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PGD Vs. Abortion: A Deep View on "Authority" and "Necessity" in Cases of Predictable Fetal Abnormality

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Abstract

Abortion usually seems to be an accident, but not in the cases of prior abortion record in mother herself, or her relatives. Here, an ethical question appears: "*In the cases in which, the mother is aware of high possibility of fetal abnormality through history of abortion for herself or her close relatives, is there any ethical commitment for mother to ignore her primary right of authority and prevent an abnormal pregnancy due to new medical technologies?*" The authors argue that "*respect*" for implanted embryo, which is a common point among all major ideas about fetal personhood, involves applying PGD in suspected cases. This idea is supported by rational arguments and philosophical reasoning as well as Islamic thought in general and Shii'a approach in particular.

Keywords: Pre-implantation Genetic Diagnosis (PGD); Abortion, Authority; Necessity; Fetal abnormality; Haraj; Shii'a Jurisprudence; Fetal Personhood

Introduction

Authority is one of the most controversial topics of philosophy, law and ethics, which is interpreted differently conforming to its context [1]. In this paper, authority means ability to evaluate the situation and consequent commission of an act willingly according to prior evaluation of the person. As it is clear by reference to stated definition, enough knowledge about the current status and sufficient power to act without any compulsion imposed by exterior causes compose features of authority. This ability to act consciously and free of external pressure involves legal and ethical responsibility of the person who unlawfully acts and imposes harm to others. In developed legal systems, there is no doubt that coercion lifts burden of responsibility from the wrongdoer and recognizes cause of compulsion status responsible for harms [2]. Islamic law acknowledges this approach by exemption of wrongdoer under circumstances of coercion from any legal and ethical liability. Coercion itself has two types: in its extreme measure, coercion involves absolute lack of intention and in its moderate definition, coercion includes occasions in which, the wrongdoer still has intention but lacks consent and is obliged due to external causes like threats to his life, wealth or reputation. Islamic perspective categorizes both types of coercion as good excuses for exclusion of responsibility.

This wide scope of responsibility exemption clearly demonstrates high value of authority in Islamic perspective which seeks responsibility in free will. The only exception arises when subject of constraint is to kill someone. Here, shii'a jurists avoid keeping the same approach and contrariwise putting burden of responsibility on the killer, even if he claims that he was under obliging circumstances and did the crime without complete consent. This differentiation is an expression of human life value in shii'a belief. In other words, there is no legitimate excuse to kill someone, even if the killer has been threatened to death otherwise.

The other expression which plays a key role in our discussion is "*necessity*". Necessity acts as a main cause for exemption from responsibility as well as compulsion [3]. For instance, in a case of a risky pregnancy which threatens mother's life, necessity shows up and permits the mother to protect her life through aborting the fetus. Although compulsion and necessity act the same in exemption from any liability, there is a significant difference between these two concepts. Despite coercion which is imposed by an external cause out of doer's will, in the case of necessity, we face an internal cause. Risk of pregnancy constitutes an internal cause for abortion, while in the case of coerced murder, an outer cause limits freedom of doer's will. Therefore, necessity includes situations where free will is internally limited conforming to social norms and personal requirements. For example, while abortion is prohibited intrinsically, common sense accepts abortion in a case where mother's life is at risk and there is no option for survival of baby and mother both. Here, two components–socially accepted norms and personal status–interact to define circumstances of necessity. In this regard, Islamic law, especially Shii'a perspective states: "*necessity authorizes prohibitions* [4]".

However, since necessity nature may lead to undermining primary rules of law, it is inevitable to apply this corrective rule cautiously and in a limited way. To diagnose necessity according to legal and ethical view, it should be prudent and conscious because most of times, it deteriorates the primary morally accepted legal rules.

Since necessity is being redefined by historical and social changes, it will necessarily be changed itself. For instance, there are several diseases which were not diagnosable before, but nowadays, they are simply recognizable and therefore preventable. So, the arose question is: "*If some dangerous position is evitable, is it true to interpret it as a law-undermining position which involves application of secondary rules instead of primary legal and ethical principles?*"

Arguments

This article does not aim at survey of necessity, as a pure theoretical problem. The aim is to scrutiny the applicability of necessity rule as mentioned before, in the case of fetal abnormalities which are nowadays diagnosable before transfer of embryo to mother's womb. PGD (Pre-Gestation Diagnosis) has made it possible to find out fetal genetic and biological abnormalities. So, it has to be discussed whether it is our duty to try to diagnose fetal abnormalities before implantation of *in-vitro* fetus. In other words, the main question here, considering advanced medical technologies including prenatal fetal diagnosis, is whether still accepted to claim that discovering a fetal abnormality after implantation, constitutes a justified excuse to abort the fetus due to necessity rule-undermining nature?

To answer this question, it should be noticed that considering fetal "*personhood*", there are 3 main theories with different outcomes:

1. The first theory is called "*human dignity*", which identifies human personhood since the fertilization has occurred.
2. "*The theory of gradualness*": in this idea instead of recognition of fetus as a human person, it should be considered as a gradually enhanced identity which does not worth equal in its different stages of development. So, abortion of a one-month embryo is less blamable than killing a 4 months one [5].
3. The third idea called "*the possession theory*" states that fetus does not possess human personhood until it is born. So, before delivery, it should be regarded as mother's property.

According to the Islamic law, the first theory is partially acceptable. It means abortion is prohibited at all stages of fetal development. Just in one case, due to necessity rule application, if mother's health is at a serious risk following pregnancy, abortion is prescribed [6]. For example, Iranian parliament has passed recently a regulation which permits fetal abortion if the fetus has some disability or genetic illness, provided that fetus has less than 4 months and Iranian forensic medicine institution authorizes the abortion [7].

The basis of the above-mentioned law is to recognize mother's right to have a life without hardship and distress. The concept of hardship which is called "*Haraj*" in Islamic law, is based on conventional judgment [8]. In other words, it is common sense of the society which defines borders of "*Haraj*" with other kinds of harm, which should be tolerated and does not pass the qualifications of a "*Haraj*" occasion. So let's ask the main question again: Is fetal abortion has to be considered necessary even if we have the chance to diagnose fetal abnormalities before implantation of *in-vitro* embryo? In other words, does necessity involve inevitability of the occurred occasion? If it is possible to diagnose the illness of *in-vitro* embryo and therefore, avoid its transfer to the mother's womb, is it still a "*Haraj*" occasion to gestate such a fetus or mother has not the right to abort because of her prior knowledge about fetal abnormality?

PGD is a new medical technology, to find out *in-vitro* embryo abnormalities which naturally show up after implantation. If it is possible to detect a disease before embryo transfer, is it legally and morally accepted to ignore this opportunity and let the disabled fetus grow in mother's womb and subsequently allow the mother to abort it because of necessity rule? Is this position has enough justification to lead to necessity rule application and therefore, permits abortion of disabled fetus which has not been monitored by PGD before?

Current Trends in Practice

WHO has got a neutral position towards PGD and left burden of decision making on national legislation respecting cultural diversity. As Professors D.C. Wertz, J.C. Fletcher and K. Berg prefer not to be involved with legitimacy of PGD in risky situations, their report to WHO suggests:

"Preimplantation Diagnosis (PID) offers an alternative to families and societies that wish to avoid abortion. Some users are women who have already had abortions following prenatal diagnosis and do not want to undergo these procedures again. This alternative, however, is costly and may not lead to a live birth. The ethical issues and counselling are similar to those in prenatal diagnosis, except that there is no pregnancy until the fertilized egg is successfully implanted. As there is no worldwide agreement as to when human life begins or when it acquires moral significance, there is no agreement about the moral status of an embryo. Nor is there agreement as to whether discarding an embryo with a genetic disorder, prior to implantation, is the equivalent of abortion. Because some families and cultures regard preimplantation diagnosis as morally preferable to prenatal diagnosis, the option should be offered if a nation has sufficient resources" [9].

At the national level, PGD is usually addressed in a wider regulatory scheme aimed at reproductive technologies or prenatal diagnosis, and four approaches can be observed: (a) Prohibition of PGD, which occurs in Austria, Germany, and Switzerland; (b) Statutory regulation setting forth the purposes for which PGD is permitted, found in France, certain parts of Australia, India and the Netherlands; and (c) A more general legislative framework that does not directly deal with PGD, combined with professional guidelines or the oversight of an authority; a "*hybrid*" system which is found in Japan, Canada, and the United Kingdom. There are also countries which, like the United States, do not provide for regulations other than voluntary compliance of PGD service providers with professional organization guidelines [10].

In Australia, all diagnostic procedures carried out, on or with a fertilising egg or an embryo must have the prior approval of the Australian Reproductive Technology Council. General approval may be provided in the Code of Practice (or Directions) or specific approval given in particular cases. Section 14(2b) of "*Reproductive Technology Council Policy on Approval of Diagnostic Procedures involving Embryo*" states:

"The Council must not grant approval to any diagnostic procedure to be carried out upon or with a human embryo unless - (a) The embryo is intended for use in the reproductive technology treatment of a woman and the Council is satisfied, on the basis of existing scientific and medical knowledge, that - (i) The diagnostic procedure is unlikely to leave the embryo unfit to be implanted in the body of a woman; and (ii) Where the diagnostic procedure is for the genetic testing of the embryo, there is a significant risk of a serious genetic abnormality or disease being present in the embryo" [11].

According to Australian Reproductive Technology Council, it is not appropriate to specify a statistical probability as the sole criterion for the risk of a genetic abnormality or disease being present in the embryo to be "*significant*". The level of risk should be measured against the risk of the disease or disability occurring in the general population. The Council should be satisfied that there is a higher risk of the embryo in question being affected by the abnormality or disease being tested for than for embryos in the general population. The significance of the risk for the persons seeking the testing may also be relevant, in

that the persons seeking treatment may have varying perceptions of the significance of risk that need to be taken into account. In assessing whether a genetic abnormality or disease is serious it is appropriate to look at environmental and personal factors as well as the impairment to body functions and structures that may arise from the condition. The assessment should consider the limits that these factors impose on the extent to which a person can engage in activities or participate in life situations [12].

England is another example foe permitting PGD providing observation of comprehensive regulations has passed. Authorising Conditions PGD was first used in the UK in 1990 to prevent the inheritance of sex-linked disorders affecting boys such as Haemophilia and muscular dystrophy by selecting female embryos for implantation. Shortly after this, the Human Fertilisation and Embryology Act 1990 (as amended in 2008) laid down the regulatory framework for assisted reproduction in the UK. The Act was implemented by the newly formed "*Human Fertilisation and Embryology Authority*" (HFEA). PGD was initially regulated on a case-by-case basis, whereby clinics applied to have a particular condition added to their license. In 2009, the regulation of PGD changed to a condition-by-condition system. Once a condition is authorized by the HFEA for PGD it is placed on an approved list. Licensed PGD clinics can then offer tests for any condition on the list. An exception to this is the use of Pre-implantation Tissue Typing (PTT) for the purposes of having a tissue-matched sibling, which is still regulated on a case-by-case basis. As the seriousness of the symptoms associated with a genetic disorder can vary among individuals, in such cases HFEA makes a decision based on the worst possible symptoms. The past 10 years have seen an increase in the overall number of conditions authorized and in the different types of disorders approved for PGD. As genetic sequencing technologies become cheaper and more accurate, these trends are expected to continue [12].

Italy, may be due to historic tradition of conservatism, has experienced a period of prohibition, but now implements PGD according to its regulatory precedent. PGD, at the beginning of Italian experience, was applied only to infertile patients with 11.1% of pregnancy rate per embryo transfer. Subsequently, when fertile patients were included, this rate increased at 30.8% pregnancies per embryo-transfer. PGD was initiated in Italy in 2002, and 42 cases using one or two blastomeres and DNA analysis were performed until 2004. In 2004, a law on assisted fertilization which prohibited PGD was passed, so it was not possible to perform PGD from 2004 to 2014. Recently, numerous Courts among which the Cagliari Civil Court and the Constitutional Supreme Court in Italy mentioned the right to PGD on the basis of Law 194 of 1978 about "*voluntary interruption of pregnancy*" declaring that "*the selection of embryos is not a crime, even in cases where this is exclusively aimed at avoiding the implantation, in the uterus of the woman, of embryos suffering from genetic transmission diseases that meet the criteria of gravity*". Since 2014, 184 procedures were performed in Italy using mainly biopsy by blastomeres and, more rarely, by Trophectoderm cell [13].

In Scotland, the primary ethical justification for the offer of PGD is that it can prevent harm to babies who are predisposed to a risk of a genetic condition.

The harm which can be prevented may be to:

"Possible future children likely to suffer from disease or disability caused by chromosomal abnormalities or genetic mutations" [14].

The Scottish approach through PGD is more theoretically justified as there are four principles initiated to ensure due process of PGD. Therefore, due to the high profile and difficult ethical issues involved in deciding who should be able to gain access to the Pre-Implantation Genetic Diagnosis service, an Expert Panel on PGD was established. The Panel, which includes wide representation from those involved in the clinical delivery of the service, to service planners, lay representatives as well as those working in the field of law and medical ethics, was tasked with advising on the criteria that should be applied in deciding which individuals should or should not be offered access to the PGD service. "*Reasonableness*", "*transparency*", "*justifiability*" and "*equitability*" were central principles adopted by the Panel to guarantee procedural fairness and accountability in the decision making processes.

The Panel agreed to adopt the generic framework developed by the National Planning Forum as a basis for decision making with regard to access to, and receiving treatment from, the PGD service. This will help to ensure that the decisions reached when discussing individual cases are reasonable, transparent and justifiable. By introducing the approach described here, the NHS Board will be able to build reasonableness, transparency, procedural fairness and accountability into its decision-making process [15].

Welsh regulatory system suggests a more objective criterion for assessing measure of risk. In order to access PGD the couple should be at risk of having a child with a serious genetic condition and this risk must be greater than 10% [15].

Ambiguity of "Risk Seriousness"

A study highlights the fact that "*serious*" genetic disorder is an extremely variable concept among geneticists. For example, a survey was carried out among geneticists from five major professional associations, including representatives from 41 countries, asking them to give examples of disorders they considered as "*lethal*", "*serious but not lethal*", or "*not serious*". Responses revealed conditions that appeared in all three categories, and there was no consistency of classification between professionals. This absence of consensus shows that permitted uses of PGD based on a "*seriousness*" test are likely to be interpreted very differently, which may create legal uncertainty for participants in the process, and may introduce both flexibility and arbitrariness in decision-making [16].

Many other concepts used in discussing selection technologies are also interpreted very differently. The distinction between diseases, disorders, and characteristics, for example, has been singled out as one worth exploring in this context. These concepts will become important as possible extensions of the use of PGD are discussed, such as using PGD to prevent "*susceptibility disorders*" and "*late-onset disorders*". Susceptibility disorders are those in which a person has a greatly increased chance of developing a particular disease in their lifetime; genes are known for increased susceptibility to colon and breast cancer, for example. Last year, the Human Fertilisation and Embryology Authority (HFEA) approved the use of PGD for Familial Adenomatous Polyposis (FAP), a familial condition leading, in almost all cases, to colorectal cancer. In these disorders, age of onset of the disease may vary greatly, and there is always a chance that preventive measures will be effective in either delaying the disease significantly or preventing it. Will a person with one of these disorders have "*a life not worth living*"? Knowing that a child carries such a mutation may cause constant anxiety and much suffering for both parents and child, and the parents may much prefer to bring into the world a child without this

"*Damoclean Sword*" over its head. But it is likely that most human beings have some form of susceptibility to one or more diseases. Late-onset disorders involve similar uncertain calculations, with a difference: The person will be affected and any uncertainty relates to the length of time available for a healthy life and the psychological effect of the knowledge that one may be, or if tested that one is, affected by such a disorder. PGD is already used for some late-onset disorders seen as "*serious*", such as Huntington disease. Other late-onset disorders call for balancing the seriousness of the disorder and age of onset with the length of the "*normal*" life the person is likely to enjoy. An attempt at quantifying a "*risk factor*" combining penetrance, age of onset, and seriousness of the disease to determine at what point selection becomes acceptable would be especially difficult with these disorders, because different persons may react very differently to the knowledge that they may or will suffer from a particular disorder. Many would leave such a decision to the parents, on the basis of appropriate information, whereas others consider it unacceptable to select among embryos not to prevent a person from having a life not worth living, but to escape normal human uncertainty and suffering.

As we see, there are thousands of disorders associated with genetic abnormalities, with varying degrees of seriousness, which arise this key question: How should it be decided which conditions it is ethical or reasonable to permit testing for? Most jurisdictions that accept but regulate the availability of PGD restrict it to cases of medical necessity, usually defined by some reference to a "*serious*" disorder or disease. Professional organizations that have issued guidelines also refer to a seriousness test. Generally, some combination of the four following criteria is seen as relevant for deciding whether PGD is appropriate: (a) The magnitude of the risk of developing the condition, (b) The seriousness of the condition, (c) The treatments and palliative care that are available for this condition, and (d) The combination of these factors to yield a high probability of a low quality of life for the child if born [11].

Conclusion

The authors believe that in cases where there are records of prior unwanted or therapeutic abortion or close family history of disability and from a medical standpoint, there is a serious risk of having a fetus with disability, Performing PGD before *in-vitro* fetus transfer to the womb is necessary as follows:

1. "*Necessity*" situation occurs only when there is no way to prevent it [16]. In our discussion, performing PGD before transfer of embryo into mother's uterus leads to awareness about possible diseases or abnormalities of the embryo. So, it is not rational to claim that fetus abnormality after implantation causes necessity situation and therefore, it will not turn primary rule of abortion prohibition to its permission. This thought is known in Shii'a jurisprudence as "*Prevention of authority*" [17] which suggests that avoidance of acting by free will at moment "A" does not deny free will itself at later moment of "B" and does not convert consequent acts of person to "unwanted" act. For example, imagine a person "C" falling down from height, while another person "D" refuses to save his life despite his capability. Even if person "D" regrets of his omission and tries to save A's life at last moments of falling but fails to save him, D's authority and free will in not saving "C" is not deniable. So, "D" must be responsible for his omission due to his authority at moment "A".
2. By considering current practices and thoughts as mentioned above, it seems that "*lethal*" and "*serious but not lethal*" condition diagnosis completely satisfies requirements for accounting a case as "*necessary*" to permit PGD. Since susceptibility disorders affection' chance increases dramatically in families with such affection record, seriousness of the risk makes it ethical and may be ethically mandatory to prescribe PGD. Late onset disorders like Huntington disease, albeit let the offspring have some time healthy life, but after a short or long while, definitely expose. So, according to the result of benefit-harm evaluation which compares between value of health for the offspring and ethical-economical costs of PGD, a crucial judgement about legitimacy of PGD ought to take place. It seems that replacement of the above mentioned various concepts with "*necessity*" will help us to determine the prescribed cases for PGD by means of a unique criteria which conceptually includes but is not limited to seriousness of risk, magnitude of the risk of developing condition and the available treatments and palliative cares for the condition. In other words, customary nature of "*necessity*" will approximates the variety of theories and concepts suggested as criteria of PGD implementation.
3. Most of Shii'a jurists do not consider an equal human respect of implanted embryo for *in-vitro* one before implantation [18]. Therefore, PGD conforms with human respect and hence, pre-implantation PGD is desirable. Although the formal Christian doctrine believes in fetal personhood since fertilization, most of theologians even among Christians, do not consider the four cells human egg as a person.
4. Most of medicines and jurists all over the world refuse to call *in-vitro* embryo waste as abortion [19]. This trend, regardless of its correctness, guides a prudent mind to judge more cautiously. So, it seems obvious that wisdom prefers to choose acts which are not certainly regarded as abortion. Therefore, PGD provides an opportunity to avoid so-called abortion through not transferring abnormal embryos to mother's uterus.
5. Considering strength of "*gradualness*" theory which involves more respect for more developed fetus, it may be concluded that wasting early embryo before implantation, has very less conflict with its human respect and even if it is not desirable, it is more justifiable from fetal abortion after implantation and in its later developmental stages.
6. Demand for prudence in human life judgements, beside the rule of "*least harm for acquisition of most benefit*" which is originated from Utilitarianist school, necessitates costs for PGD in order to avoid ethical and legal consequences of abnormal embryo transfer and its possible abortion.
7. Despite some authors [20], there is no reason to restrict prescription of PGD just for infertile couples. Since the risky condition arose from genetic disorders may occur both for fertile and infertile couples, it should be permitted to do PGD in conditions where there is a high probability of fetal genetic disorder or disease. Here, "*Necessity*" is not limited to infertile couple but includes fertile couple as well.
8. At last we recall that all these permissions are all exceptions from primary rule of "*random human nature*" [21]. Just in cases of necessity, which is definable by considering objective measures (like genetic disorders precedent in close family) and subjective ones (like personal experience of abortions due to fetal defects) as well, PGD is prescribed in order to reduce potential cases of abortion. This exception may provide a door open, through human engineering and must be dealt with carefully. PGD fruits seduce human to enhance what he believes "*fit*" for next

generations. Here, a medical issue changes its nature to a eugenics project which is not the goal of PGD as a preventive tool with a medical prescription. So, "*slippery slope*" argument stays strong and should be considered in all decision makings, whether according to a condition-by-condition or a case-by-case approach.

9. Despite some writers, PGD is not a matter of "*having a life worth living*" [22]. "*Human life*", which starts once fertilization occurs, however does not worth equal during different stages of fetal development, and however does not worth equal to a born baby life as authors believe, but on the other hand, does not require denying fetal right to live as well. It is not our duty, nor our right to judge about life worthiness. Life is worth living even with genetic disabilities. What we are seeking to reach is preventing abortion of these lives through not letting risky conditions lead to genetically defected babies. "*Authority*" of parents–who seriously suffer possibility of having genetically disabled babies-exceptionally, prescribes PGD just as far as it is "*necessary*". For further pre-implantation intervention we do not have any justifiable reason to undermine primary rule of "*respect to fetus*". Although as mentioned above, authors believe in gradualness theory for fetal personhood, considering commencement of human life once fertilization even *in-vitro* occurs, it is not morally accepted to produce *in-vitro* fetus for unnecessary conditions like sex selection, genetic enhancement or genetic eugenics.

Performing PGD is ethically mandatory, provided that there is congenital disability precedent in family, or the woman has committed abortion before, due to fetal defects. Thus, in these conditions, negligence in passing PGD has to be regarded as causing fault which leads to fetal disability, illness and possible later abortion. It is not the same in natural gestation, but when we face a laboratory gestation, medical technology provides us with tools which prevent necessity situation and abortion of abnormal fetus occurrence. Where there is room for prevention, necessity is excluded and where there is no necessity, the originally forbidden act will not be permitted.

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