

Utilization of Prenatal Diagnosis and Termination of Pregnancies for the Prevention of Down Syndrome in Israel*

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Abstract

Background: The national program for the prevention of Down syndrome includes screening (using the triple test) and invasive diagnostic tests in women at risk for a Down syndrome pregnancy. However, despite the program, the majority of Down syndrome infants are born alive (approximately 1/1000 live births)

Objectives: To determine whether the relatively high incidence of Down syndrome at birth in Israel is the result of failure of the preventive program or due to informed choices of the mothers.

Methods: We conducted a retrospective study using the national registry of Down syndrome for the years 1997 and 2004, according to the mothers' religion and place of residence and the reasons for prenatal diagnosis.

Results: Most of the babies affected with Down syndrome are born in religious or traditional conservative communities where termination of pregnancy is usually not an option.

Conclusions: In a pluralistic society like Israel with its diverse communities and dissimilar religious backgrounds and traditions, the different attitudes concerning utilization of the national program should be respected. It is necessary to tailor different approaches and solutions for the various ethnic and religious communities according to their need

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The national program in Israel for the prevention of Down syndrome includes two components: screening of young women using the triple test, and free invasive diagnostic tests for women older than 35 years at the beginning of their pregnancies. The program offers free prenatal diagnostic testing to all other women with a risk higher than 1/380 for a child to be born with Down syndrome. One might expect that such a comprehensive program will detect and prevent Down syndrome in the majority of pregnancies. This should be so, particularly in a country like Israel where the percentage of women giving birth after the age of 35 is relatively high and in a trend of growth [1]. But the reality is different: despite the availability and accessibility of the national program, more than 50% of Down syndrome cases in Israel are born alive [2]. For comparison, in countries that also have national prevention programs for Down syndrome, such as France and Australia, the rates are 31% in Paris and 25% in the Victoria region, respectively [3,4]. The aim of the present study was to evaluate the program and determine whether this

observation indicates a failure of the program or is due to the informed choice of the mothers.

Subjects and Methods

The Israel national registry for Down syndrome was established in 1980 and includes data on children born with the syndrome and on their parents. Since 1997 this registry also includes data on all pregnancies with Down syndrome that were interrupted or in which the Down syndrome child was stillborn. In addition, from 1999 the complementary data on whether a prenatal diagnosis test was performed in women with a previous pregnancy with Down syndrome are also available. The registry includes data on Israeli citizens and is almost complete for the whole country except for East Jerusalem where many of the non-Jewish children born with Down syndrome are not registered.

The present study included all women in whom Down syndrome was diagnosed between 1997 and 2004. Entering the identity numbers of these women in the national birth registry yielded information on all those who gave birth during the same period.

We evaluated the utilization of prenatal diagnosis in pregnant women whose previous pregnancy had been diagnosed with Down syndrome. In addition, we determined the utilization of prenatal diagnosis among women 35 years old or older who gave birth to a live child in the period 1999-2001. Other variables explored were the family's religion and place of residence. For the Jewish subjects we focused on four towns with an almost exclusively Ultra-Orthodox population, and three large cities where this community is in the minority and most inhabitants are secular.

Results

Between 1997 and 2004, Down syndrome was diagnosed in a child/fetus of 1785 women and 970 affected children were born [Table 1].

Outcome of pregnancies in which Down syndrome was diagnosed prenatally

Among Jews, of 1443 cases in which Down syndrome was diagnosed, 693 affected children (48%) were born alive. The rate of utilization of prenatal diagnostic tests differed according to place of residence [Table 2]. In four towns where almost all the residents are ultra-Orthodox Jews, 105 children affected with Down syndrome were born out of 110 cases diagnosed (95.5%). In contrast, in three large towns where the population comprises mostly

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Table 1. Utilization of prenatal diagnostic tests in pregnancies with Down syndrome and their interruption according to the mother's religion

	Total	No. of children born	Percentage interrupted	Used prenatal testing*
Moslems	301	247	18.7%	15%
Christian Arabs	16	9	43.7%	58%
Druze	25	21	16%	16.3%
Jews	1443	693	52%	52.1%
Total	1785	970	45.6%	

* Women over age 35 who underwent a prenatal test, 1999–2001

Table 2. Live-born Jewish children with Down syndrome according to place of residence, 1997–2004

	No. of births*	Total	No. of children born	Rate/1000 live births
4 ultra-Orthodox cities	58,000	110	105 (95.5%)	1.81
3 secular cities	45,000	62	14 (25.0%)	0.31
Jewish population	739,000	1443	693 (48.0%)	0.94

* Approximate numbers

secular Jews, of the 62 cases of Down syndrome diagnosis, there were 14 births (25%). In nearly all the cases the country of origin of the pregnant woman was not related to the use of prenatal diagnosis (data not shown). The only exception was among Jewish women born in Ethiopia, in whom an affected child was born in 50 out of 54 pregnancies with Down syndrome (92.6%).

Among Moslems, of the 301 pregnancies in which Down syndrome was diagnosed (excluding East Jerusalem where the data are incomplete) 247 (81.3%) were live born. In the various districts of Israel the rate of Moslem children born alive among the pregnancies in which Down syndrome was diagnosed was 19.5–33.3%. An exception was the southern district (the Negev) where almost all the Moslems are Bedouin Arabs [Table 3]. Among the Negev Bedouin, an affected child was born in 82 of 90 pregnancies (93.8%) in which Down syndrome was diagnosed.

Utilization of prenatal diagnosis in women at risk due to previous Down syndrome pregnancy

Among 752 women who had a least one pregnancy following a previous pregnancy in which Down syndrome was diagnosed, 380 chose not to use prenatal diagnosis (50.2%) [Table 4]. When these women were separated into two groups – those who had and those who had not given birth to a live child with Down syndrome – significant differences were apparent. Among the 307 women who had given birth to a child with Down syndrome, 236 (76.9%) chose not to have a prenatal diagnosis in subsequent pregnancies. Among the 445 women who underwent a termination of pregnancy affected with Down syndrome, 144 (32.4%) opted not to undergo prenatal diagnosis in subsequent pregnancies.

Utilization of prenatal diagnosis in women older than 35 at risk

In the 3 year period 1999–2001, the utilization rates of prenatal tests (amniocentesis or chorion villi sampling) in pregnant

Table 3. Live-born Moslem children with Down syndrome according to the district of residence of the mother, 1997–2004

	No. of births	Interruption	Percentage interrupted	Used prenatal testing*
Central district	26	6	23.1%	14.7%
Haifa district	27	9	33.3%	10.9%
Acre sub-district	77	15	19.5%	27.3%
Jezreel sub-district	62	15	24.2%	21.8%
Southern district	90	8	8.9%	6.2%

* Women over age 35 who underwent a prenatal test, 1999–2001

Table 4. Use of the recommendation to undergo a prenatal diagnosis test, following a pregnancy with Down syndrome

	Pregnancies resulting in the birth of a Down syndrome child	Pregnancies interrupted due to diagnosis of Down syndrome	Total
Prenatal diagnostic testing in subsequent pregnancies			
Yes	236	144	380
No	71	301	372
Total	307	445	752

women older than 35 were 57.8% for Christians, 52.1% for Jews, 15% for Moslems and 16.3% for Druze.

Discussion

This study explores the utilization of prenatal services for diagnosis of Down syndrome and post-diagnosis interruption of pregnancies. These procedures are provided free of charge for Israeli women older than 35 or at risk, according to the Israel National Health Insurance Law. Although several studies have demonstrated that socioeconomic differences may influence the degree of utilization of prenatal diagnosis for Down syndrome, we did not examine this factor [3,5]. In our study we concentrated on religious and traditional differences within each of the two main religious groups in Israel: Jews and Moslem Arabs, representing 76% and 16% of the population respectively [1]. In each of these religious groups the rate of prenatal diagnosis utilization was in the same range as Down syndrome interruptions – 52% for Jews and 18% for Moslem Arabs [Table 1].

This observation confirms that in Israel the utilization of invasive prenatal examination (either amniocentesis or chorion villi sampling) is lower for women who because of their religion will not undergo abortion of an affected fetus, and who know in advance that the information obtained will not be taken into consideration for performing abortion [6]. According to *Halakha*, Jewish Law, life is considered to begin after the 40th day of pregnancy. Therefore, interruption of pregnancy because of a diagnosis of Down syndrome is rarely allowed by religious authorities for a fetus older than 40 days, except in a few instances such as severe malformations of the fetus.

The tendency of ultra-Orthodox Jews to reside within their own community, either in towns or neighborhoods separated from the general population, allows in some cases the use of the place of residence as a proxy to indicate religiosity. In four towns where

the population is almost exclusively ultra-Orthodox, more than 95% of the cases diagnosed with Down syndrome are born alive. In contrast, in a sample of towns whose population comprises mainly secular Jews, only 25% of the Down syndrome cases are born alive. These very significant differences demonstrate that ultra-Orthodox Jewish citizens in Israel tend not to utilize the prenatal diagnostic tests for Down syndrome.

In the Moslem community the situation is somewhat different. Some religious authorities allow elective abortion if the fetus is affected with a severe condition, but in all cases this should be before the 120th day of the pregnancy [7]. Several studies indicate that religiosity and a tendency towards tradition constitute the major cause among Moslems for non-utilization of prenatal diagnosis [8,9]. These observations cannot be confirmed by the national registry, since the degree of religiosity in the Moslem community is not indicated and the place of residence cannot be used as a proxy to indicate religiosity because religious individuals do not live in separate communities. Probably, the differences in the utilization and rates of pregnancy termination according to the district of residence are mostly related to socioeconomic factors in the Moslem community [Table 3].

One can assume that women with a Down syndrome child are aware of their increased risk in subsequent pregnancies. Therefore, the rate of utilization of invasive tests in pregnancies following the birth of an affected child may indicate whether the birth of the Down syndrome child was the result of an informed choice or not. This observation was confirmed by our data: 76.9% of women who had given birth to an affected did not use the prenatal diagnostic services in the subsequent pregnancy, which indicates that the birth of the affected child with Down syndrome was the outcome of his or her mother's will.

It is obvious that the problem lies within the boundaries of the appropriateness (demand) side of the program and not in the accessibility (supply) side. In this respect the study shows a very low level of utilization of prenatal tests to diagnose Down syndrome in three distinct communities: ultra-Orthodox Jews, Jews born in Ethiopia, and the Bedouin in southern Israel. What the Ethiopian Jews and the Bedouin have in common is that they are traditional non-fundamental religious communities that have been living until recently in a rural environment. In addition, both communities, like the ultra-Orthodox Jews, have the lowest socioeconomic status in Israel. The low rate of utilization in those communities is probably a combination of religious, cultural, traditional and socioeconomic factors.

Moreover, several studies in the past have demonstrated that religious beliefs are the major reason for the low utilization of the program among both Jews and Arabs [2,8,9]. We can conclude from the present study that in Israel most Down syndrome infants are born as a result of an informed choice of their mothers. In other words, there is a problem of acceptability of the program by the target populations. These groups utilize, to a certain extent, the accessibility of the screening component of the program and much less the availability of the invasive tests that allow for diagnosis of Down syndrome. Even though the current program for Down syndrome prevention is funded and promoted

by the State, the choice of whether or not to use it remains with the individual pregnant woman. In a pluralistic society with its diverse communities and dissimilar religious backgrounds and traditions, the various ethnic and religious communities must be allowed their different approaches and solutions. From the practical point of view, special attention should be given to the three communities: ultra-Orthodox Jews, the Bedouin of the Negev, and Jews who originated from Ethiopia. On the national level there should be a dialogue with the leaders of the three groups in order to understand their attitudes towards the birth of a child with Down syndrome. On the community level there is a need to understand and internalize the knowledge and attitudes of the target populations, especially with regard to their opposition to pregnancy termination as a means to avoid the birth of babies with Down syndrome. A health education program and culturally sensitive information adapted to the needs of each community should be added to the current program. There is also a need for developing various services (medical and social) for children born with Down syndrome in each of the communities. These services must be designed to answer the special needs of these children to ensure their integration in their respective communities as both children and adults.

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