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Original Paper

Managing Screening Tests of Hereditary Diseases and Challenges in Their Conduction in Arab Sector of Israel

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Abstract

Hereditary diseases are a known factor in the world to mortality and morbidity of infants. The frequency of these diseases characterizes specific population segments more than others. Acknowledging the efficiency and profitability of performing screening tests, raises the question of Arab women's low responsiveness to perform the hereditary screening tests comparing to Jewish women and in general.

Keywords

genetic, screening tests, hereditary diseases, Arab sector

1. Introduction

A woman living in Israel enjoys a wide range of screening tests that she can have before and during her pregnancy. The perinatal screening tests, "which are considered as one them, imply that pregnant women go through tests that can help in identifying frequent genetic diseases or/and going through ultrasonography test that helps in allocating developmental malformations and disabilities as for example the Down syndrome". Some of these tests are financed by the health maintenance organization and others require payment (Romano-Zalicha & Shochat, 2011).

The responsiveness of women in Israel to screening tests is in constant increase. For example, between 2001 and 2011, the responsiveness to the nuchal translucency screening raised from 15.7% to 53.8% (Romano-Zalicha et al., 2011). However, the responsiveness in different population segments is not uniform. For example, 47.5% of Jewish women in Israel perform amniocentesis following recommendations of the specialists, however there are only 28.6% of the Arab women who perform this type of test. It has to be mentioned that this low rate is considered as an improvement, since the

reported responsiveness rate of Arab women to amniocentesis in 2001 was only 19.2% (Romano-Zalicha et al., 2011).

Comparing to the low responsiveness there is the consideration of the high risk of lack of responsiveness. According to the Ministry of Health (2014), the Arab sector faces an increased risk to hereditary morbidity, especially within Bedouin villages and tribes where there is an increased cases of inbreeding. In these places, the range of having an infant with malformations and the range of infant mortality is 10 times higher than the range within the Jewish sector. In 2011, the mortality data was 11.44 to 1000 live births. Moreover, the frequency of hereditary disabilities of Trisomy type (Down syndrome, Trisomy 13, Trisomy 18) among Muslims in Israel is 12.16 to 1000 live births and among Bedouins is 16.43 to 1000 live births (ministry of health, 2014). Therefore, and as can be seen from statistics, the abovementioned population is considered as of high risk to genetic morbidity and as well as of low responsiveness to screening tests.

Women's lack of responsiveness to hereditary screening tests leads to expenses that are costly for the health system in Israel. While the cost of one screening test to Beta-thalassemia disease is about 60$, the cost of locating one sick newborn is 63,000$ and the annual treatment of Beta-thalassemia newborn child is about 40,000$. Given that with proper treatment (blood transfusions and removal of iron) thalassemia patient may survive 50 years, which would save millions of Dollars through one screening test to a single disease (Koren et al., 2014).

Because of the profitability and ability of performing screening tests, the Ministry of Health tried to find out the reasons of the gaps in responsiveness. A survey was performed in 2010 on 768 women, religious ones and non-religious, giving birth in Israel shows the reasons for not having hereditary tests. Further, the survey showed another reasons which was mainly and only mentioned by Arab women who took part in the survey. It seems that they had chosen not to take the tests by their own well (Romano-Zalicha et al., 2011). The choice of Arab women not to perform the hereditary tests together with the low responsiveness to screening tests leads to the necessity to find out the factors influencing their decisions and recommend solutions for encouraging them to perform the tests and improve their responsiveness.

The article will discuss the problem of Israeli Arab women's responsiveness to the genetic perinatal screening tests. Understanding both factors that weakness and strengthen the responsiveness of women to screening tests will allow building a model that will decrease their resistance to perform the tests and improve their responsiveness to screening tests.

2. Hereditary Morbidity in Israel and in Its Arab Sector

The Hereditary morbidity is a world health challenge. The global range of severe genetic morbidity or stillbirth due to hereditary morbidity is about 5%-7% of all live births (Koren et al., 2014). However, the hereditary diseases may appear not as overt disease, but as carrying a defective gene (Mendelian heredity morbidity), and its frequency changes according to the different ethnic and geographic groups.

For example, while in the general population in the north area of Israel the Beta-thalassemia affected individuals are only 2.4% of the population, in some Arab villages the average mounts to about 9% of the cases (Koren et al., 2014). There are more Mendelian diseases that characterize different sub-populations in the Arab sector in Israel, that its frequency is even higher. A genetic survey that was conducted on the Bedouin population in the Negev showed cases of 1:5 of Carmi syndrome and 1:40 of Hypoparathyroidism or Mendelian genetic retardation (the Ministry of Health, 2014). In addition to high number of cases of hereditary morbidity, there is high risk to the morbidity expression, due to high cases of inbreeding within the Arab sector. 25% of all marriages of Muslim Arabs and Druze are marriage between relatives of first level, cousins. An additional 20% of all marriages are among more distant relatives. Among Cristian Arabs, the frequency of inbreeding is lower (21% cousins' marriage and 10% inbreeding of other classes), but it is still relatively high (Zlotogora, 2014).

3. The Screening Tests in Israel

Until the year 2017, there were (and still) several types of genetic screen tests offered to pregnant women and to women before pregnancy in Israel.

The first type is tests for hereditary diseases of Mendelian type. Since 2002, the instruction of the Ministry of Health is to include as part of the health backage the screening tests that show in specific population segments in frequency of 1:1000 or more live birth. These tests are offered to be performed by the woman once a life to check if she is carrying the gene, and in case of known family genetical diseases it is also possible to ask her spouse to go through the tests. In 2016 the screening tests procedure was updated and the recommendation to the performance of screening tests is based on 3 main criteria:

- Gravity—a disease that causes mortality in young age or great morbidity and suffer to consider preventing the birth of the sick embryo or diagnises and treats at an early age.
- Frequency/Range—the chance of having an ill child is more than 1:15,000 or the carrying frequency to the diseases recessive gene is 1:60 and up.
- Diagnosis—possibility of having over 90% accuracy in diagnosy using existing tests. (Ministry of Health, 2016).

There is also an acknowledgement that within specific population segments there are different cases of different diseases and some populations are in higher risk than others. For the Bedouin population, for example, it means a free genetic test for carrying of possible 17 different diseases, e.g., Carmi syndrome, congenital insensitivity to pain or hemolytic uremic syndrome (Ministry of Health, 2014).

The second type of tests contains screening tests in full or partial participation to frequent chromosomal disorders. These tests are performed over each pregnancy and refer only to the current pregnancy. Amniocentesis or chorionic villus sampling to diagnosy Down syndrome is considered as the common test. There are also less intrusive tests, such as nuchal translucency, which is performed during the pregnancy's first trimester. These tests are funded by the health maintenance organization for women

under the age of 35 and by the Ministry of Health for the amniocentesis or chorionic villus sampling for women over the age of 35 (Ministry of Health, 2013). The tests mentioned above are offered to all pregnant women in Israel, based on the level of risk of the populations. However, there is a difference between the responsiveness of the different population segments and their performance of these tests.

4. Non-Performing Screening Tests: Factors

The responsiveness of Arab women in Israel to perform genetic screening tests is low. According to the Ministry of Health, there are several factors that play important role in causing Arab women to not perform the screening tests:

4.1 Arab Women's Level of Willingness to Perform the Tests

The level of willingness of Arab women to perform the triple test (screening test to risk of Down syndrome) is significantly related to several factors, such as pregnancy planning; number of pregnancy; availability of awareness material, number of children (less or more than 3); adherearance to additional health insurance ($p<0.05$). It is worthy mentioning that the correlation between the triple test and the family income was not significant ($p=0.07$), which contradicts the claim that chorionic villus sampling, for example, was not performed due to cost considerations (Romano-Zalicha et al., 2014).

It has to be mentioned that along the years the economic factor becomes less relevant. One of the reasons is that, by the instruction of the Ministry of Health, the basic tests basket to each pregnant woman includes free screening tests to every hereditary disease that its carrying frequency is over 1:60 in the discussed population. It is important to emphasize that these tests are aimed to diseases with Mendelian heredity (driven from carrying gene by the parents) and not point mutations or trisomy. For the frequent trisomy, there are tests as amniocentesis, which are fully funded by the Ministry of Health after the age of 35 and before—in pregnancies declared in risk by screening tests as nuchal translucency or Alpha fetoprotein (ministry of health, 2013). It means that the economic accessibility of screening tests is reasonable. For example, a hereditary test to CF is fully funded by the state, but only 11.7% of Arab women performed the test.

4.2 Religiousness Level/Status

According to Romano-Zalicha et al. (2011), in a survey performed among women in Israel about the lack of responsiveness to screening tests, the religiousness level was reported as one of the reasons to not perform the test. Moreover, this survey had shown that there is a majority among the Arab women questioned about their level of practicing their religion or the tradition level of impact on their lives, in comparison with the Jewish women (87.6% vs. 62.1%). This is due to two possible explanations. One explanation is that some screening tests, such as amniocentesis or chorionic villus sampling are known as having a risk of miscarriage before the 24th week in 1%-2% of the cases. Even though research examination of 42,716 women that performed amniocentesis and 8899 women that performed chorionic villus sampling had shown that the chance of miscarriage after performing these tests is lower than before performing (Akolekar, Beta, Picciarelli, Ogilvie, & d'Antonio, 2015), the fear still

exists and it is interpreted as risk of miscarriage that is forbidden by religion. On the other side, the responsiveness to screening tests of nuchal translucency, that not endanger the fetus, is much higher among Arab women than in Jewish women (70.6% vs. 61%, p=0.01) (Romano-Zalicha et al., 2014).

The other explanation is that diagnosis of malformation of fetus is one of the reasons recognized by the Israeli law to perform intentional abortion in all pregnancy stages. However, according to the Muslim law, abortion is allowed only if the pregnancy endangers the mother's life, and some Fatwas allow abortions in rare cases as long as the woman is still in her 120th day of pregnancy (Zlotogora, 2014).

4.3 Information Gaps

In some area such as Gaza and Saudi Arabia there is awareness the benefit of going through screening tests before wedding. The young couples are fully aware of the need in hereditary tests and hereditary morbidity (Cousens, Gaff, Metcalfe, & Delatycki, 2010). However, in Israel the the compulsory guide about conducting screening genetic tests is only by nurses in family health center during the first meeting in the first trimester at pregnancy, Also there is very little information on the subject of advertising in the public (the Ministry of Health, 2014). There are also very few open publications on this subject and its meaning is that hereditary morbidity carrying couples marry without knowing. It is a phenomenon characterizing all women in Israel and not only those of Arab sector. According to Romano—Zalicha et al. (2014), there is a huge relation between getting the information brochure and performing screening tests that leads the Arab women to go through the tests. Namely, a better accessibility of information could improve the responsiveness of Arab women to perform the tests. The information issue may also be referred to public media that may help increasing the awareness to hereditary morbidity. The diseases that are mediatized, as cystic fibrosis (CF) are shown in low frequency among Arab population in Israel. While the national average of carrying the gene CF is 1:45, it is 1:236 among the Arab Muslims in Israel and less than 1:1000 among Israeli Druze (Zlotogora, Grotto, Kaliner, & Gamzu, 2015). It can be concluded that as long as the level of awareness of the population on its existence and number of cases is low, the level of willingness to perform the tests is low as well.

Facultative choice vs mandatory choice—this reason has to be taken with extreme caution. A common reason that rose in the survey in Israel for not performing the screening tests among Arab women was lack of will (Romano-Zalicha et al., 2014). While the world health organization notes that screening tests have to be performed voluntarily only, there are countries, such as Saudi Arabia, in which performing screening tests is mandatory by national law. In Greek Cyprus, performing screening tests was first mandatory by Christian religious law and later by legislation, while lack of written certificate of performing genetic counseling is unequivocal obstacle to perform marriage ceremony by the church. In Gaza Strip, not performing screening tests may serve as a legitimate ground for divorce. It has to be mentioned that performing screening tests is not mandatory and it comes back to the couple who want to get marry or are already married. It is, at the end of the day, up to them whether to get marry or whether to perform the tests or not (Cousens et al., 2010). The fact that in Israel, performing the

screening tests is not mandatory and it is just a recommendation, it increase the indifference of the patients towards the tests and this may have a negative impact on the health outcomes of the patients (the Ministry of Health, 2014). .

4. Discussion

Low responsiveness to performing screening tests still existing amongs certain populations despite the world awareness of their importance. In Israel, it refers to the Arab women. It is agrreg among scholars that the Arab population has the highest average of genetic morbidity (Romano-Zalicha et al., 2014; the ministry of health, 2013). National survey that examined the reasons for lack of responsiveness showed some common explanations (Romano-Zalicha et al., 2014), but there is a disagreement in the literature about the real influence of those factors.

One common reason reported by the participant of the survey is the financial factor—the cost of performing the tests. According to Romano-Zalicha et al. (2014), the correlation between the income level of the Arab women and performing the screening tests was not significant ($p=0.07$). In addition, according to the Ministry of Health, many tests that are common in Arab population usually performed with full subsidization of the health maintenance organizations or the Ministry of Finance (the Ministry of Health, 2013; the Ministry of Health, 2016).

Another reason explanation is the level of religiousness. Romano-Zalicha et al. (2014) found that the Arab women reported higher level of religiousness comparing to Jewish women further, there is a faith in the public that performing of specific screen tests as chorionic villus sampling may increase the chance to have miscarriage. Although it has been demonstrated in research that the risk is not higher than the risk of miscarriage without performing the test (Akolekar et al., 2015), there is still a fear that may be accepted by religious resistance.

Another reason is information gaps existing among the Arab population. In some countries in the world there is health promotion of hereditary screen tests to legal obligation to perform the screening as an exclusive condition to marriage (Cousens et al., 2010). In Israel, the first time Arab women faces the issue is when they are already pregnant and visit the family health centres for pregnancy follow-up in the first trimester (the ministry of health, 2014). This shows that the lack of information about the existence of these tests had led to their low level of responsiveness (Romano-Zalicha et al., 2014).

Another factor is the woman's will. This factor came as a significant factor in the survey of Romano-Zalicha et al. (2014) but without detailing the meaning of the answer "because it is their will" and without examining the correlation between this factor and other factors in regression exam. Not much literature was found on this issue, although according to Cousens et al. (2010), in countries in which not performing screening tests may be a ground for divorce (Saudi Arabia, Gaza), women's responsiveness to screening tests is higher. On the one hand, it is inappropriate to speak of coercion of tests in the national level, but on the other hand this issue of lack of patient's will requires additional examination.

5. Summary and Recommendations

Performing screening tests for hereditary morbidity is an efficient way in health and economic aspects to reduce incidences of morbidity and mortality related to genetic defects. Many diseases that are common among the Arab population in Israel have screening tests subsidized by the Ministry of Health. However, the responsiveness of Arab women to the screening tests is 10% lower comparing to Jewish women. Examining the different factors influencing the Arab women's willingness to perform the screening tests showed several elements. Some of these elements, as the economic, are already known to the health system and are responded by subsidization and the Ministry of Health's participation in the tests' cost based on relevant criteria. Other factors, as information gaps, refer to gaps and faults in the systematic reference to the issue of screening tests. This refers to the importance of the written material and the minor reference of health workers to the question of hereditary screening tests excluding the time of pregnancy after the marriage. For this issue, there is a place to examine the source of the gaps in making the information accessible for Arab women and Jewish women and the possibility to raise the awareness to the existence and importance of screening tests among Arab women, not only in a single meeting during the pregnancy follow-up. Moreover, the literature showed the unique factor for the Arab population in Israel, namely, women just "do not want" to perform the test. This factor requires more profound examination to identify the sources, the reasons and the attitudes in the bases of this refusal.

In summary, due to the world acknowledgement and as well as of the Ministry of Education of the importance in performing hereditary screening tests, the gaps in performing these screening tests point out the need in research and guiding in system level to improve Arab women's responsiveness to perform screening tests.

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