptista
PhD in Nursing
Lecturer at the State University of Paraíba UEPB
Brazil

Inácia Sátiro Xavier de França
PhD in Nursing
Lecturer at the post graduate program in public health. Researcher of CNPQ
Brazil

Rui Verlaine Oliveira Moreira
Philosopher, Doctor of Theology from the University Lateranenese
Lecturer at the post graduate program at the UFC
Brazil

Abstract

This paper consists of a case study on blind woman with the possibility of genetic transmission. The paper aims to understand the motivation for procreation, existential dilemmas experienced by blind mother and moral judgments that determined her choice. The social group expressed moral judgments sustained rational beliefs and values of the collective unconscious about the disability. The health professionals used empirical principles of bioethics regarding life and dignity. However, some of them left a gap in terms of special care for a blind woman. Concluded that there was a conflict that has raised moral decision-making mother heteronymous, based on moral judgments legislated by the natural inclinations for procreation.

Key-words: Ethics, Nursing; Personal Autonomy; Blindness; Pregnancy

1. *Introduction*

Knowledge acquired in the field of genetics is used in genetic therapy, to predict metabolic diseases, reach preventive diagnoses in people at risk of transmission or illness, degenerative diseases and prenatal diagnosis in fetal cells(1). Human genome mapping entails the idea of predicting and preventing human health problems, as well as moral, theological and philosophical concerns, given the possibility of illegal use of this knowledge to promote eugenics(2). Geneticists affirm that genetic diseases are incurable, but some are treatable. In most cases, some genes increase the risk factors for other diseases. In Brazil, among adults with chronic diseases, 10% have some genetic problem and 33% of pediatric hospitalizations are associated with genetic problems. In 1966, 564 genetic diseases were known, which increased to 3,307 diseases in 1992. And, as a result of the information produced by the Human Genome Project, the number of diseases characterized with a genetic component tends to increase(3).

In 1998, the World Health Organization-WHO recommended that scientists should adopt the International Guidelines on Ethical Issues in Medical Genetics and Genetics Services, attempting to standardize minimal ethical adequacy criteria for the use of diagnosis and treatment methods.

In the same year, an Ibero-American Network on Bioethics, Law and Genetics was founded, aimed at maintaining contact and information exchange among regional specialists and stimulate studies, research projects and information dissemination about social, ethical and legal aspects related to human genetics(3,4). These guidelines are related to ethical issues inherent in individuals though, without an ethical position prohibiting procreation in case of hereditary genetic risk.

Beyond genetic issues, the author of a South Korean study reports the experience of physically disabled women, describing experiences and needs related to pregnancy, delivery and postpartum, demonstrating that, despite these women's autonomous decision in favor of motherhood, social expectation regarding the maternal role they would play were low(5). Another author of a research involving 13 women, mostly wheelchair users, discusses reactions and attitudes against these women's pregnancy and report that, despite attitudinal barriers, they faced the skepticism and chose motherhood, in response to the historical conviction that women are predestined to be mothers(6). In New Zealand, a study demonstrates that the ethical conflict pregnant women experienced related to the delivery type was solved through an informed consent term, mediated by the midwife with whom the woman established a relation based on friendship, respect, confidence, which contributed to her autonomy to choose normal birth, to the detriment of fetal risk(7).

Any ethical conflict demands decision making linked with the self-determination of the conflict subject. Autonomy, in turn, depends on the rational use of conscience and manifests itself in the form of positive freedom, as a supreme principle of morality, given that moral law does not depend on the contents of the objects of this will. In other words: autonomous action is incompatible with action out of interest, characteristic of human beings. Autonomy as an expression of positive freedom means an obligation to do assigned by moral law(7,8). When action contains autonomy of will, independently of the natural law that guides phenomena and the contents of moral law, this is called freedom in the negative sense or heteronomy. Hence, autonomous action in its positive form is ruled by universal moral principles, called "categorical imperative", whose function is to adapt the will to the form of the law. The essence of the categorical imperative or moral law is as follows: *Act only according to that maxim whereby you can at the same time will that it should become a universal law*(8).

2. The Problem

Blindness can be congenital or acquired. Acquired blindness derives from infectious diseases like measles, scarlet fever, and meningitis; from infectious diseases like trachoma, hypovitamin A retinopathy of prematurity, glaucoma, eye trauma, and from metabolic diseases like diabetes, arterial hypertension and lupus. Congenital blindness can derive from diseases during pregnancy such as rubella, toxoplasmosis, histoplasmosis, cytomegalovirus, gonorrhea, syphilis, chlamydia and maternal malnutrition; and genetic-hereditary causes such as cataract, albinism, and optic nerve atrophy.

Blind people become adults, want and have children. If the cause of blindness is acquired, the children are not affected but, in case of genetic blindness, there is the probability of transmitting the responsible gen and the possibility of repeated blindness. In this case, genetic counseling is recommended. From a biological viewpoint, the research problem seems simple as, once the genetic imperfection has been identified, it is enough not to have children. As mentioned though, blind people want and have children, even in cases of genetic blindness. The problem moves beyond the purely biological sphere and into the field of humanity and ethical implications. This study looks at ethical reflections about the right to conceive, even for patients with a genetic imperfection.

The motivation for this research derives from the researchers' seventeen years of experience with blind people, during which they had the rare opportunity of contact with blind men and women who had children, mostly resulting from unions between blind people, some of whom have genetic imperfections. Among these, one couple stood out, due to genetic blindness and the choice of pregnancy; today, their son is approximately 13 years old and has evolved towards total sight loss. In view of the above, the goal in this research was to understand the motivation to have children, existential dilemmas the blind mother experiences and the moral judgment that determined the choice to have children.

3. Method

Qualitative and integrative case study, carried out in Fortaleza, Brazil from 08/04/2008 to 09/05/2008. The subject, intentionally selected, was a blind woman who has a child from her marriage with the blind father.

The child, 13 years old at the time of study, also evolved to blindness, given the genetic transmission. The couple has a higher education level and was aware of the probability that their child would inherit their genetic burden. Only the woman served as the subject because the couple was divorced and a joint research was not possible. The blind mother agreed to take part in the study and, on her suggestion, data were collected by e-mail, as she uses the computer with the help of software that reads the content displayed on screen in a digital voice, while the keyboard is a common device for blind and seeing people.

The semi structured interview script contained guiding questions about: being genetically blind; the decision to conceive; the social reaction to conception by disabled people. Questions were sent by e-mail and, for each question, the respondent received one week to elaborate her response. When necessary, after receiving a response, the researchers went deeper into the same theme, only moving on to the next theme when the previous one was saturated.

In data analysis, the discourse analysis technique(9), aimed at understanding how a symbolic object generates meanings and how the object is loaded with meaning for the subjects. After reading and rereading the answers, discourse was standardized, in line with the answers' meanings, and distributed in thematic groups: Do I want to be a mother with genetic blindness? Can I be a mother with genetic blindness? Should I be a mother with genetic blindness? The identification of moral judgments permeated the experience of being a mother with possible genetic transmission of blindness. These groups were interpreted in the light of bioethics and Kantian ethics.
The study was submitted to the Research Ethics Committee at *Universidade Federal do Ceará*. Ethical principles, freedom to participate and withdraw from the study, beneficence, non-maleficence, secrecy about the subject's identity and use of study data for research purposes only. The purpose and method were explained during a previously arranged meeting with the study subject and, after solving doubts, the Free and Informed Consent Term was signed.

4. *Results and Discussion*

A human being's biography is molded by social events. And the conflicts permeating one's personal history derive from the structure of the society the person lives in; from the expectations, beliefs and values adopted as conditions or means to reach a certain rationally assessed and intended goal. Hence, solving personal conflicts requires knowledge about the intelligible structure that grants meaning to a given conduct.

It is important to highlight that knowing and acting are inseparable. And that any decision-making should be guided by reason. In Kantian terms: before its execution, human action is subordinated to a scale of values, ruled by practical reason or free will and independent from conditions of the sensory world, in which humans have the freedom to execute a given action or not. Hence, the supreme principle of mortality is autonomy of will, guaranteed by the categorical imperative that means an obligation to do assigned by moral law(7,8).

The premise that behaviors are manifestations of moral judgments remits to the idea that solving a human conflict demands dialectic reflection, adopting beliefs, values, philosophy, culture and historical reality, aiming to establish the value judgment that should guide moral action, capable of maintaining social cohesion. This reflexive action does not dismiss an answer to the following questions: Do I want to? Can I? Should I? These inquiries made room to think about the existential conflict this study subject experiences and to understand the unfolding of the moral judgments that influenced decision making with a view to its solution. Therefore, some of the mother's statements will be used to outline the three thematic groups presented next.

4.1 Do I want to be a mother with genetic blindness?

The interviewed subject reveals her concern with the desire to get pregnant without clarity about the diagnosis of her blindness: *We have something affecting our retina, which the doctors cannot define... Some doctors classify it as a hereditary disease and others as a genetic disease.*

The lack of a defined diagnosis made the subject feel insecure and demonstrated the limitations of medicine — if, on the one hand, medical science advances and helps to solve certain problems, on the other, it opens up a range of uncertainties, generating different bottlenecks(10), a fact that made it difficult in this study to make a decision about whether to have a child or not. Risk is always a probability though.

Blindness is a concrete reality in the interviewed subject's life, as well as the possibility of its transmission to the children, as "hereditary disease" and "genetic disease" signal this risk early. It should be asked: what singular knowledge object motivates a person with genetic blindness to want to conceive a child?

The possible explanation is that people define their *I* according to their representations of themselves, in line with images, ideas, concepts they have about themselves. These representations are constructed as a set of values loaded with affection, which can be positive or negative(11). The study subject affirms academic education, with a specialization degree in Visual Impairment and Mental Impairment. She works as a teacher for people with visual and other associated impairments. Her socioeconomic condition is stable. These positive attributes grant her the notion of being able to, of being and acting well in case she conceives a child vulnerable to blindness. Her representation of herself is inscribed in her statement: ─ *I love what I do and I increasingly attempt to do the best I can.* Having the character to do well constitutes a virtue that drives her to seek happiness through motherhood.

It needs to be taken into account that procreation is a legitimate female claim, a millenary premise based on the biblical-theological perspective. Catholic Teaching defends that the marital act should remain open to procreation and condemns abortion, contraception, contraceptive sterilization and artificial procreation. For the followers of the religion, procreation is part of the goal of sexuality and the complementariness of genders(12).

According to catholic doctrine, neither men nor women can decide on procreation because they participate in God's decision to create. Acting differently means rejecting God and human life itself(12). In this belief, couples that do not procreate renounce their Divine mission and expose themselves to the plural society's disbelieving looks, as non-conception or absence of maternal love provokes social estrangement and individual discomfort. Hence, the greater the affective load linked with the desire to procreate, the more central its position in the set of representations about oneself.

4.2 Can I be a mother with genetic blindness?

Democratic societies attempt the solve human moral conflict in the least violent way possible because, as heirs to the illuminist values that defend liberal democracy, moral disagreement is considered a quality and a mark cultivated(13).

With regard to the ethics of procreation involving a blind person with possible genetic transmission, inspired by the principle of responsibility, the couple should make a decision about conception or not, and determine how many children they intend to have. This premise moved medical conduct, centered on the bioethical principle of autonomy: ─ *The physician-geneticist was quite concise and uninterested, conniving, like most health professionals: You only have two options, have a child or not... She didn't even consider the fact that this was about a child and that there was a blind couple there, in conflict.*

The objective dimension of responsible parenthood demands knowledge and respect for the biological laws that are part of human beings, as well as assessment of born or future children's wellbeing. This means that the couple's responsibility should be proportional to the values and conditions in which the procreation can occur. The couple's right to abstain or not from fertile acts is subordinated to the assessment of certain conditions, deriving from life or health risks(12). Decision-making can be supported by genetic counseling, as non-directive as possible, and any genetic care, including screening and testing, should be voluntary(3).

It should be highlighted that there is no moral law without freedom. That is why human will is constantly influenced by the pleasure of trespassing moral law(7), putting will at the service of natural inclinations, to the detriment of moral rules. That is why the moral can take two forms: heteronomy and autonomy.

In heteronomy, there is unilateral respect and, as it is ruled by natural inclinations opposed to the morality of will, it is destitute of the categorical imperative. Heteronomy is a false expression of moral law. The latter is marked by false freedom since, if one acts according to the legality of duty, duties are coercively imposed and not as elaborations of conscience, so that people act out of fear for reprisals(7).

Beyond the analysis of female strategies to deconstruct the asymmetric power between the genders, we could not do without an interpretation of the meaning of mothers' role in our culture, within the perspective of religious or lay codes of conduct that still regulate human reproduction and which, in our perspective, constituted the causal link of the existential conflict the research subject reported on.

In line with literature, the ethical differences that guide the elaboration of codes of sexual conduct reproduce and interweave the values attributed to sexuality and biological reproduction. These two leads weave the imaginary and define the morality and ethics of motherhood. Men and women's sexual behavior is regulated by standards of conduct whose construction is based on sexual desire. The naturalization of the procreation function and the power asymmetry between the genders goes back to the Adamic myth that is passed on from generation to generation, correlating woman's social role with her reproductive capacity. Procreating means guaranteeing social reproduction – the child becomes self-projection, the way to perpetuate oneself. This and other historical memories make room to adopt a heteronymous moral responsible for influencing the female psyche, inducing it to maternal inclinations destined to reproduce and renew life. And it explains the interviewed subject's maternal inclination: *In fact all we wanted was to have a baby! We lived in a big conflict: the desire to have a baby and, at the same time, the possibility that our child would be born blind.*

By affirming: *all we wanted was to have a baby*, the subject manifests a personal ethics according to the value judgment she herself pre-adopted, and which moved the existential conflict generated by the dilemma between the desire to procreate and the fear of genetically transmitting blindness.

When remitting the moral conflict the partners experience to the ethical-legal sphere, we observe that the right for a child not to be born in certain conditions is not postulated in this context, neither is the material future of people with congenital impairment guaranteed. If this right were acknowledged, this would entail severe ethical consequences, as parents, geneticists and obstetricians would be the target of essentially eugenic normative pressure(14). Therefore, health professionals should offer parents full information about possible genetic or hereditary risks and respect their freedom to choose. The parents are responsible for choosing consciously, according to the autonomous moral.

The autonomous moral is expressed in those acts in which reason by itself determines will, so that autonomy expressed the acquisition of moral conscience. People perform their duties because they are aware of their need and meaning. Performing them constitutes a categorical imperative. This is about autonomy, an effective moral originating in mutual respect, as action does not result from coercion. Will, based on ethical and moral principles, determines action, which occurs through duty(7,8).

The categorical imperative obliges autonomous individuals to set a measure and an end for themselves, and even prohibition, no matter how many inclinations impel them to want. That idea motivated us to proceed with data analysis, correlating the moral judgments of social capital with the following inquiry: How does a blind person, aware of the risk of genetically transmitting blindness but wanting to get pregnant, perceive the experiences of resentment and repression deriving from social capital?

By wanting and considering that she could be a mother, the study subject needed to construct a moral judgment to counter the coercion she was a target of: ― *People used to ask us: And what if he's born blind? How will you manage? Don't you think you should avoid having a child? Ain't he going to get revolted when he grows up?*
In social discourse, there is a moral judgment that coercively appeals with a view to influencing the subject's attitude and behavior of wanting, towards responsible parenthood. And more than that. Implicitly, social discourse puts an end to discrimination and disbelief in the potential of disabled people. It is the collective unconscious unfolding in order to express, on the one hand, the prejudice that is socially imputed to people who are different. And, on the other, attempting to establish a communication system that favors conscious support for everyone to adopt the same rational moral judgment and feel socially cohesive.

Not sharing the same moral judgment in a given social reality usually arouses greater repression of what deviates from the standard among its members, increasing the individual perception of symbolic violence, influencing the formation of negative social capital by adopting a set of attitudes and behaviors that jeopardize interactions and support levels among those who disagree. That is what happened to the study subject. The degradation of group interaction took the form of weakness and affective neediness: ― *Questions were as countless as possible, nobody was concerned with us at any time, and everything they actually wanted to know was whether he (the child) would be blind or not.*

The subject perceived social coercion as disrespect, lack of love and did not manage to displace the conflict related to the idealization of a moral judgment that would justify her inclination towards having a child.

4.3 Should I be a mother with genetic blindness?

The fact that the partners were blind and that the experience of blindness in a society in which the social inclusion of disabled people remains marked by gaps that affect children's education, access to street furniture and fixtures, to health good and services, to education and work(15,16) demanded parents to reconsider a pregnancy in which the child would be at risk of a congenital impairment: *Sometimes I kept thinking, if I wasn't being irresponsible, because of having the medical knowledge and nevertheless wanting a baby!*

It is obvious that a person's quality of life does not exclusively depend on the genetic background. Moreover the absence of vision does not necessarily eliminate or reduce the desire to be a mother (20). What grants quality to life is the wealth of the affective background, expressed as love and mutual care. This premise was not sufficient, though, to calm down the wanting subject. Her reconsideration of a pregnancy that entailed the possibility of such a risk contributed for the affective dimension of the moral development phase to be invaded by love, fear, insecurity and guilt.

By questioning herself about the decision to have a child, the subject stages an unprecedented ethical dilemma that justifies her decision-making. This statement is justified by the fact that we did not find any reference to this kind of conflict in literature. International documents about human rights, fundamental human rights in Constitutions, and even fourth-generation rights related to ethics in genetics do not refer to the right for a woman to get pregnant in the circumstances presented in this study.

We present the following citation to try and elucidate the moral judgment the subject adopted in acknowledging her right to get pregnant: *We started a great battle with a view to not allowing anyone to comment on the choice we made. Sometimes people were more anxious than we, the parents. (...) They were even indiscrete, unpleasant. (...) The first visits were quite surprising! Almost everyone who came hardly talked to me. Hardly anyone was concerned with whether I was feeling fine or not. All people revealed their anguish and curiosities.*

When group interaction is not effective, people can be stimulated to get isolated in a defensive attitude or mobilized, with a view to elaborating a moral judgment that strengthens their ability to undertake a moral action that is beneficial, even if this action goes against the Kantian teaching that one should act according to *a maxim whereby you can at the same time will that it should become a universal law*(8).

Kantian ethics preaches that free will grants human beings the capacity of self-determination, independently of co-acting sensitive impulses. Hence, how can the subject's conduct be explained in deciding to have a child, clashing with this maxim? There are three possible explanations: 1- coercion may be connected with an unfair law in case it is used to impede a fair use of freedom. In this case, conduct may occur for heteronymous reasons only; 2- a person's moral conduct may be located at the level of ethical selfishness, guiding him/her to behave in line with one single primitive duty, which is to do the best for him/herself; 3- human conduct can be classified as moral selfishness. In this case, people lead all ends to themselves because they only perceive utility in what is useful, so that choosing to want depends on its utility and on the extent to which this entails personal happiness(16).

Finally, inspired by Kant, there are two safeguards: 1- the merit or guilt of a moral action remains totally hidden, as responsibility for the act can only be related with the empirical nature(12); 2- it is impossible to find in experience, with absolute certainty, that the maximum of an action was exclusively based on rational moral judgments(8). In view of these safeguards and from another perspective, we can infer that the subject's moral conduct was based on the contemporaneous society's beliefs and values which, based on Fundamental Human Rights, attempt to acknowledge disabled people's dignity and guarantee their social place through legal capital. It was based on bioethics, whose central concepts applicable to this study are respect for moral plurality, diversity, tolerance and autonomy.

4.4 Moral judgments guiding the experience of being a mother with possible genetic transmission of blindness

The protection of a person's fundamental rights lies at the base of the Brazilian Democratic and Social State of Right and serves as a distinctive element in case of intervention in any of these rights. In this research, we highlight the Right to Freedom of Conscience or Conviction and the Right to Seek Happiness with Dignity for the sake of reflection.

With regard to the Right to Freedom of Conscience, the subject made use of this right and guaranteed it by adopting the following moral judgment:

It did not matter if he came blind because, nevertheless, considering all difficulties he would face, we would already be there to help him with the slightest difficulty he might face. After all, it was not that hard to accept and mainly to understand such an expected and wanted child, in case he'd be born blind. When I got pregnant, I didn't get very concerned either as, before I got married, I had already taken care of my younger brother. What comforted me was the fact of knowing that I was pregnant now. During my pregnancy, I liked to see myself pregnant, I liked my belly that was growing. I also used to think about what my first procedure would be in order to find out if he would be blind or not.

The establishment of the moral judgment that sustained decision marked derived from the heteronymous conduct moved by natural inclination, allied with the formation of self-sufficiency habit that allow the subject to actively participate in the environment she lives in. And, beyond the autonomous moral Kant proposed, it derived from the Federal Constitution, article 226, § 7º, as follows: *based on the principles of the human person's dignity and responsible parenthood, family planning is the couple's free decision. It is the State's role to offer educational and scientific resources to exercise this right, prohibiting any coercive form by official or private institutions*(17).

With regard to the Right to Seek Happiness with Dignity, the moral judgments should be highlighted which permeated the user-health professional interaction throughout the pregnancy and delivery experience, as follows: *I have known two important physicians in my life: The geneticist and the physician who accompanied my prenatal care and, consequently, my delivery. They were both very important in their specialty area and mainly in their time. The geneticist had to give me a short and objective opinion. She informed us that we had a 25% chance of having a blind child. She also told us that we still had 75% to choose. He could be born NORMAL [...] You only have two options: have a child or not [...] I think that, in her profession, she had no other option. She did her job and there definitely wasn't anything else to say. Perhaps I wanted to hear another diagnosis and felt shocked, perhaps, by what I heard. In fact, her role was small and short, considering the time of my pregnancy. The other physician (obstetrician), besides taking care of me month by month, was very careful, advised me wherever possible, within the limits of his knowledge, and attempted to help me so that I would be entitled to what he considered to be the best care.*

By advising the couple, the geneticist settled doubts by establishing, based on statistical data from scientific literature, or from professional experience, the probability that the couple would conceive a child with or without the risk of inheriting blindness. The criterion used was that of probable benefit, which tends to be used in decision-making.

Health professionals' conduct towards the couple was worthy. Medical professionals should offer the best possible treatment and get even better by recommending, based on solid scientific bases, a correct alternative,(18) in the sense of guiding human genetics actions. Hence, the geneticist and obstetrician were ethically correct, as one cannot assume that a risk, being uncertain or unknown, is nil or unimportant. They used the Kantian categorical imperative: *Act only according to that maxim whereby you can at the same time will that it should become a universal law*(8). Finally, based on Pessini(19), we can affirm that these professionals' conduct reflects a moral judgment that respects human life in all of its expressions and moments, as early as the transmission of life, independently from the stigmas "perfect", "imperfect", "normal", "impaired", which are commonly applied to people. And they definitely understand that welcoming who is "perfect" only, according to moral standards, should arouse indignation, as this is a form of eugenics. A diagnosis that affirms the existence of a deformation or the prediction of a hereditary disease cannot be equivalent to a death sentence. The Catholic Christian moral rejects this idea, as all human beings carry the marks of the Creator. And, originating in him, they gained the dignity and natural right to exist and flourish.

5. Conclusion

The possibility of a diagnosis predicting late blindness aroused a moral conflict in the blind woman that led to heteronymous decision making, based on moral judgment ruled by natural inclinations towards procreation. The reaction by her social group took the form of rational moral judgment, based on the beliefs and values that inhabit the collective unconscious, related to the conception of what it means to be a disabled person. Resilient to social coercion, the woman decided to get pregnant.

Her pregnancy experience was marked by medical care centered on the Kantian categorical imperative and on bioethical principles of respect for life and people's dignity. This conclusion should not be generalized. The goal is for this study to contribute to reflections about disabled people's activities in procreation, particularly in case of possible genetic transmission of the disability, a theme that has not been discussed in health literature. Likewise, we recommend further research involving these people, with and without predisposition to genetic problems as, independently of this genetic possibility, these people are considered asexual and the social imaginary does not believe that they are sexually active, and even less that they can have children.

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