



Late presentation of pregnant women with chromosomal abnormalities: A barrier to legal and safe abortions in Muslim majority countries

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Abstract

Introduction: In Islamic countries, the prenatal diagnostic procedures are planned considering legal and religious limitations. We aimed to evaluate the indications of presentation and problems related to religious and legal limitations for presentation of Muslim parents for prenatal screening of chromosomal abnormalities.

Methods: A cross-sectional study was performed on consecutive 920 pregnant women presenting for screening of congenital and chromosomal anomalies to Educational Medical Centers of Tabriz University of Medical Sciences, Tabriz, Iran, between 2011 and 2015. Previously prepared questionnaire forms were utilized for collection of information from patients and their medical records.

Results: In total, 153 cases had an indication for amniocentesis, and this procedure revealed that 141 fetuses (92.2%) did not have any congenital abnormalities, but 12 cases (7.8%) had some sort of abnormality, requiring pregnancy termination. These cases included 8 fetuses (5.2%) with trisomy and four (2.6%) with single gene diseases. Of 12 patients, the justifications for pregnancy termination were issued for 7 women by the provincial Legal Medicine Organization. However, the remaining 5 patients could not obtain legal justifications for termination of their pregnancies, mostly because of late presentation, obligating them to choose illegal methods for pregnancy termination.

Conclusion: Regarding the legal and religious limitation of pregnancy termination after 18th week in Islamic countries, it is highly recommended that the first trimester screening programs be performed in Islamic countries in order to obtain early decision-making.

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Introduction

Abortion is the ending of unwanted pregnancy before the fetus is available to sustain an independent life. Though the procedure of induced abortion is safe, a big fraction of abortions is performed in unsafe conditions causing great deal of morbidity and mortality. It is estimated that 19-20 million unsafe abortions are performed annually around the

globe, mostly in societies of poor economic standards.¹ Abortion is also a controversial issue not only because of the great impact on the socio-economic status of a nation, but also because of how religion views the topic.² Abortion is prohibited in almost all major religions. In Islamic scholarship, abortion is forbidden after the 4 months of gestation.³ Thus, in countries in which sharia law is

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dominant or the constitution is based on religious teachings, it is important to act based on the dominant cultural context, and failing to do so can cause great suffering for families. So, the termination of pregnancy should be performed before the 16th week of gestation, giving the legal choice of a safe abortion to families. One of the main reasons for abortion is the existence of non-curable abnormalities in the fetus, in which abortion is a gateway to prevent the birth of a highly disabled individual. Prenatal diagnosis provides valuable information about pregnancy. This information is important for the parents who are prone to giving birth to a disabled child and can help them decide about terminating a pregnancy complicated with chromosomal or congenital abnormalities.⁴

Amniocentesis is a medical technique for withdrawing amniotic fluid from the uterine cavity. It has diagnostic and therapeutic indications with the most common diagnostic indications including prenatal genetic studies, and evaluation of the fetus for infections and anomalies.⁵ The procedure should be preceded by appropriate counseling regarding the purpose, risks, and alternatives.⁶

The most common invasive procedure performed as a diagnostic medium in the second trimester is amniocentesis.⁷ Although the technique is simple and has been accepted as a reliable and low risk method,⁸ it carries serious complications including loss of pregnancy.^{7,9}

Making the decision of performing prenatal diagnostic amniocentesis because of trisomy syndromes is in need of comparing the risks and hazards of giving birth to a disabled child and the risks arising of amniocentesis-related miscarriage.¹⁰ This study was performed to evaluate the indications of presentation and problems related to religious and legal limitations for presentation of Muslim parents for parental screening of chromosomal abnormalities.

Methods

The present cross-sectional study was performed on randomly selected consecutive

pregnant patients presenting for screening of congenital and chromosomal anomalies to Educational Medical Centers of Tabriz University of Medical Sciences, Tabriz, Iran, between June 2011 and June 2015.

Patients: Inclusion criteria consisted of being pregnant, being at high risk for trisomy syndromes suggested by nuchal translucency scan (NT scan) or nuchal fold (NF) and double, triple, or quadruple marker tests,¹¹⁻¹³ the history of having a fetus or newborn with chromosomal abnormalities or known congenital single gene disorders, mothers aging 40 years or higher based on personal demand, and parents with structural chromosomal abnormalities. Exclusion criteria consisted of rejecting the participation in the study and rejecting the procedure after giving information about the sampling method, fetal risks of invasive intervention, or financial problems. Of all the patients presenting to the medical centers which the study was being done, a total of 920 pregnant women presented before or after 18th week of gestational age (GA) for evaluation of fetal chromosomal status were chosen randomly. The randomization was done by the RandList software (version 1.2). Of 920 patients, 153 cases had an indication for amniocentesis and underwent this procedure. Figure 1 demonstrates the process of the study.

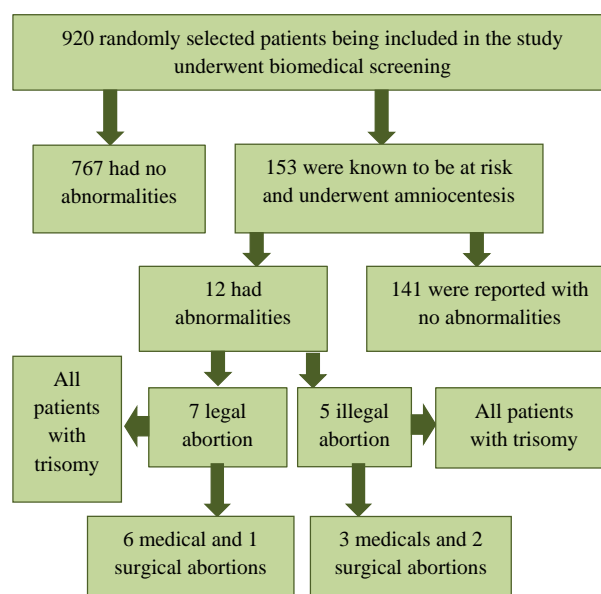


Figure 1. Consort diagram of the study

Questionnaires' design: The prepared questionnaires were used for collection of information from patients and their medical records. For all pregnant women, demographic data, GA at amniocentesis, and pregnancy outcome were recorded. Questionnaires were designed by the Delphi method in two rounds of consultation with the research development task force of Tabriz University of Medical Sciences.

Ethical considerations: All participants were provided an informed written consent about significance of karyotype abnormalities and outcomes of prenatal diagnosis including complications and indication of pregnancy termination; the study protocol was in compliance with the Helsinki Declaration and was approved by the Ethics Committee of Tabriz University of Medical Sciences. In all stages of study, patients' information was anonymous and based on codes, and patients could refuse to take part in the study at any stage.

Technique of amniocentesis: An expert obstetrician performed all amniocentesis at second trimester between 16 and 22 weeks of gestation. Amniocentesis was performed by the Amended Canadian Guideline for Prenatal Diagnosis.¹⁴ A 20-gauge needle was used for aspirating the fluid from the uterus under aseptic condition with ultrasound guidance. After the procedure was done, patients were rested for 1 hour in the hospital ward and were educated about the potentially hazardous symptoms of chorioamnionitis. The fetal anatomy and fetal

conditions were evaluated by ultrasonography (US) before the procedure. After procedure, the patients were scheduled for the next visit approximately 2 and 4 weeks later.

Statistical analysis was done by SPSS software (version 16, SPSS Inc., Chicago, IL, USA). Quantitative data sets were shown as mean \pm standard deviation (SD), and qualitative data were presented as frequency and percent (%). For statistical analysis, collected data were studied using descriptive statistical methods, the mean difference test for independent groups, and chi-square or Fisher's exact tests. A P-value < 0.05 was considered statistically significant.

Results

Of 920 pregnant women included in the study, 58.7% presented before the 18th week and 41.3% presented after 18th week of gestation for evaluation of fetal genetic status. Overall, based on blood screening methods (double, triple, or quadruple tests) 153 cases had an indication for amniocentesis and underwent this procedure.

Table 1 shows the indications for amniocentesis in studied patients presenting for evaluation of fetal chromosomal status. As it could be seen, the most common risk was having Down syndrome (DS).

Of 153 patients being assessed, 141 fetuses (92.2%) did not have any congenital abnormalities, but 12 cases (7.8%) had abnormality requiring pregnancy termination.

Table 1. Indications for amniocentesis

Indication		n (%)
Double marker test	Down syndrome	40 (26.1)
	Trisomy 18	1 (0.7)
	Trisomy 18 and Down syndrome	1 (0.7)
Triple or quadruple test	Trisomy 18 and Down syndrome	2 (1.3)
	Down syndrome	87 (56.9)
	Trisomy 18 risk	3 (2.0)
Single gene diseases	Down syndrome	1 (0.7)
	SMA risk	13 (8.5)
	Duchenne syndrome	1 (0.7)
Previous anomaly	Previous neonate with Down syndrome	3 (2.0)
	Previous neonate/fetus with congenital abnormality	1 (0.7)
Total		153 (100)

SMA: Spinal muscular atrophy

Table 2. Pregnancy termination in patients with abnormal test results (n = 153)

Status		n (%)	
Need for termination	Not needed	141 (92.2)	
	Needed	12 (7.8)	
Legal permission for termination	Given	7 (58.4)	
	Not given	5 (41.6)	
Method of termination	Legal [7 (58.33)]	Medical	6 (85.7)
		Surgical	1 (14.3)
	Illegal [5 (41.66)]	Medical	3 (60.0)
		Surgical	2 (40.0)

These cases included 8 fetuses (5.2%) with trisomy and four (2.6%) with single gene diseases: one with Duchenne syndrome and three with spinal muscular atrophy (SMA). Results are summarized in table 1.

12 patients presented to provincial Legal Medicine Organization¹⁵ for requesting justification for pregnancy termination.

The justifications were issued for 7 women (4 with single gene diseases and 3 with trisomy) according to current law. However, the remaining 5 patients (with trisomy) could not secure a justification for pregnancy termination, mostly because of late presentation [after 18th week, according to last menstrual period (LMP) of GA].

Table 2 indicates the status of pregnancy termination in patients with abnormal test results.

Discussion

We studied the indications of presentation and problems related to religious and legal limitations for Muslim parents for prenatal screening of chromosomal abnormalities in 920 pregnant women presenting before or after 18th week of gestation for chromosomal screening tests.

The most prevalent age at which our patients presented was 15 up to 26 weeks of gestation. In Islamic Republic of Iran abortion with medical indications is legal only before the 18th week of gestation.

The combination of serum marker values and amniocentesis is a method of prenatal screening in the first trimester of pregnancy.¹⁶ Second trimester genetic amniocentesis increases after positive screening tests.¹⁷ A combined test performed at the 12th week of gestation enables us to estimate the risk of

fetal trisomy with great accuracy of 85%-90% and the false positive results of about 5%.¹⁶ Evaluation of combined test in prenatal diagnosis of congenital fetal anomalies in 745 pregnant women showed that interpretation of available screening tests could prevent loss of recourses and proceed to early diagnosis.¹⁶

Neonates with trisomy 13, trisomy 18, and triploidy have the potential to be delivered alive or be associated with an increased rate of abortions, intrauterine death, and a decreased life span. Lakovschek et al. investigated the survival rates for neonates with chromosomal abnormalities and concluded that zero cases of triploidy were born alive. The live birth rate was 13% for trisomy 18 and 33% for trisomy 13. These infants died 87 hours after partum.¹⁸

Balkan et al. performed 1068 second-trimester amniocentesis. Abnormal screening result was the most common indication for amniocentesis (37.6%). Of 52 cases (4.9%) with detected chromosomal aberrations, 39 cases were numeric and 13 were structural. The highest detection rate of chromosome aberrations was in cases undergoing amniocentesis for abnormal maternal serum screening combined with abnormal ultrasound findings (8.0%). They suggested that supplementary actions, such as a routine program of antenatal sonography and maternal serum screening, should be added to increase the efficiency of genetic amniocentesis.^{19,20}

The subject of abortion is affected by political, religious, emotional, ethical, psychological, sociological, medical, and legal issues.²¹ For example, while the right to legal abortion has been given by the Supreme Court of the United States of America (USA),

several limitations have been permitted. Before legalizing abortion in 1973, many women were maimed or lost their lives due to illegal abortions.²² Women, even now, are faced with multiple political, institutional, medical, and social hurdles even in countries where abortion is legal,²³ obligating them to choose unsafe abortion which is defined as termination of pregnancy by people lacking the necessary skills, and/or in an environment without minimum medical standards.²⁴ Nearly 50% of all abortions performed worldwide and even more in developing countries in 2008 were unsafe.²⁵

About 40% of women live in territories where abortion is prohibited by the law. Abortion laws are still restrictive in many countries and there are a few countries that give women the right to terminate a pregnancy legally according to their individual beliefs.²³

Issues and problems related to abortion are an important conversation in ethics of medicine. In countries such as Iran and other countries with a majority of Muslim citizens, abortion is discussed from an Islamic perspective, but again, the legalization of abortion varies in different Islamic countries.^{26,27} The indications of pregnancy termination in Muslim countries of the Middle East and North Africa regions are risk of woman's life (all countries), risk to maternal physical health (Jordan, Kuwait, Morocco, Qatar, Saudi Arabia), risk to physical and mental health (Algeria), definite fetal impairment (Kuwait, Qatar), rape (Sudan), and all grounds in first trimester (Tunisia, Turkey).²⁸ Abortion in Iran is restricted to cases with strong therapeutic indications as defined previously by the country law, but even in the case of illegal abortions, postoperative care is widely available in Iran's public and private sectors as part of the integrated health system.²⁷ This was true about the five mothers in our study who performed termination by illegal ways including medical or surgical method.

The limitation for pregnancy termination is not limited to Islamic countries. Dutch law

permits the couple to terminate pregnancy up to 24 weeks; thereafter, the legal possibility of termination is limited.²⁹ In a study by Stuck et al., the view of Evangelical Lutheran Church in America (ELCA) toward termination of pregnancy varied depending on the severity of the genetic abnormality. Severity was based on life compatibility, and they viewed termination as an option from 23% (DS) to 62% (anencephaly).³⁰

The Iranian parliament has ratified some laws in recent years including the Therapeutic Abortion Act in 2005. The Act allows abortion after diagnosis by three gynecology and obstetrics specialists and a confirmation by the Legal Medicine Organization.^{27,31}

Bazmi et al. suggested that in spite of many efforts made to legitimize abortion in Iran, it has to be kept working on the issue in order to add some other diseases to the list of indications in future,³² because lack of access to safe abortion has been a massive contributing factor to high rates of maternal mortality and morbidity around the globe.³³

Hessini discussed the abortion laws in nearly all Islamic countries and highlighted the necessity of strategies which enables all Muslim women to benefit from their sexual and reproductive rights.²⁶ Hessini also studied the abortion services in these countries and concluded that factors including progressive interpretations of Islam have resulted in laws allowing for early abortion on request in some countries; others permit abortion on health grounds or in cases of rape or fetal impairment.²⁸ Boland and Katzive studied these laws in 196 countries and suggested that the general trend toward liberalization of abortion-related laws should be challenging to reverse.³³

Safe abortion is still limited in most territories with a majority of Muslims living in them, and illegal abortion is still a hot topic of public dialog. It is urgent to have effective policies to manage public health challenges such as abortion with culturally and socially appropriate solutions.²⁷ Shapiro discussed the possible action plan to a more lenient abortion policy in Muslim countries

and concluded that with putting more focus on legal Islamic texts in which the view on abortion was less strict and vague, and by constructing a suiting policy framework which could work in Muslim countries, gradual reforms could be possible.³⁴

Conclusion

In Islamic countries, the screening of single gene disease is usually performed earlier and the diagnostic procedures are planned considering legal and religious limitations. However, this is not true about the trisomies in which the screening is not considered as important as in single gene diseases, and for the mothers presented in the late first or even in second trimester for screening, diagnostic tests and decision for continuation or termination of their pregnancy are made after 16th or even 18th week of gestation. So, regarding the legal and religious limitation of pregnancy termination after 18th week in Islamic countries, the parents who decide to terminate the pregnancy in this period, because of late access to the results of genetic tests, are encountered with a major problem, obligating them to choose illegal ways to terminate the pregnancy, with so many unnecessary surgeries which are not indicated. Therefore, it is highly

recommended that the first trimester screening programs including 12th week US, double marker test, and if necessary chorionic villus sampling (CVS) be used in Islamic countries in order to obtain early decision-making, and prevent illegal acts, their medical complications, and guilt.

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Authors' Contribution

All of the authors contributed equally.

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Conflict of Interest

Authors have no conflict of interest.

Ethical Approval

The study protocol was approved by Medical Ethics Committee of Tabriz University of Medical Sciences (No. 5/4/10631).

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