ATTITUDE OF WOMEN AND THEIR HUSBANDS REGARDING PRENATAL INVASIVE TESTING ATTENDING GENETIC CLINIC AT A TERTIARY REFERRAL CENTER, INDIA

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ABSTRACT

Introduction

Prenatal Invasive Tests (amniocentesis and chorionic villous sampling) are used during pregnancy for detection of genetic anomalies. Due to the fear of fetal loss or various other reasons, the couples who seek to avail these tests are usually in dilemma though the chances of fetal loss following the invasive tests are very minimal.

Objectives

To assess the attitude of high-risk pregnant women and their husbands regarding the prenatal invasive tests who are referred to the genetic clinic of a tertiary referral center in India.

Methodology

A descriptive, cross sectional study was undertaken in 60 pregnant women who came to genetic clinic at a tertiary referral center in India for counseling on the prenatal invasive testing. Convenience sampling technique was used. Data was collected using a self-developed, validated semi structured questionnaire. There were total 14 items in the questionnaire where the response "Yes" was given score 3, "Uncertain/did not think about it" was given score 2 and "No" was given score 1. Maximum score was 42 and minimum was 14. The subjects were contacted by the principal investigator after the counseling for test was done by the trained counselor. The questionnaire was also administered separately to 49 accompanying husbands to assess their attitude regarding the tests. Mean, percentage, standard deviation, range and Pearson's correlation were calculated. SPSS 16.0 version was used for data analysis.

Results

Almost half of the women reported that they had adequate information regarding the test following counselling. Both the women and their husbands had unfavorable attitude towards the tests i.e. 21.98 ± 5.44 and 22.27 ± 5.11 respectively despite adequate information following counselling. The main reasons for declining the tests were fear of identification of birth defects, fear of termination of pregnancy and influence by other family members other than their husbands. There was a significant positive correlation between the attitude of women and their husbands towards declining the prenatal invasive tests ($r=0.973$) at $p<0.05$.

Conclusion

The pregnant women as well as their husbands had unfavorable attitudes towards prenatal invasive tests despite adequate information following counselling suggesting congruency indecision making regarding the invasive tests.

KEY WORDS

amniocentesis, chorionic villi sampling, prenatal diagnosis

INTRODUCTION

Pregnancy is a joyous moment for the women but a baby with genetic anomalies like Down's syndrome is likely to cause undue stress on personal, family life, relationships as well as parents' work.[1] Due to a large population and high birth rate as well as consanguineous marriage favored in many communities, the prevalence of genetic disorders in India is very high. An estimated 21,400 babies with Down syndrome, 9,000 with ß- thalassaemia and 5,200 with sickle cell disease are born each year in India.[2] Therefore, screening for chromosomal disorders is necessary to detect genetic abnormalities. The commonly used biochemical markers which can be carried out at 11-14 weeks of gestation are inhibin A, serum Alpha-Feto Protein (AFP), free Beta Human Gonadotropin(ß-hCG), total hCG, Pregnancy-Associated Plasma Protein A (PAPP- A), unconjugated estradiol (uE3). Other less common markers are Placental Growth Factor (PlGF), Placental Growth Hormone (PGH), Invasive Trophoblast Antigen (ITA), Growth Hormone Binding Protein (GHBP) and Placental Protein 13 (PP13). Ultrasonography, and other invasive as well as non-invasive prenatal diagnostic tests on the basis of presence of cell-free fetal DNA in maternal plasma are also used for screening.[3] Screening should be carried out during pre-pregnancy stage itself.[4] Commonly used invasive diagnostic tests during pregnancy for detection of Down's syndrome are amniocentesis or Chorionic Villous Sampling (CVS), with or without prior screening. These tests are nowadays referred as reference tests. These tests possess risk for miscarriage at around 0.35% to 1%.[5,6] The prenatal invasive tests which have been adopted in second trimester have been abundantly used since the 1980s. The results of first and second trimester screening programs have also increased the dilemmaforopting the tests in detecting chromosomal anomalies.[7]

A recent study done in France in 2018-19 showed that around 21% women expressed favorable attitude toward invasive testing with complete karyo typing.[8] Similarly, in Romania it was found that 78.9% participants had a positive attitude for screening, 88% had insufficient knowledge and 68.3% made a value-consistent decision for the uptake of prenatal screening.[9] A study conducted among twenty-three Asian women in the United States about their attitudes towards prenatal genetic testing showed the emergence of four themes: diverse expectations from genetic counselors, weighing of risks and benefits with regards to genetic testing decisions, having mixed views on termination for fatal and non- fatal genetic conditions.[10] Another finding from Netherlands concluded that almost all women (99%) in the high-risk group and 89% of women in the low-risk group were informed about invasive prenatal diagnostic procedures.[11]

In the last two decades, several studies have been conducted in India in different aspects of prenatal invasive testing such as the profile of women/couples who seek those tests and for gender identification.[12] However, studies addressing the attitude of women having the fetal genetic risk factors and their husbands towards the testing is very scarce in developing countries.

The present study aimed to explore attitudes of pregnant women and their husbands who were about to make their decision regarding the prenatal invasive testing.

METHODOLOGY

A descriptive, cross sectional study was undertaken on 60 women with their accompanying husbands who came to genetic clinic, Department of Pediatrics at All India Institute of Medical Sciences (AIIMS), New Delhi for counseling regarding the prenatal invasive testing. The All India Institutes of Medical Sciences (AIIMS) are a group of autonomous government medical colleges of higher education among which AIIMS, New Delhi is a tertiary referral center located at New Delhi, northern part of India, which is also the capital of the country. Sample size was calculated using formula N= Z^2*P*Q/E^2, where N= sample size, Z= Z value i.e.1.96 for 95% confidence level, P= percentage picking a choice, expressed as decimal which is 3.9 (there was 3.9% of uptake of prenatal testing in the study) i.e. 0.039,[13] Q= 1-P, i.e. 0.961, E= Margin of error which is 0.05. We had planned to include same number of husbands, i.e. 60 women and 60 husbands but only 49 husbands accompanied the pregnant women during the counselling. Rest of the women came with other family members. The duration of this study was 6 months (March 2012 - September 2012). Sample included all pregnant women who were referred to genetic clinics at AIIMS, New Delhi for prenatal diagnostic testing (gestational age ranging from 15 weeks to 23 weeks) and who were willing to participate in the study. Convenience sampling was adopted for the study. We enrolled 10 subjects each month including minimum of 2 subjects in each week. Semi-structured questionnaire was separately administered to both women as well as their husbands which was a 3-point Likert scale and the choices were categorized into “Yes”, “No”, “Uncertain/ did not think about it”. During the process of data collection, any doubts or queries arising from both respondents as well as principal investigator was made clear at the site. There were total 14 items in the questionnaire where the response “Yes” was given score 3, “Uncertain/did not think about it” was given score 2 and “No” was given score 1. Maximum score was 42 and minimum was 14. The Higher scores depicted favorable attitude (of women and their husbands towards tests). The scores ranging from 14-28 was defined as unfavorable attitude and from 29-42 as highly favorable attitude towards the prenatal invasive tests. Validity was maintained by consulting with the experts. It was pretested among 10% of sample size, i.e. 6 pregnant women and 6 husbands. The pretested samples were excluded from the main study. Tool was constructed in English translated in Hindi and was again back translated in English. Ethical clearance for the study was obtained from Institute Ethics Committee/Ethics Sub-Committee, AIIMS, New Delhi, India. Information sheet was developed and given to the study participants. Informed consent was taken from all the

subjects. Confidentiality of the subjects was maintained. Inclusion criteria for sample selection were: pregnant women who had fetal genetic risk factors and were referred to genetic clinics at AIIMS, New Delhi for prenatal diagnostic testing who could communicate in Hindi or English. For data analysis, descriptive statistical methods included mean, standard deviation, frequency, range and percentage. Inferential statistical methods included Pearson's correlation test. The level of significance was $p<0.05$. Data was entered in Microsoft EXCEL and analyzed using SPSS 16.0 version.

RESULTS

Nearly half the women (46.7%) were in the age groups 21 – 30 years followed by 31–40 years age group (43.3%). Majority of the women were from the urban residence (85%) and Hindu by religion (75%). All the women were literate and more than 30% of them had higher secondary level of education. Fifteen percent of the women had consanguineous marriage. Table no. 1 shows the socio demographic profile of the women attending genetic clinic.

Table 1: Socio demographic characteristics of the women n=60

Variable	Category	Frequency (%)
Age	<20 years	2 (3.3%)
	21 – 30 years	28 (46.7%)
	31–40 years	26 (43.3%)
	>40 years	4 (6.7%)
Residence	Rural	9 (15%)
	Urban	51 (85%)
Religion	Hindu	45 (75%)
	Muslim	6 (10%)
	Christian	6 (10%)
	Sikh/others	3 (5%)
Education (women)	Primary	4 (6.7%)
	Secondary	12 (20.0%)
	Higher Secondary	20 (33.3%)
	Graduate	14 (23.3%)
	Postgraduate and above	10 (16.7%)
Type of marriage	Consanguineous	9 (15%)
	Non consanguineous	51 (85%)
Type of family	Joint	40 (66.7%)
	Nuclear	20 (33.3%)

The obstetric characteristics of the women are depicted in the Table no. 2. The two most common reasons for referral were advanced maternal age i.e. above 35 years (38.3%) followed by abnormal USG (30%). More than two-thirds of the respondents (66%) were pregnant for the second time. Majority (80%) had no still birth in the past and 16.67% had 1 still birth previously. Interestingly 33.3% of them reported that the pregnancy wasn't planned. Around 16.67% of the women stated that there was the history of genetic anomaly in the previous child.

Table 2: Obstetric characteristics of the women n=60

Variable	Category	Frequency (%)
Reasons for referral	Advanced maternal age	23 (38.3%)
	Abnormal USG	18 (30.0%)
	Abnormal biochemical marker	10 (16.7%)
	Multiple termination of pregnancies	2 (3.3%)
	Previous affected child	7 (11.7%)
Total no of pregnancies	1	12 (20%)
	2	40 (66.7%)
	≥3	8 (13.3%)
Prior still birth(s)	0	48 (80%)
	1	10 (16.67%)
	≥2	2 (3.33%)
Prior miscarriage(s)	0	53 (88.3%)
	1	4 (6.7%)
	≥2	3(5%)
Prior induced termination of pregnancy(s)	0	56 (93.3%)
	≥1	4 (6.7%)
Pregnancy planned	Yes	40 (66.7%)
	No	20 (33.3%)
Previously affected child with genetic anomaly	Yes	10 (16.67%)
	No	50 (83.33%)

Table no.3 shows the attitude of women towards the PIT. Nearly two-thirds of the women (63.27%) said that they had enough support from other family members to make a choice. Likewise, 89.8% of the respondents said that they were choosing without pressure from others. Majority of the respondents (85.71%) believed that their decision was not influenced by religion or culture and 81.63% of the women reported that they will opt testing in future pregnancies also. But, majority of the respondents (89.80%) were worried as they were offered the test.

Table 3: Attitude of women towards prenatal invasive tests n=60

Components of attitude	Responses (Frequency %)		
	Yes	No	Uncertain/didn't think about
Have enough information to make decision	23 (46.94%)	7 (14.29%)	19 (38.77%)
Know which options are available	34(69.39%)	9(18.37%)	6 (12.24%)
Know the risks and side effects of each option	38 (77.55%)	4 (8.16%)	7 (14.29%)
Clear about the best choice	36 (73.47%)	3 (6.12%)	10 (20.41%)
Aware of benefits of test	39(79.59%)	3(6.12%)	7 (14.29 %)
Clear about which benefits matter most	37 (75.51%)	6 (12.24%)	6 (12.24%)
Feel sure about what to choose	37 (75.51%)	5 (10.20%)	7 (14.29 %)
Have enough support from others to make a choice	31 (63.27%)	3 (6.12%)	15 (30.61%)
Choosing without pressure from others	44 (89.80%)	0	5 (10.20 %)
Think decision(s) is/are not influenced by religion or culture	42 (85.71%)	2 (4.08%)	5 (10.20%)
Want to take test in future pregnancies	28 (57.14%)	3 (6.12%)	18 (36.73%)
Not worried as offered screening test	3 (6.12%)	44 (89.80%)	2 (4.08%)
Consider termination of pregnancy if fetus has any defect	40(81.63%)	1(2.04%)	8 (16.33%)
Think that prenatal invasive testing is useful	42 (85.71%)	1 (2.05%)	6 (12.24%)

Table no. 4 depicts the attitude of husbands towards the test. Majority of the husbands (76.7%) responded that they knew the risks and side effects of each option. Most of the husbands (75%) said that they were clear about the best option for PIT.

Table 4: Attitude of the husbands regarding the prenatal invasive testing n=49

	Yes	No	Uncertain/didn't think about it
Have enough information to make decision	30 (50%)	7 (11.7%)	23 (38.3%)
Know which options are available	43(71.7%)	10 (16.7%)	7 (11.7%)
Know the risks and side effects of each option	46(76.7%)	5 (8.3%)	9(15.0%)
Clear about the best choice	45(75.0%)	4(6.7%)	11(18.3%)
Aware of benefits of test	47(78.3%)	5(8.3%)	8(13.3%)
Clear about which benefits matter most	44(73.3%)	6(10.0%)	10(16.7%)
Feel sure about what to choose	46(76.7%)	4(6.7%)	10(16.6%)
Have enough support from others to make a choice	38(63.3%)	2(3.3%)	20(33.4%)
Choosing without pressure from others	53(88.3%)	0	7(11.7%)
Think decision(s) is/are not influenced by religion or culture	53(88.3%)	2(3.3%)	5(8.4%)
Want to take test in future pregnancies	37(61.7%)	4(6.7%)	19(31.6%)
Not worried as offered screening test	4(6.7%)	54(90.0%)	2(3.3%)
Consider termination of pregnancy if fetus has any defect	53(88.3%)	1(1.7%)	6(10.0%)
Think that prenatal invasive testing is useful	52(86.7%)	0	8(13.3%)

Table 5: Correlation of scores of attitudes towards prenatal invasive testing of women with scores of attitudes of husbands n=98

Respondents	Mean scores of attitudes towards PIT (Mean ±SD)	Correlation coefficient (r)	p-value
Women	21.98 ± 5.44	0.973	0.009
Husbands	22.27 ± 5.11		

r Pearson's correlation coefficient *p<0.005

The reasons for not undergoing the testing as reported by the women were fear of identification of birth defects (50%), followed by fear of termination of pregnancy (30%) and influence of family members (20%).

DISCUSSION

In this study, the attitude of the high-risk pregnant women following counselling was unfavorable towards the prenatal invasive tests despite the fact that majority of the pregnant women were from urban area with higher education and in the age group of 21-30 years. Similar demographic profiles were observed in the studies done by Tsai GJ, et al[10] where 48% of women were below the age of 30 years and by Graaf IM De et al where around 80% of the women were from the urban residence.[11,14,15] It is also important to note that post counselling; both women and husbands had unfavorable attitude towards the prenatal invasive tests in spite of the reporting that their knowledge and understanding was adequate and both of them were mature enough to make the decisions on their own.

The questionnaire was also administered separately to their accompanying husbands which also revealed the unfavorable attitude toward the PITs; which is statistically significantly correlated and is congruent to the attitude of their wives. This is against the general belief of Asian model of paternalistic dominance in health care and decision-making process.[16]

In our study, consanguineous marriages in high risk pregnant women were relatively more common accounting 15 % whereas it was very low in the study by Tsai GJ, et al[10] where only 1% of them had consanguineous marriage. This may be due to consanguineous marriage being common in Muslims which were second to Hindu in our study by religion.

The major reasons for referral were advanced maternal age (38.3%) followed by abnormal USG (30.0%), abnormal biochemical marker, multiple spontaneous termination of pregnancies and previously affected child. Though Majority (66%) were pregnant for the second time and 80% had no still birth in the past. Only, 16.67% respondents reported that they had one still birth which is lesser than that of the study done by Mikamo S.[16] The lesser figures of still births and miscarriages in the present study might be due the fact that advanced maternal age followed by abnormal USG were the major reasons for referral unlike the other studies[14,17] where previous history of affected child and previous miscarriage(s)/still births accounted major reasons for referral.

Nearly half of the women reported that they had enough information to make decision which is lesser than the study done in Netherlands.[12] This might be because of the social and cultural influence while making decision and seeking the opinion from other family members and close relatives in the present study. Fifty seven percent of the women opted for testing in future pregnancies if required which is congruent to study done by Bryant L.[17] Eighty five percent of the women reported that the religion has no influence on their decision regarding the test and this finding is contrary to the study done in France.[8] This might be because of the fact that the Catholics have very strong religious beliefs and their religion guides most of the decisions in life.

In this study, 81% of the women reported that they would consider termination of pregnancy if the fetus had any defect which is similar to the finding of another study.[18] The

major reasons for not undergoing the testing as reported by the women were fear of identification of birth defects (50%), followed by fear of termination of pregnancy (30%) and influence of family members (20%).

CONCLUSION

The women as well as their husbands had unfavorable attitude towards the PIT. So, better knowledge regarding the procedure and associated risk of complications of the prenatal invasive test improves the decision making of women for opting the prenatal invasive testing.

Hence, similar studies can be done in other similar low- and middle-income countries having similar religion, ethnicity as well as educational background with larger sample size for generalizing the outcomes of the study. The health personnel (doctors and nurses) should take into account these facts that proper counseling has to be done as soon as the women are referred for the invasive tests and this will facilitate the women in better decision making.

LIMITATIONS OF STUDY

Sample size is small. Findings of the study may not be generalized to other settings as it was done at a single site in India.

Implications of the study are that the health personnel (doctors and nurses) should be sensitized for the need for genetic counseling so that they can: a) Generate more dedicated counsellors mainly through Continuing Medical/ Nursing Education and in-service programs, b) Assign adequate personnel to these areas (e.g. genetic OPD) in order to function effectively.

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CONFLICT OF INTEREST

There is no any conflict of interest during the study.

FINANCIAL DISCLOSURE

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