



Prenatal diagnosis in Islamic countries: A narrative review in 2013

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ABSTRACT

To review the current situation regarding prenatal diagnosis in Islamic countries, a descriptive study (narrative review) has been done based on the available data in formal international and national published documents in 2013. The sources were papers, websites and electronic books. Time limitation of searches has started 20 years ago. The main languages were English and Persian.

Forty seven nations were officially referred as Islamic since more than 50% of the citizens are Muslims. The holy Qur'an and Islamic traditions (Shari'ah) are the core of the civil laws, however, the legal grounds for prenatal diagnosis differ in Islamic countries. The main ground is the endangerment of a mother's life, however, severe suffering of parents (Osr va Haraj) is also considered in the Islamic Republic of Iran. Some other important issues such as pregnancies as a result of rape should be discussed more in some Islamic countries. Many "hard to treat diseases" such as chromosomal disorders, major hemoglobinopathies, inborn error of metabolism, Duchene muscular dystrophy, spinal muscular dystrophy are being diagnosed early in embryonic period that medical abortion is advisable.

Prenatal diagnosis is an acceptable practice in both religious and secular governments in the so-called Islamic countries.

Introduction

The main goal of the review is to demonstrate the current situation regarding prenatal diagnosis (PND) in Islamic countries. Basically, the main object for "Genetic Services for the Community (GSC)" is to help families/persons

at risk for having healthy offspring(s). Additional benefits would be for the prevention of disability and costs of care of the affected individuals of the community.¹ In spite of the high costs for the implantation of needed skills

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and equipment, cost benefit calculations are usually in favor of “preventive measures”.² However, the situation of important health-related indices, such as mortality rates, rate of malnutrition and infectious diseases are also important in the health policies.³ Economic situations of countries, as well as the political and social factors, have immense effect on planning for GSC. The main challenges for implanting GSC, including PND are more or less the same in developing countries. They can be summarized as the following list in no particular order:

- Big population
- High birth rate
- Low total income of the country
- Less than enough budget for health-related sectors
- High illiteracy rate / Lack of “Education” when it comes to lifestyle and practice
- High rate of consanguineous marriages (kind of arranged marriage)
- How well developed the health infrastructures are/ network is?
- Burden of infectious diseases and malnutrition
- Lack/ less than enough political commitment
- Support of religious leaders.
- Social/ political turmoil, natural disasters

- Cultural aspect such as “stigmatization issue” for heterozygote females

According to international declarations on medical genetics, and considering the culturally approved guidelines, as a necessary act, it should be followed by scientists, ethicists, jurists and lawyers in all countries, irrespective of religious or secular states.⁴ A national well-controlled system and ethical supervision is needed for critical issues of

medical genetics. More distinct supervision is necessary for non-disease traits such as gender of embryo, as these subjects might be prone to misuse, when appropriate technology emerges, “eugenics” may grow insidiously. An intelligent and educated body should be responsible in applying ethical issues in newly-developed fields in medical genetics.^{5,6} Medical ground for prenatal diagnosis is mainly for severely malformed or affected fetuses with genetic diseases which are the cause of severe mental retardation. Treatment options for fetuses are limited even in developed countries. Upon the termination of pregnancy, specific legislation and ethical issue exists in different cultures. Islamic laws are applicable for all Muslims wherever they live, but people usually can only benefit the legal and available options in the country of residence.⁷ In principle, the holy Quran condemns the killing of humans (except in the case of defense or as capital punishment), but it does not explicitly mention abortion. This leads Islamic theologians to take up different viewpoints: while the majority of early Islamic theologians permitted abortion up to 120 days after conception, many countries today interpret these precepts of protecting unborn children more conservatively.⁸⁻¹¹ Although there is no actual approval of abortion in the world of Islam, there is no strict, unanimous ban on it, either. Islam has not given any precise directions with regard to the issue of abortion. Hence it is not a matter, which has been clearly stated in the Shari'ah (Islamic Law), but rather an issue that pertains to the application of our knowledge of the Shari'ah. Such application may vary in conclusion with a difference in the basic premises of one's arguments. The Qur'an clearly disapproves of killing other humans: “Take not life which Allah has made sacred” (6:151; see also 4:29) “If a man kills a believer intentionally, his recompense is Hell, to abide there in forever” (4:93).¹² Allah, the almighty

went even further, making unlawful killing of a single individual human being equal to mass murder of the whole of mankind: "Because of that, we ordained for the children of that if anyone killed a person not in retaliation for murder or for spreading mischief on earth, it would be as if he killed all mankind, and who saved a life, it would be as if he saved all mankind" (Al-Maidah, 5:32). As to whether abortion is a form of killing a human being, the Qur'an does not make any explicit statements. Only Surah 17:31 warns believers in general: "Kill not your children for fear of want, we shall provide sustenance for them as well as for you, verily the killing of them is a great sin".¹²

Materials and Methods

A descriptive study based on the available data in the formal international and national published documents was done in 2013. The sources were papers, sites and electronic books. Time limitation of searches has started 20 years ago, unless it was necessary to look deeper. The main language was English, unless it would be necessary to use Persian or Arabic languages. No judgmental opinion or comparison was made. Figures, pictures and tables produced by others were presented with reference.

Results

In 2012, there were 47 countries officially called as "Islamic" as more than 50% of the citizens are Muslims. Table/Fig. 1 shows the political situation according to report of IMF's (International Monetary Fund) World Economic Outlook Database in 2013.¹³⁻¹⁵

The Islamic Republic of Iran with a population of more than 75 million,^{16, 17} crude birth rate of 18.5, growth rate of 1.2%, is a successful example for control of population growth amongst developing countries.

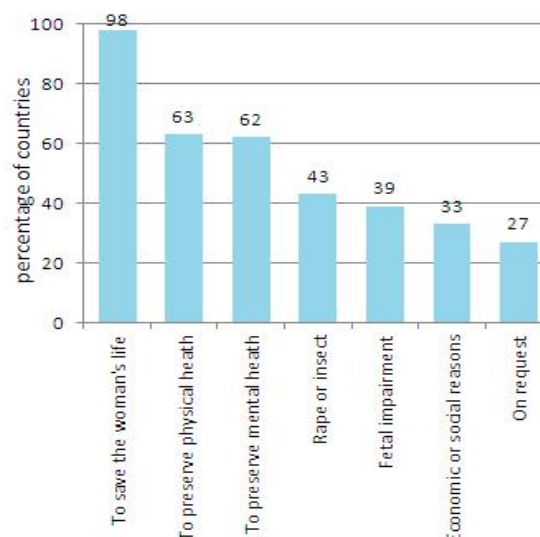


Figure 1: Proportion of Islamic countries according to the legal reasons for abortion, 2012.

Currently, the disease categories allowed to use prenatal diagnostic methods are as follows:

1. Chromosomal aberrations: known chromosomal syndromes with early death/severe mental retardation.
2. Gene defects: beta thalassemia major, hemophilia, Phenylketonuria (PKU), Severe Immune Deficiencies.
3. Sever fetal anomalies: Open Neural Tube Defect, renal agenesis, hydrops fetalis.
4. Infectious diseases: congenital rubella infection.

The main ground for asking an abortion is mother's life endangerment and/or great suffering of parents in raising the child (Osr va Haraj).⁸⁻¹¹ Medical abortion is legal in the following steps:

A. Written request of the guardian to the "Medical Council" (Legal guardian of the fetus is the father and in the event of his death, paternal grandfather will be the substitute. For mother to be the legal guardian of the fetus/child, there are special circumstances to be proved by strong evidence; such as death or severe mental disability/ abusive behavior or addiction of father and grandfather(s).

Table 1. Grounds for legal abortion in some Islamic countries¹⁵

Country	To protect woman's life	Physical health	Mental health	Rape	Fetal defects	Socio-economic factors	On request
Bahrain	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Iran (details)	Yes	No	No	No	No	No	No
Iraq	Yes	No	No	No	No	No	No
Jordan	Yes	Yes	Yes	No	No	No	No
Kuwait	Yes	Yes	Yes	No	Yes	No	No
Lebanon	Yes	Yes	Yes	Yes	Yes	Yes	Varies
Oman	Yes	No	No	No	No	No	No
Qatar	Yes	Yes	Yes	No	Yes	No	No
Saudi Arabia	Yes	Yes	Yes	No	No	No	No
Syria	Yes	No	No	No	No	No	No
United Arab Emirates	Yes	Yes	Yes	No	No	No	No
Yemen	Yes	No	No	No	No	No	No
Pakistan	Yes	Yes	Yes	No	No	No	No
Afghanistan	Yes	No	No	No	No	No	No

B. Definitive diagnosis of disease to be covered according to the list.

C. Written and signed opinion of 3 independent specialists who are consulted by the legal body.

D. Written permission for an approved hospital.^{18, 19}

Transfusion dependent beta thalassemia major (TDTM): The prevention of this genetic disorder is the first and has become a model for implantation of prenatal diagnosis for other diseases. That is the reason for covering it in more details. It is the most prevalent genetic disease in the country as well as in the world.²⁰ Before the activation of a taskforce for prevention of the disease, at least 1000 new the patients used to be born each year.^{21, 22} Financial burden of disease on the health system and humanitarian aspect were catastrophic.²³ TM was the first disease that was

accepted for legally-induced abortion in 2005.^{18, 19} The prevention of TM started in the early eighteenth century. In the beginning, the main strategies were: increasing professional and public awareness, providing laboratory equipment and skilled technicians, prenatal screening of couples, genetic counseling of at-risk couples, as well as prevention of unwanted pregnancy of already married gene carriers(minor couples).^{20,21} The carrier rate in the Mazandaran sea border and south of Iran is about 11% of the population and in the whole country is about 4%.²² About 50% of at-risk couples decide to marry, where there is potentially 1 in every 40 couples at risk of having TM child.^{22, 24} Unwanted pregnancy rate is reported as up to 60% in the country. Also, there are researches (unpublished) that illegal abortions were more prevalent in families who had an affected TM child comparing with

matched unaffected families. As a result, it is indicated that legal abortion of affected fetuses was a must for the success of prevention programs. The program was successful, as new cases dropped to a third of before prevention program has started.²³ In some provinces such as Mazandaran with the patient /population of 1/1000 which is the highest rate of Iran new cases of TM in the whole province became fewer Chorionic Villus Sampling (CVS) is the preferred method for measuring, because it yields results at an earlier time than amniocentesis.^{24, 25} In order to decrease emotional stress of couples and family and no contraindication by laws, the best method for diagnosis of affected zygotes is "Pre-implantation Genetic Diagnosis Preimplantation Genetic Diagnosis (PGD), which is recently available in Iran.²⁶ So far, this technique is being used for having a child, as choice of a preferred gender is an option. Illegal abortion is not popular in order to have preferred gender. Periodic assessment of the protocols is being done by researchers,²⁷ as well as the acceptance of at risk population and physicians.^{28, 29} There are at least 24 mutations that can be diagnosed in the country. The most prevalent mutation is IVSI-II with the prevalence of 50-80 percent in different areas.^{30, 31}

There are two PND centers under the Ministry of Health in Tehran and Mazandaran provinces plus many private centers. There is a genetic network which contains up-to-date information of the field. Cost is covered by medical insurances since 2008. Therefore, there now seems to be a wider acceptance in the public for PND services.³² One of the most puzzling differential diagnosis of being minor thalassemia (beta gene mutation carrier) is alpha globin gene deletions/mutation. The definitive diagnosis of alpha globin gene deletion/mutation is possible and neonatal screening is recommended by some colleagues.³³

Down syndrome: There are no national programs for prenatal diagnosis of Down syndrome, but all needed laboratory and imaging facilities as well as the possibility of definitive diagnosis are available in Iran.³⁴⁻³⁸ Termination of pregnancy on the ground of "Osr va Haraj" is possible. Most cases are being diagnosed by routine ultrasound imaging of pregnancy. Advanced maternal age and previous child with Down syndrome are also the common reasons for requesting laboratory tests.

Congenital infections: The Center for Disease Control (CDC) of United States recommends screening of pregnant women for HIV (not mandatory), Hepatitis B, Chlamydia pneumonia, Syphilis. In Iran, routine check of HBS antigen is a common practice but not mandatory to Ministry of Health yet. In high risk women such as drug addicts, this is recommended to be repeated towards the end of pregnancy. Affected women will be treated by specialists in infectious diseases. Neonates will receive hepatitis B antibody or vaccine as appropriate.³⁹ Congenital rubella syndrome in early pregnancy the may be subject for termination of pregnancy but if the diagnosis is confirmed before 16 weeks of pregnancy.⁴⁰

Open Neural Tube Defect and Spina Bifida:

There is no special screening program, but as ultrasound imaging of pregnancies are routinely done, the most affected fetuses are subject to medical abortion. Big closed neural tube defects and important anomalies such as holopencephaly, anencephaly are being terminated, if diagnosed early. Folic acid administration for all girls and women in child bearing age is routine in general health policies.^{41, 42} Since 2004, there is instruction of use for iron and folic acid supplementation for all females of 11 years and onward, also

fortification of flour with folic acid has been introduced since 2002 in a southern city as a pilot study.^{43, 44}

Inborn error of metabolism: Marriage between first cousins is very popular in Iran.⁴⁵ As a consequence; birth of children with inborn error of metabolism is not rare. Usually there is history of mentally retarded sibling or early death of newborns. If definitive diagnosis is made, study of future pregnancies is usually possible. However, these tests are usually expensive and are not covered by insurance companies. Phenylketonuria is one of “hard to treat diseases” which PND is available for.

Miscellaneous diseases: Many other important diseases are preventable such as Duchene muscular dystrophy, and spinal muscular dystrophy.

Discussion

With the progress of technology and science, apart from the already known diseases, more and more disorders will be subjects that PND can be applicable. Health issues are quite diverse in nature and each country has to decide the most important ones.¹ The main health problems of many developing countries still are malnutrition and infectious diseases. In these countries control of genetic disorders is not the most important priority. However, the extent of covered disorders and acceptable grounds are also related to beliefs and commitment of policy makers. It is a chance that Islam has an open mind to science and ever changing situations. In spite of existing orthodox beliefs in Islam, new regulations are always the subject of debate. For example none of the fetal conditions is accepted as a ground for legal medical abortion, even fatal malformations such as anencephaly. The only ground to get the permission for termination of pregnancy is endangerment of

mother's life, however, the “major difficulty to raise the child by the parents” is another accepted ground⁹⁻¹¹ The technical word of this is “osr va haraj” in Arabic language. The definition and applicability of such situation is subject to reasoning by experts in “Shariat” and medicine.

Another remaining issue would be the time or the age of embryo for the termination of pregnancy. The different times of ensoulment have been reported. The earliest date from conception that is equal to 40 days.⁹⁻¹¹ Usually this date is too early to do the diagnostic procedures with available diagnostic methods. Termination beyond the earliest date would be illegal and subject to penalty. However, and in the real world, the last date for legal abortion is 4 months after the conception reported by ultrasound. In any situation if the main owner of the offspring that would be the father was in agreement with termination, the public prosecutor does not reopen the file.

Overall, prenatal diagnosis is currently an acceptable and favored act in Islamic countries which have both secular and religious governments.

Conflict of Interest

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