e - ISSN - 2349 - 8005

INTERNATIONAL JOURNAL OF ADVANCES IN CASE REPORTS

Journal homepage: www.mcmed.us/journal/ijacr

ATTITUDE OF SAUDI PARENTS WITH AND WITHOUT AN AFFECTED CHILD TOWARDS PRENATAL DIAGNOSIS AND TERMINATION OF PREGNANCY

Ayman Alsulaiman[1], Altaf A. Kondkar[2,3], Khaled K. Abu-Amero[2,3*]

[1]Department of Genetics, Research Center King Faisal Hospital and Research Center, Riyadh, Saudi Arabia.
[2]Department of Ophthalmology, College of Medicine, King Saud University, Riyadh, Saudi Arabia.
[3]Glaucoma Research Chair, Department of Ophthalmology, College of Medicine, King Saud University, Riyadh, Saudi Arabia.

Corresponding Author:- **Khaled K. Abu-Amero**
E-mail: abuamero@gmail.com

Article Info
Received 15/03/2014
Revised 17/04/2014
Accepted 28/05/2014

Key words: Genetic diseases, Prenatal diagnosis, Survey, Termination of pregnancy.

ABSTRACT
Objective to assess the attitudes of Saudi parents with and without an affected child, towards prenatal diagnosis (PND) and termination of pregnancy (TOP) for various medical and non-medical conditions. A descriptive cross-sectional study. A total of 400 Saudi parents completed a structured questionnaire which sought their views towards PND and TOP for 30 different hypothetical medical and non-medical conditions. The results were scored, compared, and comments noted. Parents attitudes varied with different conditions. Overall, there was high acceptance for PND (varying from 56.5% - 88%) and low acceptance for TOP (varying from 0% - 57.7%) for different conditions in this cohort among both men and women. Overall, the response towards PND and TOP did not vary significantly with parents having an affected or unaffected child among both men and women; however, TOP score was significantly (p=0.0251) influenced by gender. Further analysis revealed that men with affected child had significantly (p=0.0269) greater acceptance towards TOP as compared to other groups. Saudi parents are favorably inclined towards PND and there is a strong correlation between parents' attitudes toward PND and TOP in a range of diseases. The decision for TOP is influenced by having an affected or unaffected child among Saudi men.

INTRODUCTION

Congenital health problem and genetic disorders constitute a substantial medical and socio-economic burden in the Kingdom of Saudi Arabia [1]. In addition, they also have a significant psychological and social impact on the patient, the parents, their families, and the community at large. Although these disorders are relatively uncommon, they can cause high incidence of infant mortality (eg. Trisomy 13 or 18) or are frequently severely affecting the quality of life (eg. Thalassaemia, Cystic fibrosis) often leading to impairment of an individual's ability to function independently [2]. Prenatal diagnosis (PND) can offer an alternative for couples carrying a high risk of affected offspring and provide them with an informed choice for termination of pregnancy (TOP). Diagnostic amniocentesis for the prenatal testing of genetic defects began in the 1960s and 1970s. Since the early reports of the use of cultured amniotic cells for fetal rhesus D determination, fetal sex determination, chromosome abnormalities, and metabolic disorders [3], numerous centers now offer prenatal testing and the list of indications has grown tremendously [4]. With technological advances in molecular genomics, non-invasive PND [5] which utilizes cell free fetal DNA in maternal plasma may soon provide safer testing options to parents and avoid the risk of miscarriages associated with invasive diagnostic testing (chorionic villus sampling or amniocentesis) [6]. It is important to note however, that successful implementation of the services provided for prevention and control of

genetic disorders are affected not only by the ethical and technological limitation of the tests but also restricted by certain cultural, traditional, and religious beliefs. In addition, the legal challenges related to TOP vary between countries. It is therefore extremely crucial to consider the attitudes of the parents towards these preventive genetic programs and services and to address their views and concerns such that it respects the rights and interests of all involved.

Public attitude towards PND and TOP have been previously assessed in various medical situations including, hemoglobinopathies [7], Down's syndrome [8,9], Parkinson's disease [10] and deafness [11]. We and others have previously reported that attitudes of Saudi parents towards PND and TOP are not entirely dictated by the severity or the debilitating effects associated with various genetic diseases, but also influenced by awareness, social issues, cultural, and religious factors [7,12,13]. In this study we investigated the attitudes of Saudi parents (n=400) towards PND and TOP for 30 different conditions and sought to evaluate whether this response varies with parenting an affected or unaffected child.

METHODOLOGY

The Study Population

A descriptive cross-sectional study was undertaken at King Faisal Specialist Hospital and Research Center (KFSH&RC) in Riyadh, Saudi Arabia, to survey parental attitudes towards PND and TOP for 30 different hypothetical scenarios for the period July 2002 through February 2003. KFSH&RC is one of the largest tertiary care centers in the Middle East, which provides health-care services to all the sections of the Saudi society in the Kingdom and is representative of the population sample of Saudi Arabia. Parents coming from different regions in Saudi Arabia to use the medical facilities were included. Parents with an affected child were selected from different clinics including, hematology, cystic fibrosis, metabolic, and deafness. And in the other group, parents without an affected child were selected from visitors to the outpatient clinics, accompanying their father or mother to the clinic. The study had the approval of the institutional research and ethical committee at KFSH&RC. The study adhered to the tenets of the declaration of Helsinki and informed consent was obtained from each participant.

Questionnaire Design and Interview

A questionnaire was designed and evaluated with the help of a group of multi-disciplinary team that included experts in the field of genetics and genetic epidemiology. The primary aim of the questionnaire was to integrate the demographic and socio-economic characteristics of the participants, as well as their attitudes towards PND and a possibility of TOP of affected embryos. Accordingly, the major sections in the questionnaire included: demographic and socio-economic information; and response to a series of 30 different medical and non-medical scenarios in terms of PND and TOP.

The interview for both the parents was conducted separately and took about 60-80 min. A trained genetic counselor explained to each participant all the conditions in a simplified language avoiding medical terminologies to make it easier for the participants to understand. As an example, instead of Turner's syndrome, *"child would be a very short female who might have some medical problems, a normal lifespan, and would not be able to have children."* A participant was given three options for each scenario (yes, no, do not know) and their response was noted.

Data Analysis

The questionnaire data was entered into the Statistical Package for the Social Sciences (SPSS) program. Data was initially summarized in the form of frequencies and percentages. Descriptive statistics were used to calculate mean and standard deviations (SD). Student's *t*-test and Mann-Whitney U test were used to calculate difference between the mean values. Chi-square test was performed to determine difference between frequencies with Fisher's exact test (with Yates correction as applicable). Based on the response to the questionnaire PND and TOP scores were calculated as described previously [11]. To determine the difference between the correlated proportions non-parametric Cochran Q test was used.

RESULTS

The study was conducted in July 2002 through February 2003. Of those approached, there was an overwhelming response and 94.8% (400/422) agreed to participate. The reason cited for refusal included "sensitive" (n=7); "in hurry" (n=6); and "practical problems" (n=9).

A total of 400 individuals participated in the study consisting of 4 groups of one-hundred each. These included - men with an affected child and an unaffected child (n=100 in each group); and women with an affected child and an unaffected child (n=100 in each group). The demographic and socio-economic characteristics of participating men and women are shown in Table 1.

It is apparent from Table 1 which compares fathers without affected children, and fathers with affected children, that fathers with affected children were significantly older, had more than one wife, and had more number of children. Fathers without affected children had significantly higher income. However, there were no significant differences in the level of education between the two groups of fathers.

Similarly, as shown in Table 1, the mothers with affected child were found to be significantly less educated, have lower income, and more number of children as compared to mothers with unaffected child. However, there was no significant difference in age between the two groups. Of note, a partner (both parents) attending the clinic with affected child was highly significant as

compared to those with unaffected child. Furthermore, most of these women were providing new data, different from the men's data.

In order to assess parents' attitudes toward PND and TOP in a range of different conditions that were presented in the questionnaire, responses are described based on the three categories of response in the questionnaires, namely "No", "Yes", and "Not sure". Individual respondents gave their answers based on their views about the conditions. The views of all respondents were then summarized for each condition in terms of the percentage giving each reply, and the conditions were ranked according to the percentage of "yes" responses. Figures 1 and 2 shows that there was a clear gradation in personal acceptance of prenatal testing and termination of pregnancy, which was highest for severe learning difficulty and lowest for the child not being of the sex desired by the parents in case of prenatal testing and also a clear gradation in personal acceptance of termination of pregnancy; running from child born without brain (anencephaly) to child is not of sex desired by parents. The majority of parents of affected children had more than one affected child. The overall acceptance rate (in all groups combined) towards PND was found to be 75%. Among men there was a high degree of acceptance for Severe LD/MH (92%), Thalassaemia (91%), and Quadriplegia (91%) as compared to Severe LD/MH (84%), Thalassaemia (82%), and Phenylketouria (82%) in women and was found to be comparable.

The overall acceptance for TOP was found to be 25%. The highest TOP acceptance rate was seen for Anencephaly (62%), Severe LD/MH (59%), and Trisomy 13 or 18 (52.5%) among men as compared to Anencephaly (53.5%), Trisomy 13 or 18 (53.5%), and Duchenne muscular dystrophy (46%) among women and was again observed to be comparable.

We next evaluated whether the attitude of parents towards PND and TOP varies with parenting an affected or unaffected child. A univariate analysis showed that gender was found to significantly influence the TOP score (p=0.0251). Further analysis showed that men with affected child showed significantly greater acceptance towards TOP as compared to other groups (p=0.0269) [Table 2]. There were no significant differences in the mean/median rank scores with respect to socio-demographic variables such as age group, education, income, partner attending the clinic, husband married to another wife, and number of children towards PND and TOP. Interestingly, as shown in Table 3, significant differences were seen in the men group for some of the conditions such as Huntington's disease (p=0.03), Klinefelter syndrome (p=0.015), and schizophrenia (p=0.043); and a trend was seen towards deafness (p=0.053) and dwarfism (p=0.057), where an increased acceptance of TOP was observed. However, no such differences were observed in the women group (Table 4).

Statistically, it is important to know if parents have significantly different views of prenatal testing and termination of pregnancy for different genetic conditions. The non-parametric Cochran Q test for the difference between correlated proportions was used because, in this study, there were thirty conditions to be compared. A Q value of 1100.77 was significant at $P<0.001$ in case of prenatal testing, and $Q = 1961.85$ was significant at $P<0.001$ in case of termination of pregnancy. This finding indicates that Saudi parents held very different attitudes to the different conditions in this study. In order to find out if there is a relationship between parents' collective attitudes toward prenatal diagnosis and their collective attitudes towards termination of the pregnancy. Spearman's test was run to find the correlation between the two attitudes, based on the numbers saying 'yes' for each condition. It should be noted that some kind of positive relationship was anticipated, since at an individual level, people who said 'no' to prenatal diagnosis did not say 'yes' to termination of pregnancy. However, of those who wanted prenatal diagnosis (usually the majority), only a proportion wanted termination of pregnancy, so the relationship between the two attitudes at a collective level remains of interest. It was found that the collective responses correlated significantly and positively with each other (prenatal diagnosis and termination of pregnancy in different conditions presented in the questionnaire, Spearman's *rho* = + 0.896, $p<0.001$).

Table 1. Demographic and socio-economic features of participating men and women

Variables	Men with Affected child (n=100)	Men with Unaffected child (n=100)	Women with Affected child (n=100)	Women with Unaffected child (n=100)
Age in years, mean (±SD)	37.8 (7.4)	35.2 (6.5)*	31.6 (6.1)	30.9 (5.9)
≤ 35, N	68	78	92	92
> 35, N	32	22	8	8
Education, N				
Primary to secondary	55	57	54	42**
University and above	16	28	21	53
Husband with > 1 wife, N	20	8*	12	8
Income in SAR, N				
≤ 10,000	55	41*	88	74*
> 10,000	45	59	12	26

No. of children, mean (±SD)	5.1 (2.4)	3.3 (2.4)**	5.17 (2.6)	3.2 (2.1)
No. of affected children, N				
1	42	-	46	-
> 1	58	-	54	-
Partner attended the clinic, Yes, No. (%)	-	-	54	22†

*p<0.05; **p<0.001; †p=3.14 E-05

Table 2. Effect of gender on choice of prenatal diagnosis and termination of pregnancy

Variables	Category	PND score†Mean (±SD)	P value	TOP score Mean (±SD)	P value
Gender	Male	78.04 (25.39)	0.133	28.10 (22.26)	**0.025**
	Female	75.80 (31.34)		35.57 (28.23)	
Male (with)	Affected child	78.50 (23.56)	0.556	32.08 (24.02)	**0.027**
	Unaffected child	77.58 (27.21)		24.11 (19.68)	
Female (with)	Affected child	74.15 (33.21)	0.326	37.00 (30.41)	0.624
	Unaffected child	77.46 (29.42)		34.15 (25.94)	

†PND, prenatal diagnosis; TOP, termination of pregnancy

Table 3. Response to prenatal diagnosis and termination of pregnancy in 2 groups of participating men

Genetic Conditions	Category				P value
	Men with affected child (n=100)		Men with unaffected child (n=100)		
	PND†	TOP	PND	TOP	
	Yes (No.)	Yes (No.)	Yes (No.)	Yes (No.)	
Absent Limb	83	29	82	18	0.160
Alzheimer's disease	49	5	61	6	0.950
Anencephaly	86	60	84	64	0.700
Autism	71	19	73	12	0.220
Blindness	78	17	74	11	0.360
Cancer	83	20	75	10	0.150
Cleft lip and palate	50	1	63	5	0.360
Coronary at 50yrs	56	3	67	5	0.930
Cystic fibrosis	92	31	80	17	0.170
Deafness	76	12	77	4	**0.053**
Diabetes	86	35	82	20	0.107
Duchenne muscular dystrophy	94	50	84	31	0.180
Dwarfism	64	8	61	8	0.920
Epilepsy	87	29	78	13	**0.057**
Fragile X syndrome	79	19	80	15	0.510
Grossly overweight	70	16	72	10	0.250
High risk of alcoholism	75	34	62	15	0.074
Huntingdon's disease	81	27	76	11	**0.030**
Klinefelter's syndrome	83	36	75	14	**0.015**
Mild LD/MH	64	4	68	5	0.810
Moderate LD/MH	81	14	72	6	0.150
Not the preferred gender	35	0	47	0	-
Phenylketonuria	92	28	77	16	0.270
Proteus syndrome	83	28	84	24	0.600
Quadriplegia	96	53	87	38	0.360
Schizophrenia	83	39	77	19	**0.043**
Severe LD/MH	94	63	90	55	0.690
Thalassaemia	96	43	88	36	0.730
Trisomy 13 or 18	93	56	85	49	0.860
Turner's syndrome	73	20	68	13	0.360

†PND, prenatal diagnosis; TOP, termination of pregnancy.

Table 4. Response to prenatal diagnosis and termination of pregnancy in 2 groups of participating women

Genetic Conditions	Category				P value
	Women with affected child (n=100)		Women with unaffected child (n=100)		
	PND†	TOP	PND	TOP	
	Yes (No.)	Yes (No.)	Yes (No.)	Yes (No.)	
Absent Limb	79	30	77	25	0.610
Alzheimer's disease	58	16	58	12	0.490
Anencephaly	75	51	82	56	1.000
Autism	68	22	70	12	0.100
Blindness	72	22	74	13	0.150
Cancer	77	28	75	24	0.690
Cleft lip and palate	64	11	71	5	0.100
Coronary at 50yrs	58	10	60	9	0.770
Cystic fibrosis	70	32	74	19	0.080
Deafness	77	19	75	14	**0.470**
Diabetes	82	48	78	33	0.230
Duchenne muscular dystrophy	77	51	86	41	0.200
Dwarfism	65	18	66	17	0.850
Epilepsy	78	32	75	32	**0.890**
Fragile X syndrome	76	30	73	20	0.270
Grossly overweight	72	18	72	12	0.310
High risk of alcoholism	75	35	68	26	0.510
Huntingdon's disease	69	27	77	23	**0.410**
Klinefelter's syndrome	74	28	77	31	**0.840**
Mild LD/MH	68	16	65	8	0.160
Moderate LD/MH	73	23	76	18	0.420
Not the preferred gender	42	0	42	0	-
Phenylketonuria	80	35	84	33	0.710
Proteus syndrome	80	44	81	39	0.620
Quadriplegia	79	50	83	38	0.220
Schizophrenia	81	33	80	33	**0.960**
Severe LD/MH	86	52	82	38	0.310
Thalassaemia	81	41	83	40	0.850
Trisomy 13 or 18	81	51	82	56	0.740
Turner's syndrome	72	31	77	25	0.370

†PND, prenatal diagnosis; TOP, termination of pregnancy

Figure 1. Parents attitude to prenatal diagnosis in different conditions.

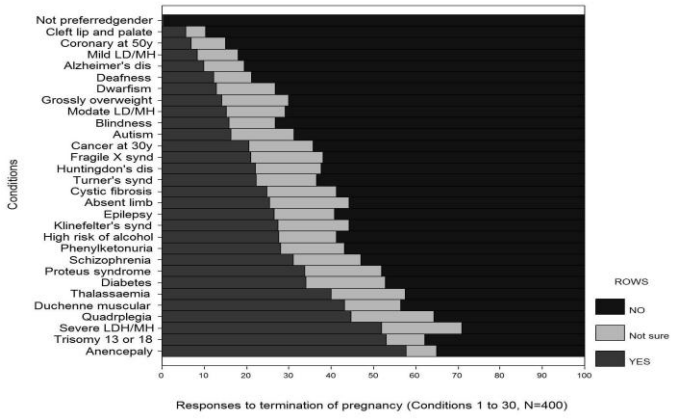
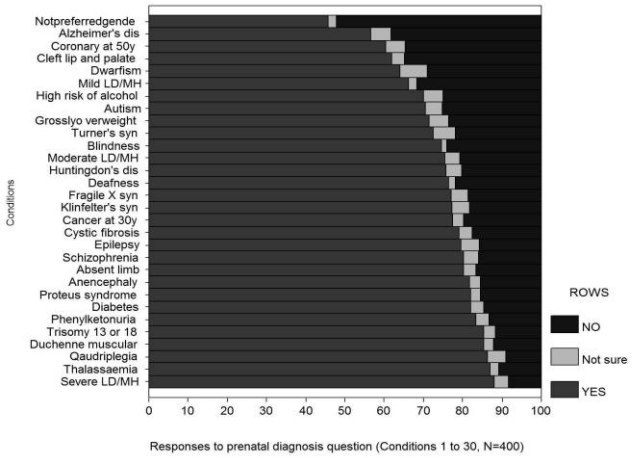


Figure 2. Parents attitude to termination of pregnancies in different genetic conditions



DISCUSSION AND CONCLUSION

This study was successful in assessing the attitude of Saudi parents having an affected or unaffected child towards PND and TOP in a range of 30 different conditions, and a wide range of views were discovered. Although the response varied with different genetic conditions, as expected there was a high level of acceptance for PND and some degree of acceptance towards TOP for a range of different conditions evaluated in this sample population. However, it must also be remembered that even if the attitudes reported are valid, attitudes should not be confused with behaviour; what people say does not always indicate what they will do. For instance, other studies showed that a majority of those at risk of Huntington's disease said they would have a genetic test when it became available, yet only a small proportion underwent the test when it did become available [14]. Similar findings have been obtained for predictive testing for cancers in the both United States [15] and Europe [16]. Other studies have shown that after finding out that their child is affected with Down's syndrome, a much higher proportion of parents are willing to terminate the pregnancy than attitude studies would suggest [17].

In this study, the overall acceptance rate for both PND and TOP was found to be comparable to our previously published report [11]. With the exception of gender, no other confounding variable was found to influence the parents attitude towards PND or TOP. Although the overall TOP acceptance rate among women with affected child (30.13%) and unaffected child (25.06%) was higher than in men with affected child (26.63%) and unaffected child (18.33%); it was interesting to note that men with affected child showed significantly higher acceptance for TOP as compared to men without an affected child; and no such significant difference was noted among the 2 group of women population. These findings suggest that a significantly high percentage of men would opt to terminate a pregnancy under a given genetic condition as opposed to women. This is expected, because the decision to terminate a pregnancy is not easy and is strongly influenced by religious and cultural beliefs, and many other emotional factors. These factors may tend to hinder a woman's decision to terminate a pregnancy despite the severity of a disease. This however, also raises a possibility that when the parents face the real implications in their life, they might change their minds and opt to terminate a pregnancy.

Hence, genetic counselors should explore the implications that parents might face with their affected child according to their culture [18]. However, in a country like Saudi Arabia, where termination is not allowed in all genetic conditions, there is no point in the genetic counselor exploring the implications with the family, in the case of conditions for which termination is not allowed, unless others reproductive technologies can be offer such as pre-implantation genetic diagnosis. While most parents in this study wanted PND to find out whether their baby had the condition or not, they were not willing to consider TOP for most of the conditions. This suggests that parents reason for wanting PND was not alone to terminate the affected fetus. However, there was a strong tendency that conditions for which many parents wanted PND were also the conditions for which many of them wanted TOP. This is in contrast to the study of Zlotogora and Reshef [19] which reported that Muslims' parents doing prenatal diagnosis only to know the health status of the baby.

According to the findings in the present study, the characteristics of each condition have a large impact on how parents perceive that condition, which indicate that the medical characteristic of the condition, e.g., whether the individual has a chronic debilitating disease, a learning difficulty, or only minor anomalies, may influence parental decisions about prenatal testing as found in other study [20]. However, many studies [10,21-24] have looked at attitudes to prenatal diagnosis and termination of pregnancy without specifying the kind of condition that causes impairment or disability to the child.

In the present study, conditions were ranked according to the parents attitudes towards TOP. In the cases of mild disorder or in the cases of severe clinical conditions, rank orders were similar to those reported from other populations [20,25,26]. For instance, data from participants in the present study and in the above three studies showed that the situation in which they would be least inclined to favour termination of the pregnancy was gender preference (0.4%, 2%, 1.9% respectively), and one of their highest ranked choices was severe learning difficulty (58%, 55%, 35.7% respectively). For prenatal diagnosis [25,26] a similar trend was found in rank order for gender preference (18%, 34.4% respectively) and one of the highest conditions in the ranking order was severe learning difficulty (68%, 78% respectively).

It should be noted that in this study none of the parents were favorable toward TOP in case of gender preference, which might indicate that when termination of pregnancy offering to public parents will not terminate the pregnancy in cases where the child will be normal. In addition, the positive attitude towards prenatal diagnosis found in this study reflects the overall positive attitudes of the population towards health care. Hence, it should be borne in mind that it makes sense for health service planners to understand the implications that the parents with an affected child might face when there is a lack of health services around them.

In conclusion, Saudi parents are favorably inclined towards PND and there is a strong correlation between parents attitudes toward PND and TOP in a range of disease conditions. The decision to terminate a pregnancy is significantly influenced by having an affected or unaffected child among Saudi men. New technologies may provide parents with more reproductive choices but also present them with more dilemmas.

ACKNOWLEDGEMENT

KKA, Ph.D and AAK, Ph.D are supported by the Glaucoma Research Chair programs at the Deanship of Scientific Research, King Saud University, Riyadh, Saudi Arabia.

REFERENCES

1. Al-Gazali L, Hamamy H, Al-Arrayad S. Genetic disorders in the Arab world. (2006). *BMJ*, 333(7573), 831-834.
2. Ron G, Headley J, Oakley L, Kurinczuk JJ, P. Brocklehurst, Hollowell J. (2009). Inequalities in infant mortality project briefing paper 3. Towards an understanding of variations in infant mortality rates between different ethnic groups. *Oxford: National Perinatal Epidemiology Unit*, 1-10.
3. Epstein CJ, Schneider EL, Conte FA, Friedman S. (1972). Prenatal detection of genetic disorders. *Am J Hum Genet*, 24(2), 214-226.
4. Pletcher BA, Toriello HV, Noblin SJ, Seaver LH, Driscoll DA, Bennett RL, et al. (2007). Indications for genetic referral: a guide for healthcare providers. *Genet Med*, 9(6), 385-389.
5. Daley R, Hill M, Chitty LS. (2014). Non-invasive prenatal diagnosis: progress and potential. *Arch Dis Child Fetal Neonatal Ed*, 99(5), F426-30.
6. Tabor A, Alfirevic Z. (2010). Update on procedure-related risks for prenatal diagnosis techniques. *Fetal Diagn Ther*, 27(1), 1-7.
7. Alkuraya FS, Kilani RA. (2001). Attitude of Saudi families affected with hemoglobinopathies towards prenatal screening and abortion and the influence of religious ruling (Fatwa). *Prenat Diagn*, 21(6), 448-451.
8. Belahcen A, Taloubi M, Chala S, Thimou Izgua A, Mdaghri Alaoui A. (2014). Mother's awareness and attitudes towards prenatal screening for Down syndrome in Muslim Moroccans. *Prenat Diagn*, 34(9), 821-30.
9. Kellogg G, Slattery L, Hudgins L, Ormond K. (2014). Attitudes of Mothers of Children with Down Syndrome Towards Noninvasive Prenatal Testing. *J Genet Couns*, 23(5), 805-13.
10. Scuffham TM, McInerny-Leo A, Ng SK, Mellick G. (2014). Knowledge and attitudes towards genetic testing in those affected with Parkinson's disease. *J Community Genet*, 5(2),167-177.
11. Alsulaiman A, Mousa A, Kondkar AA, Abu-Amero KK. (2014). Attitudes of Saudi parents with a deaf child towards prenatal diagnosis and termination of pregnancy. *Prenat Diagn*, 34(2), 153-158.
12. Alsulaiman A, Hewison J, Abu-Amero KK, Ahmed S, Green JM, Hirst J. (2012). Attitudes to prenatal diagnosis and termination of pregnancy for 30 conditions among women in Saudi Arabia and the UK. *Prenat Diagn*, 32(11), 1109-1113.
13. Alsulaiman A, Abu-Amero KK. (2013). Parent's attitude toward prenatal diagnosis and termination of pregnancy could be influenced by other factors rather than by the severity of the condition. *Prenat Diagn*, 33(3), 257-61.
14. Bundey S. (1997). Few psychological consequences of presymptomatic testing for Huntington disease. *Lancet*, 349(9044), 4.
15. Lerman C, Marshall J, Audrain J, Gomez-Caminero A. (1996). Genetic testing for colon cancer susceptibility: Anticipated reactions of patients and challenges to providers. *Int J Cancer*, 69(1), 58-61.
16. DudokdeWit AC, Tibben A, Duivenvoorden HJ, Frets PG, Zoeteweij MW, Losekoot M, et al. (1997). Psychological distress in applicants for predictive DNA testing for autosomal dominant, heritable, late onset disorders. The Rotterdam/Leiden Genetics Workgroup. *J Med Genet*, 34(5), 382-390.
17. Mutton D, Ide RG, Alberman E. (1998). Trends in prenatal screening for and diagnosis of Down's syndrome: England and Wales, 1989-97. *BMJ*, 317(7163), 922-923.
18. Pivetti M, Melotti G. (2013). Prenatal genetic testing: an investigation of determining factors affecting the decision-making process. *J Genet Couns*, 22(1), 76-89.
19. Zlotogora J, Reshef N. (1991). Prenatal testing for genetic disorders among Arabs. Prenat Diagn. Mar 1998;18(3):219-224.
20. Wertz DC, Rosenfield JM, Janes SR, Erbe RW. Attitudes toward abortion among parents of children with cystic fibrosis. *Am J Public Health*, 81(8), 992-996.
21. Verweij EJ, Oepkes D, de Boer MA. (2013). Changing attitudes towards termination of pregnancy for trisomy 21 with non-invasive prenatal trisomy testing: a population-based study in Dutch pregnant women. *Prenat Diagn*, 33(4), 397-399.
22. Ahmed Set al. (2012). Attitudes towards prenatal testing and termination of pregnancy in British Pakistani parents and relatives of children with recessive conditions in the UK. *Prenat Diagn*, 32(10), 954-959.
23. Tsianakas V, Liamputtong P. (2002). Prenatal testing: the perceptions and experiences of Muslim women in Australia. *J Reprod Infant Psychol*, 20(1), 7-24.
24. Menahem S, Grimwade J. (2003). Pregnancy termination following prenatal diagnosis of serious heart disease in the fetus. *Early Hum Dev*, 73(1-2), 71-78.
25. Hietala M et al. (1995). Attitudes toward genetic testing among the general population and relatives of patients with a severe genetic disease: a survey from Finland. Am J Hum Genet, 56(6), 1493-1500.
26. Hewison J, Green JM, Ahmed S, Cuckle HS, Hirst J, Hucknall C, et al. (2007). Attitudes to prenatal testing and termination of pregnancy for fetal abnormality: a comparison of white and Pakistani women in the UK. *Prenat Diagn*, 27(5), 419-430.