

Prenatal Diagnosis for Detecting Congenital Malformations: Acceptance among Israeli Arab Women

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Key words: consanguinity, congenital malformations, prenatal diagnosis, termination of pregnancy

Abstract

Background: A high rate of consanguineous marriages exists within the Israeli Arab community, with approximately half occurring between first cousins. This contributes towards a high incidence of congenital malformations and autosomal recessive diseases, many of which are detectable at prenatal diagnosis.

Objectives: To assess the levels of both awareness and acceptance regarding prenatal diagnosis and termination of pregnancy among a group of Arab women in order to devise the optimal means of providing genetic counseling and general health services.

Methods: A total of 231 Arab women of childbearing age were interviewed 3 days postpartum to assess their knowledge of prenatal diagnosis and termination of pregnancy, their willingness to undergo prenatal diagnosis, and their opinions on termination of pregnancy in the event of a severely affected fetus.

Results: Half the women believed that prenatal testing is not an effective (or accurate) tool for diagnosing an affected fetus. A quarter had poor knowledge on prenatal diagnosis, and a quarter believed that prenatal diagnosis does provide the correct diagnosis. Ninety-five percent said they would agree to undergo prenatal diagnosis; and in the event of a severely affected fetus, 36% said they would agree to a termination of pregnancy, 57% said they would not, and 7% were undecided.

Conclusions: There is a need for special intervention programs, with guidance by health professionals, geneticists and religious authorities, that will inform this population on the increased risk associated with consanguinity, stress the importance and effectiveness of prenatal testing to identify severe congenital malformations, and help them to accept prenatal diagnosis and termination of pregnancy if indicated.

IMAJ 2000;2:346-350

Most live in towns and villages that are largely isolated and cut off from the rest of the country [1]. This has resulted in a situation where different dialects are often spoken by the residents of two neighboring towns or villages. Another effect is the restriction of a specific genetic disorder to a specific town or village due to a founder effect. For example, situated 20 km northeast of Tel Aviv in an area of 15 square kilometers there are six geographically and socially separate villages, each with its own distinct genetic disorder. In the village of Kalansuwa one family has 55 members who suffer from maternally transmitted deafness [2]; in the town of Taibe some families have a high incidence of congenital malformations [3] while others have hemolytic anemia due to an alpha-globin defect (Hb Taybe disease) [4]; in the town of Tira several members of a large family have arthrogyrosis [5]; in Jaljulia and Jisr-Alzarka some families have members with thalassemia; and in Kafr Kasem there are many cases of congenital deafness and blindness (personal communication). The situation in this one relatively small area is representative of the entire Israeli Arab population, which numbers approximately one million.

Many studies undertaken to assess the contribution of consanguinity to the incidence of congenital malformations [3-9] found that the rate is approximately 2.5 times higher among children of consanguineous couples than among the offspring of unrelated parents. While the main cause is the expression of autosomal recessive diseases, structural congenital malformations also occur whose exact mode of transmission has not been elucidated.

A survey of the Israeli Arab community found that almost 16% of the offspring of first-cousin marriages had a congenital malformation [3]. For more distant relatives, the rate was 15.2%. Among unrelated couples the rate was 8.3%, and for couples where the two partners came from different villages it was 5.8%.

Prenatal diagnosis

The main problem is the refusal in traditional religious Moslem communities to accept the concept of termination of pregnancy if prenatal diagnosis has definitively identified a fetus affected with a major congenital malformation or

The Arab community of Israel comprises Moslems, which make up the vast majority (93.2%), and Christians (6.8%).

genetic disorder. Prenatal diagnosis is available for many of the disorders that are prevalent in the Israeli Arab community, and can be performed in most of the maternity hospitals in Israel. Since the entire population of Israel is covered by health insurance, there is no cost for testing women at risk for such diseases.

The purpose of this study was to assess the levels of awareness and acceptance regarding prenatal diagnosis and termination of pregnancy among a group of women from the Arab towns of Taibe and Tira and the village of Kalansuwa. This information will enable us to devise the best methods of offering genetic counseling and general advice on health matters to this community.

Methods

A sample of 231 Arab women of childbearing age (16–46 years, mean 27) from Taibe, Tira and Kalansuwa were randomly selected to be interviewed on the third day after delivery in the Department of Obstetrics at the Sapir Medical Center, Kfar Saba from September to December 1998. The interviews were conducted by an experienced psychologist and consisted of four sections. Section 1 recorded information about the couple's demographic background and socioeconomic status (defined according to the income of the family, husband and wife together). Section 2 recorded the couple's reproductive history, and section 3 examined the level of knowledge of the women regarding the various tests used for prenatal diagnosis. After this section was completed, the interviewer provided a detailed explanation about prenatal diagnosis options to each woman individually, and then asked the woman whether she would be willing to undergo these tests if indicated. A hypothetical question was then posed: if she were pregnant and it was found during the first trimester that the fetus was severely affected, would she agree to terminate the pregnancy? She was asked to explain her answer. In section 4, each woman was asked about her biological relationship, if any, with her husband.

The study population was divided into two groups: those in favor of termination of pregnancy in the event of a severely affected fetus and those against. These two groups were compared using the χ^2 test.

Results

Table 1 shows the proportion of consanguineous marriages within the study population. Sixty-eight couples (29.45% of the total) were consanguineous, and almost half of these were marriages between first cousins (33 couples, 48.53% of all the consanguineous marriages).

Table 2 shows the levels of awareness and acceptance of prenatal diagnosis and termination of pregnancy in the study population. A total of 113 women (49.0%) thought that prenatal diagnosis was an inaccurate test for the detection of the fetal anomaly, and a further 55 women (23.8%) had poor knowledge about prenatal diagnosis. Fifty-one women (22.05%) did believe that prenatal diagnosis gave the correct

Table 1. Consanguinity among the study population

Parental consanguinity	No.	(%)
First cousins	33	(14.3)
First cousins once removed	8	(3.45)
More distantly related	27	(11.7)
Not related	155	(67.1)
Did not respond		(3.45)
Total	231	(100)

diagnosis, while four (1.7%) thought that prenatal diagnosis carried the risk of injury to the fetus or injury to the mother. Eight women (3.45%) had no opinion at all.

Notwithstanding the relatively low levels of awareness, the vast majority of the women (219, 94.8%) said that they would agree to undergo prenatal diagnosis if indicated. Of the remaining women, six (2.6%) said that they would refuse prenatal diagnosis and six (2.6%) were uncertain.

When asked their opinion on termination of pregnancy in the event of a severely affected fetus, 83 women (36%) said they would agree to the termination of such a pregnancy, 131 (56.7%) said they would not, and 17 (7.3%) were undecided. In order to compare the women who were opposed with those in favor, the 17 women who were undecided were excluded, leaving a total of 214.

Table 3 compares the obstetric histories of the 131 women (61.2% of the total of 214) opposed to termination of pregnancy in the event of a severely affected fetus, and the 83 women (38.8%) in favor. The obstetric data include the number of pregnancies, the number of terminations, the number of spontaneous abortions, and the number of family members. No significant difference was found between the two groups for any of these parameters.

Table 2. Awareness and acceptance of prenatal diagnosis and termination of pregnancy in the study population

	No. of women	Percentage
Level of awareness		
Correct diagnosis	51	22.05%
Inaccurate diagnosis	113	49.0%
Injury to fetus	2	0.85%
Injury to mother	2	0.85%
Poor knowledge	55	23.8%
No answer	8	3.45%
Total	231	100%
Acceptance of prenatal diagnosis		
Yes	219	94.8%
Uncertain	6	2.6%
No	6	2.6%
Total	231	100%
Termination of pregnancy if the fetus is affected		
Yes	83	35.95%
No	131	56.7%
Uncertain	17	7.35%
Total	231	100%

Table 3. Obstetric history of the study population: comparison between those opposed to and those in favor of termination of pregnancy if the fetus is severely affected*

No. of pregnancies	No. of women who have undergone termination of pregnancy		No. of women who had spontaneous abortion		No. of family members			
	Opposed (%)	In favor (%)	Opposed (%)	In favor (%)	Opposed (%)	In favor (%)		
1	32 (24.4)	19 (22.9)	0	7 (8.45)	21 (16.05)	7 (8.45)	40 (30.55)	20 (24.1)
2	36 (27.5)	16 (19.3)	1 (0.75)	0	5 (3.8)	5 (6.0)	35 (26.7)	19 (22.9)
3	22 (16.8)	17 (20.5)	0	0	3 (2.3)	0	18 (13.75)	21 (25.3)
4	15 (11.45)	12 (14.45)	0	0	0	0	22 (16.8)	10 (12.05)
5	6 (4.6)	10 (12.05)	0	0	1 (0.75)	0	8 (6.1)	8 (9.65)
6	10 (7.65)	4 (4.8)	0	0	1 (0.75)	0	5 (3.8)	3 (3.6)
7	4 (3.05)	3 (3.6)	0	0	0	0	2 (1.55)	1 (1.2)
8	4 (3.05)	2 (2.4)	0	0	0	0	0	1 (1.2)
9	1 (0.75)	0	0	0	0	0	1 (0.75)	0
10	0	0	0	0	0	0	0	0
11	1 (0.75)	0	0	0	0	0	0	0
0	0	0	130 (99.25)	76 (91.55)	100 (76.35)	71 (85.55)	0	0
Total	131 (100)	83 (100)	131 (100)	83 (100)	131 (100)	83 (100)	131 (100)	83 (100)

* No significant difference was found between the two groups in the distribution of numbers of pregnancies, spontaneous abortions, and number of family members.

Table 4. Profiles of couples opposed to and in favor of termination of pregnancy if the fetus is severely affected

Education	Women		Husbands	
	Opposed (%)	Agreed (%)	Opposed (%)	Agreed (%)
None	1 (0.75)	0	5 (3.8)	0
Primary school	39 (29.75)	5 (6.0)	28 (21.35)	15 (18.1)
Secondary school	81 (61.85)	56 (67.5)	88 (67.2)	55 (66.25)
High school	10 (7.65)	22 (26.5)	10 (7.65)	13 (15.65)
Total	131 (100)	83 (100)	131 (100)	83 (100)
<i>P</i> value	<0.0001		<0.09	
Socioeconomic background				
Low	54 (41.2)	19 (22.9)		
Middle	66 (50.4)	35 (42.15)		
Total	131 (100)	83 (100)		
<i>P</i> value	<0.0001			

Table 4 compares the educational level and socioeconomic status of the 131 women and their husbands who were opposed to termination of pregnancy with those of the 83 women and their husbands in favor. Women who were willing to accept termination of pregnancy were more educated than those who opposed it ($P < 0.0001$), and the socioeconomic status was also higher among those in favor than among those opposed ($P < 0.0001$).

The 131 women who said they would refuse to terminate a pregnancy if the fetus was severely affected were asked to explain why. Most, 67.9%, gave reasons associated with their religious beliefs: "It is not allowed by the religion" (19.85%), "It is killing a human being" (12.2%), "It is the decision of G-d" (7.65%), "It is a present from G-d" (18.3%), "G-d created him/her" (6.1%), "G-d will take revenge if I terminate the pregnancy" (3.8%). Of the rest, 6.1% said "It is

my luck," 8.4% said "The doctors are not always right," 4.6% said "My husband does not agree," and 13% gave no reason.

Discussion

This study demonstrates that within the Arab Moslem population of Israel there is a high level of opposition to termination of pregnancy in the event of a severely affected fetus: 131 (61.8%) women were opposed, compared with 83 (38.8%) in favor. Opposition was more prevalent among the less educated women and those of low socioeconomic status. The study also shows a poor level of awareness about prenatal diagnosis within the population studied. Only 22% thought that prenatal diagnosis gave the correct diagnosis, while 49% believed it gave an inaccurate diagnosis.

The high level of opposition to termination of pregnancy shown in this study correlates well with the results of a recent study carried out among Bedouin couples in southern Israel [10]. In that population, 39.2% of the women for whom pregnancy termination was a realistic option chose to terminate the pregnancy.

Many studies on the acceptance of prenatal diagnosis have been conducted in North America and Europe [11–14]. A study in Sardinia on the acceptance of first-trimester prenatal diagnosis for beta-thalassemia found that all the couples surveyed would choose chorionic villus sampling over second-trimester diagnosis [11]. Of two studies carried out in Lebanon, one surveyed 83 couples at risk for hemoglobinopathy [12]. Most of the families were not completely aware of their genetic risk, although 59% of the couples were definitely in favor of prenatal diagnosis, 18% were opposed to such testing, and 23% were uncertain at

the time of interview. All but one of the families who were opposed to prenatal diagnosis were Moslems, the one exception being Christian. The second study from Lebanon [13] was conducted in order to assess the awareness of both the disease and prenatal diagnosis, and to evaluate the significance to these families of the financial burden involved in paying for prenatal diagnosis. It was found that approximately half of the 44 families interviewed would opt for prenatal diagnosis. A study of British Pakistanis in England [14] demonstrated that many of the families were at high risk for beta-thalassemia, and most requested first-trimester prenatal diagnosis.

It is known that socioeconomic status can influence the families' decision regarding prenatal diagnosis. This may correlate with lower awareness of genetic risk, increased parental consanguinity, and reduced acceptance of prenatal diagnosis. However, in our previous study of 610 families in Taibe [3], the largest town in the study, we showed that there were no significant differences between the type of relationship between the parents (i.e., whether they were first cousins, more distantly related, or not related at all) in the distribution of the number of offspring or in socioeconomic status. In our current study, it is interesting that the women who said they would agree to termination of pregnancy if the fetus was severely affected were better educated than those who were opposed. Similarly, the families agreeing to such termination were of a higher socioeconomic status than those opposed (low socioeconomic status – 41.2% opposed, 22.9% agreed; middle status – 50.4% opposed, 42.15% agreed; high status – 8.4% opposed, 34.95% agreed).

We found in the current study that 49.0% of the women surveyed did not believe that prenatal diagnosis gave the correct diagnosis, and a further 23.8% had poor knowledge about the feasibility of prenatal diagnosis. On the other hand, 22.05% of the women did believe that it provided the correct diagnosis. Despite the fact that women's attitudes differ, we observed that after the interviewer had explained prenatal diagnosis to each woman in detail almost 95% said they would agree.

We have recently received permission in writing from the Mufti of Jerusalem (a senior religious advisor in Islam) that, in his opinion, it is acceptable to terminate a pregnancy during the first 120 days if the fetus is known to be definitely affected (personal communication). It would be interesting to know whether the women would have changed their minds if we had told those who were opposed to termination of pregnancy that we had received this permission.

We indicated in our previous report [3] that parental consanguinity plays an important role in the incidence of congenital malformations. In the present study, almost 30% of the couples studied were consanguineous, and nearly half of these were first cousins. This figure is lower than that found in a 1992 nationwide survey of parents of Israeli Arab second-graders (44%) [6,15]. Clearly, any attempt to reduce the incidence of consanguineous marriages in this popula-

tion must be approached with great care and handled with sensitivity, since such marriages have been practiced for hundreds of years and are deeply ingrained in these communities. Nonetheless, there are ways of tackling the issue, such as the various control programs already mentioned. The objectives of any such program must be:

- To inform the community about the risks of congenital malformations associated with consanguineous marriages.
- To identify the prevalent genetic disease in each community in order to be able to screen for carriers where possible.
- To advise couples about the importance of premarital testing, emphasizing its accuracy and significance in terms of making a contribution to their health.
- To inform them of the religious opinion regarding permission to terminate a pregnancy during the first 120 days in the event of a severely affected fetus.
- To provide prenatal and genetic counseling services, including prenatal diagnosis, and to educate as many people as possible to utilize these services [16].
- To provide folic acid supplements 2 months prior to a planned pregnancy until the end of the first trimester.

Once the women themselves accept the concept that termination of pregnancy is permissible in these circumstances, this should have a significant impact on the incidence of malformed live-born children.

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