Attitude toward Prenatal Testing and Termination of Pregnancy among Health Professionals and Medical Students in Saudi Arabia

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Abstract

Keywords

- prenatal diagnosis
- termination of pregnancy
- noninvasive procedures
- invasive procedures

This study was aimed at assessing the attitude of health care professionals in Jeddah city toward prenatal diagnosis (PND) and termination of pregnancy (TOP). A cross-sectional study was conducted, and the participants completed a self-administered questionnaire. Approximately 82% of participants showed a consistent trend of accepting PND when appropriate, and 47.5% of the respondents were in favor of TOP if the fetus had a severe disease. Compared with men (69.3%), a significantly greater number of women (88%) accepted to have PND. The most acceptable prenatal diagnostic tests in the study were invasive techniques as most of the participants thought that noninvasive tests were nonspecific.

Introduction

Of all neonates, 2 to 3% have one or more major congenital abnormality, of which at least 50% are caused exclusively or partially by genetic factors. The incidences of chromosome abnormalities and single gene disorders in neonates are approximately 1 in 200 and 1 in 100, respectively.¹ Prevalence of single-gene disorders increases with consanguinity that is common in Arab countries. In Saudi Arabia, consanguinity is present in 30 to 70% of all marriages, depending on the province, and in 67.3% of families of handicapped children.^{2–4}

The progress in genetics research has improved the diagnosis and enhanced the knowledge of the etiology of genetic disorders, thereby enabling diagnosis of genetic diseases prenatally. Prevention of child birth with major genetic condition relies on prenatal diagnosis (PND) and termination

of affected pregnancies (TOP).^{5,6} Invasive PND techniques for genetic diseases (e.g., amniocentesis and chorionic villus sampling) are now available along with the other conventional noninvasive measures, such as ultrasound (US) and maternal serum screens.⁶ PND is now widespread in many countries; not only does it allow parents to make an informed choice regarding reproductive options but it also plays a major role in reducing the incidence of genetic disorders in population. However, PND that is late or ambiguous raises a new level of complexity regarding the decision of TOP, not only for parents but also for health care providers and policy makers.^{7,8}

In Islam human life begins at the time of ensoulment, which is stated in the Hadith (Sayings of the Prophet Mohammed) to be at 120th day from the moment of conception, which is equivalent to 134 days from the last menstrual

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period (LMP) used by obstetricians. Prior to that moment the embryo has sanctity, but not reaching that of a full human being.⁹

Fatwa (an Islamic edict) 4 of the Islamic Jurisprudence Council of the World Islamic League (Organization of Islamic Countries) at its 12th session (15–22 Rajab 1410H/10–17 February, 1990 CE) in Makkah Al-Mukarama agreed by a majority vote to allow for the option of abortion under certain specific conditions. The *fatwa* determined that an abortion may take place only if a committee of specialized, competent physicians has decided that the fetus is grossly malformed and that its life would be a calamity for both the family and itself. The malformation must be untreatable, unmanageable, and very serious, and the abortion may only be performed prior to the 120th day of conception (computed from the date of fertilization, not the last menstrual cycle). On basis of this *fatwa*, abortions of serious congenital disease are performed in the hospitals of Saudi Arabia.^{9–13}

PND is practiced sporadically in Saudi Arabia. There is no national program to screen for fetal anomalies due to the potential need for TOP. In spite of the *fatwa* 4, there is no consensus on which fetal anomalies are acceptable indications for TOP prior to 120 days. However, some diseases, such as thalassemia, sickle cell disease (SCD), or Down's syndrome (DS), are not indications for TOP. Parent's decision on TOP (if allowed) is influenced by level of awareness, education, religion, culture, social environments, and personal perception on the severity of the condition; however, a major determinant of TOP decisions is the attitude of health care professionals toward PND and TOP.^{7,8,14–17} The attitude of health care professionals toward PND and TOP has been studied in some countries such as Sri Lanka and Japan.^{5,18} However, there is currently a gap in the literature regarding the attitude toward PND and TOP among health care professionals in Saudi Arabia. Jeddah is a cosmopolitan city and the commercial capital of Saudi Arabia. It is situated on the Western Coast by the Red Sea. This study reports the results of a self-administered questionnaire survey aimed at assessing the attitude of health care professionals in Jeddah toward PND and TOP.

Subjects and Methods

The cross-sectional study was conducted on 179 health care professionals from different hospitals while attending a scientific meeting of medical students in 2014, held in Jeddah, Kingdom of Saudi Arabia. The sample included all the attendees who were willing to participate in this study; the response rate was 90%.

The participants completed a self-administered questionnaire comprising two sections. Section 1 collected demographic information about the participants and personal history of hereditary diseases. Section 2 contained questions aimed to test the participants' knowledge regarding PND and assess their attitude toward TOP. The validity of the questionnaire was assessed by local experts. The participants were asked to consider the TOP were allowed by religious authorities in Saudi Arabia for providing answers to

questions on "attitude toward TOP." Ethical approval was obtained from the local research ethics committee. The survey answers were coded and computerized statistical analysis of obtained data was done using SPSS version 16. Chi-square test was used. A *p* value of < 0.05 was considered significant.

Results

In all, 179 participants were enrolled in this study. Of the participants, 129 were native to Saudi Arabia. There were 34 physicians from different specialties (14 pediatrics, 5 medical genetics, 4 neurology, 4 clinical nutrition, 3 laboratory medicine, 2 radiology, 1 neonatology, and 1 cardiology). The age range was 18 to 58 years, and the mean age was 26.9 years. All participants were Muslims. A positive family history of genetic diseases was noted in the case of 33 participants (18.4%), with the most common diseases being SCD, thalassemia, and glucose 6-dehydrogenase (G6PD) deficiency. The demographic data of the studied group are summarized in ►Table 1. The survey results on the participants' general knowledge about hereditary disorders and acceptance of PND and TOP are summarized in ►Table 2. The percentage of participants who thought PND of DS is possible was higher at 64% (115/179), compared with those who did not think so (11%; 21/179) and the remaining were indecisive. A significant number, that is, 60.3% (108/179), of the study population believed that not all genetic disorders could be diagnosed prenatally; 23.5% (42/179) thought that all genetic disorders could be detected prenatally, and 16.2% (29/179) were not sure. Overall, 82.1% (147/179) of the participants showed a consistent trend of accepting and encouraging PND when appropriate whereas 7.8% (14/179) was against that, and 10.1% (18/179) did not know. Further, 47.5% of the participants had positive attitude toward TOP as an important option if the fetus has a severe disease, whereas 34.15% did not think so, whereas 33 (18.4%) were indecisive (►Table 3).

On stratification according to gender, nationality, presence of a family history of genetic disease, and occupation, no significant difference was noted regarding the participants' view that PND can detect all genetic diseases (►Table 4). Compared with men (43/62; 69.3%), a significantly (*p* = 0.0395) greater number of women (104/117; 88%) responded that they would encourage their patients to have PND. When respondents were classified based on occupation, 73.5% of physicians and 41.4% (*p* = 0.001) of the medical students believed that TOP was an important option if the fetus had a severe disease. Overall, 59/179 (33%) of the participants thought that US screening for congenital abnormalities is an effective method, whereas 62/179 (34.6%) disagreed and the rest were undecided. In our study, 24 (70.6%) of the participants thought that PND by amniocentesis with chromosomal analysis was more accurate, whereas 82.4% thought that DNA analysis was accurate (►Table 5). When asked whether they had discussed these issues previously as part of their undergraduate curriculum or at their institutes, 46.9% of the students and 76.5% of the

Table 1 Demographic and social data of the participants

Demographic data	All participant 179(%)
Sex	
Men	62 (34.6)
Women	117 (65.4)
Age (y)	
Mean	18–58
Social status	
Married	28 (15.6)
Single	151 (84.4)
Family history	
Positive	33(18.4)
Negative	146 (81.6)
Nationality	
Saudi	129 (72.1)
Other than Saudi	50 (27.9)

physicians responded affirmatively. Further, 86.2% of the students thought that these issues warranted further discussion.

Discussion

Congenital and genetic disorders are responsible for a major proportion of infant mortality, morbidity, and disability in Arab countries^{19,20} due to high prevalence of consanguineous marriages that increase incidence of autosomal recessive disorders.¹¹

Tests used in PND, especially those for diseases with a low incidence, must have good sensitivity in addition to acceptable levels of specificity.²¹

Not surprisingly, the issue of PND and subsequent recommendation for TOP raises many serious concerns for individuals and families and prompts serious questions about the way in which society views and cares for both children and adults with disabilities and the inability of our society to

appropriately care for disabled children and the risk of eugenic pressure.^{1,22}

The knowledge of the sample population was explored using a self-administered questionnaire designed by the authors. The first set of questions crudely tested the participants' knowledge of PND in general. Most participants answered these questions correctly. The second set of questions, however, tested the participants' acceptance of PND tests and TOP.

Prenatal Diagnosis

When asked about whether PND is possible for all genetic diseases, 60.3% correctly answered in the negative and indicated that PND is not possible for all genetic diseases but only for some; this suggested that the participants had good knowledge. While genetic testing enables the assessment of genetic risk and diagnosis, it may not always identify all the possible gene mutations that can cause a particular condition or may have limited predictive value.^{23,24} Although the percentage of the participants who thought that PND can detect all genetic diseases was small at 23.5% (►Table 2), with no significant difference between physicians (17.65%) and students (24.8%) (►Table 4), this finding may indicate the possibility of health care workers missing opportunity to identify risk factors or record data on the family history of genetic disorders. This finding highlights the need for educating all medical personnel regarding PND.

Overall, 147/179 (82.2%) of the participants had positive attitude toward the general idea of PND and were willing to encourage their patients to undergo prenatal testing when needed. However, the principle of nondirective counseling must be applied in all instances of PND. It should be clear that a pathologic result in no way automatically means TOP.²⁵ This percentage is significantly high compared with those reported previously in study conducted by Babay,²⁶ which revealed that 61.1% of pregnant Saudi women accepted the general idea of PND. The high ratio of our participants was expected as the study population comprised a highly educated group of medical students and physicians, which is similar to observation by Al-Aama et al,²⁷ per which the influence of education at the university level may override any cultural or familial differences. Our finding of a significantly higher number of women (88%) likely to encourage PND than men (69.3%) was similar to the study done by Alsulaiman and Hewison,²⁸ in which the mothers' attitudes toward TOP were more favorable, which may be attributed to the notion that women may bear the burden of the unwell child to a greater extent than men.

Some Muslim scholars argue that abortion is permissible if the newborn might be sick in such a way that its care would be exceptionally difficult for the parents (e.g., deformities, mental retardation).²⁹

Termination of Pregnancy

In the present study, the attitudes to TOP were much less favorable than those toward PND, as 47.5% of the participants believed that if a fetus had a severe disease, TOP (abortion) was an important option, whereas 34.1% did not accept this

Table 2 The knowledge and attitudes toward PND and TOP

Yes (%)	Variable
42 (23.5)	PND is possible for all genetic diseases
147 (82.1)	Accept and would encourage their patients to have PND
85 (47.5)	Believed TOP is an important option if a fetus has a severe disease
115 (64)	PND of DS is possible
50 (28)	PND of SCD is possible

Abbreviations: DS, Down's syndrome; PND, prenatal diagnosis; SCD, sickle-cell disease; TOP, termination of pregnancy.

Table 3 Testing the knowledge and attitude between all persons included in the study (179)

No (%)	Yes (%)	Variable questions
108 (60.3)	42 (23.5)	PND possible for all genetic diseases
14 (7.8)	147 (82.1)	Accept and would encourage their patients to have PND
61 (34.1)	85 (47.5)	Believe TOP is an important option if a fetus has a severe disease

Abbreviations: PND, prenatal diagnosis; TOP, termination of pregnancy.

Table 4 Stratification of participants' attitudes toward the PND and TOP

Variable	PND is possible for all genetic disease (%)	<i>p</i>	Accept and would encourage PND (%)	<i>p</i>	TOP is an important option (%)	<i>p</i>
Sex						
Men (62)	18 (29.2)	0.1182	43 (69.3)	0.0395 ^a	33 (53.2)	0.8700
Women (117)	24 (20.5)		104 (88)		52(44.4)	
Nationality						
Saudi 129	32 (24.8)	0.5069	110 (85.3)	0.4729	48 (37.2)	0.3891
Others 50	10 (20)		37 (74)		37 (30)	
Family history						
+ve (33)	11 (33.3)	0.0962	29 (87.9)	0.3321	13 (39.4)	0.3388
–ve (146)	31 (21.2)		118 (80.8)		72 (49.3)	
Job						
Physicians (34)	6 (17.6)	0.5010	24 (70.6)	0.0785	25 (73.5)	0.001*
Students (145)	36 (24.8)		123 (84.8)		60 (41.4)	

Abbreviations: PND, prenatal diagnosis; TOP, termination of pregnancy.

^a*p* < 0.05 significant.

due to ethical and religious issues. These values were similar to those reported in the study by Shoham-Verdi et al in which only 6 of 11 (54.5%) pregnancies with the diagnosis of a trisomy were terminated (all cases terminated were trisomy 21; one case of trisomy 21, 1 case of trisomy 13, and 3 cases of trisomy 18 were diagnosed and were not terminated)¹⁶ and those reported in the study by Babay, wherein 29.1% of the pregnant women did not accept the idea of screening,²⁶ mainly because of the nonacceptance of TOP as an option and also doubt over the accuracy of the tests.²⁶

Subgroup analysis of the participants regarding their approach toward TOP showed that there were no significant differences except when data were analyzed with regards to occupation, when 73.5% of the physicians considered

termination as an important option in comparison with 41.4% of the medical students. This may be explained by the greater practical experience of the physicians and greater level of information and trust toward the PND tests. In real life, parents required to make a decision may not behave similarly as many factors other than perceived severity, such as gestation, family composition, experience with the condition, and parents' level of education, are known to influence the decision to terminate an affected pregnancy, if that option is available and allowed by religious authorities.^{16,30} For all questions, no significant difference was noted in the responses with regard to nationality, as most of the participants of other nationalities were also Arabs (from Egypt, Jordan) and Indians who shared the same sociocultural background and were expected to have the same attitude regarding these issues.

Ultrasound

Overall, 33% of the participants thought that PND for structural abnormalities using US was acceptable and accurate; while the acceptance rate was 61.1% in another study on pregnant females undergoing routine follow-up. This high acceptance rate in the previous study was probably because it is a familiar part of a routine antenatal care and noninvasive in nature with no adverse effects.²⁶

Table 5 More specialized question for physician as regards methods of PND of DS

Yes (%)	Variable
10 (29.4)	PND by maternal serum screening is accurate
24 (70.6)	PND by amniocentesis is accurate
28 (82.4)	PND by DNA analysis

Abbreviations: DS, Down's syndrome; PND, prenatal diagnosis.

Invasive Prenatal Diagnosis

PND of chromosomal anomaly by amniocentesis (which is an invasive technique) has a detection rate close to 100% but carries 0.5 to 1% risk of miscarriage. Other noninvasive methods (NIMs) using maternal serum and ultrasound have detection rates ranging from 60 to 90%.²⁵

More specialized questions were also included for health professionals with regard to the accuracy of PND by maternal serum screening, amniocentesis with chromosomal analysis, and DNA-based tests for single-gene disorders. Only 29.4% of the participants believed in the accuracy of maternal serum screening because they believed it was not a specific test and may cause false-positive results and that it must be followed by diagnostic invasive tests. The acceptance rate for this test was higher, at 53%, in the study done by Babay et al, which was probably because the participants were pregnant women who preferred noninvasive techniques even if they were less accurate than others.²⁶

DS is one of the major causes of mental retardation and so is of major socioeconomic concern. The overall incidence of DS worldwide is reported to be 1/600 to 1/800 live births.³¹ Several reports from different parts of the world have indicated an increase in the incidence of DS with respect to ethnicity and maternal age.^{31–33} The incidence in Saudi Arabia is reported to be 1.80 to 2.34 per 1,000 births.^{34,35}

In our study, 24 (70.6%) of the participants believed that PND by amniocentesis and chromosomal analysis was more accurate, whereas 82.4% thought that DNA analysis was more accurate. This study is similar to the study done by Yotsu-moto et al,⁵ in which the health professionals had positive attitude toward invasive technique in comparison with the pregnant women who preferred noninvasive techniques. Medical professionals consider the diagnostic accuracy and reliability of the test to be more important.

This is different from the study by Babay, in which only 34% accepted invasive procedures, probably because of the associated risk of abortion.²⁶

The main disadvantage of NIMs is that a certain percentage of the affected fetuses will not be detected, even with the relatively high sensitivity. In addition, the noninvasive tests determine the risk for only three autosomal trisomies.^{1,10,27} Moreover, they cannot rule out chromosomal abnormality, whereas invasive diagnostic tests will detect many other chromosomal abnormalities and single-gene disorders in addition to the autosomal trisomies (detection rate close to a 100%).^{25,36} Overall, 46.9% of the students and 76.5% of the health care professionals had knowledge about both PND and TOP, respectively. The fact that the participants had previously discussed these issues as part of their undergraduate curriculum or at their institutes may explain their positive attitude toward PND and TOP and why they favored the more accurate and reliable invasive techniques to NIMs to a greater extent than general population.

Of all students, 86.2% thought that these issues should be discussed in greater detail in their undergraduate curriculum, which means that they are inclined to learn about these topics. As expected, mass education, especially at high school and university levels, can play a major role in increasing the

level of knowledge regarding PND. It has also been suggested that PND should be included in the university curriculum.³⁷

In the past, Islamic authorities in Saudi Arabia have permitted TOP only if the woman's life was at risk. With the increase in the awareness of genetic conditions and widespread availability of PND, Islamic authorities have now given a *fatwa* according to the severity of the condition. Islamic authorities agreed that two physicians should reach a consensus on whether the condition is severe and communicate their decision to the Islamic authority.²⁸ Ngim et al (2013) showed the importance of the *fatwa* to Muslim parents and how their attitudes to TOP changed after they had been informed of the appropriate *fatwa*.³⁸ However, physicians sometimes have different opinions about the severity of a condition and parents' views are not necessarily taken into account.²⁸ Physicians need to have a clearer view about parents' perspectives so that they can convey the parents' views to the religious authorities. Thus, the parents' views may influence whether a condition is deemed severe by the religious authorities, and thereby whether termination is permitted.²⁸ Undoubtedly, every physician in the 21st century must have a working knowledge of the principles of medical genetics and their clinical application, especially with regard to screening programs and PND. Hence, a new curriculum for medical genetics has been designed and included in the curriculum of second year medicine to address the basic and clinically relevant core knowledge and skills that need to be acquired by graduates of the Faculty of Medicine of King Abdulaziz University.

The present study is limited because it did not include more places across the country.

Conclusion

Awareness regarding prenatal diagnostic tests and their availability and techniques was widespread in the study population of medical students and staff; this was evident from the fact that 82.1% of the participants accepted and would encourage their patients to undergo PND. This percentage is expected to increase with the inclusion of medical genetics in the undergraduate curriculum for medical students in King Abdulaziz University.

The most acceptable PND tests for participants were invasive techniques (amniocentesis); most of the participants thought that noninvasive tests (maternal serum screening and US) were not specific, were likely to afford false-positive results, and must be followed by invasive tests. Therefore, to save time and money, they preferred to proceed directly to invasive techniques. The debate over TOP remains as controversial as ever; the overall acceptance of TOP was only 47.5% due to ethical and religious causes despite the fact that PND and opting TOP on the detection of serious devastating diseases (prior to 120 days from conception) will reduce the incidence of such diseases. Therefore, it is clear that factors other than the severity of the condition affect the attitude of the parents toward TOP, including their level of education, and influence the parents' decision to terminate an affected pregnancy, even if it is available and allowed by religious authorities.

Conflict of Interest

None.

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