

IMPROVING THE PERFORMANCE OF THE MANAGEMENT OF GENETIC SCREENING AMONG ARAB WOMEN IN ISRAEL

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Abstract: *This study examined the management of the performance of genetic screening tests by Arab women in Israel, the rate of responsiveness to genetic screening tests among Arab women in Israel, and the link between socioeconomic status, education, and religion, and the responsiveness to performing genetic screening tests among the research population, and the factors that influence Arab women's decision to perform genetic screening tests prior to pregnancy. The study addresses existing opinions and perceptions regarding Arab women's level of adherence to pre-pregnancy genetic screening tests. This is an empirical quantitative research and its findings related to the responses given by Arab women, considered the most important stakeholder, the clients of the genetic screening test system. The main findings are that women have a great deal of support for a binding law mandating the performance of tests as well as the requirement to predicate marriage on tests, and for enforcing its application.*

Another finding is that there is a strong influence of religion and Muslim clerics on the willingness to perform tests among the population. . A special contribution of the study is a change in religious policy by the Chairman of the Muslim Court in Israel, who issued a fatwa (religious order) that commands and directs the Muslim population to perform the tests. Recommendations are made concerning the development of a national program that promotes genetic health and directly influences responsiveness to pre-pregnancy tests aimed towards the main stakeholder group that is Arab women in Israel.

Keywords: *management performance; genetic screening; Arab women, Israel.*

JEL Classification: *H75, I18, D73.*

1. Introduction and background.

One of the most important resources in human life is health. The very availability of health is associated with one's ability to reach self-fulfilment, to fulfil one's most basic needs, and to develop in society (Behjati, 2014). To provide this resource, an

organization is required. This organization, by its very definition, must be aimed at the design, production, distribution, and maintenance of the product (Samuel, 2006). The structure of the healthcare system includes a government representative as the head of the organization, most often the Minister of Health, although in the last Knesset (Israeli parliament) this was a deputy minister who acted as a minister (Knesset, 2019), a CEO, and 6 divisions that include:

- The Health Division, which managing and deals with coordination between the various bodies, health promotion and preventative medicine.
- The Medical Division, which sets professional standards and policies and oversees their implementation.
- The Medical Technologies, Information and Research Division, which promotes innovation, with an emphasis on managing equal treatment.
- The Professional Headquarters, which deals with legal questions, budget management, budgeting and pricing, and the Information Department.
- The Government Medical Centers Division, which deals with accreditation, work processes and human resources of government hospitals, including general hospitalization, mental health, and geriatric care.
- The Regulatory Division, which deals with managing the health funds, but also includes the Ombudsman and the Information Systems Department. (Ministry of Health, 2019).

The various divisions have multiple management powers or special associations. For example, control of government hospitals managing is not under the Medical Centers Division, but rather the Professional Headquarters, while the Information Systems managing are associated with the Regulatory Division and not with the Technologies Division (Ministry of Health, 2019).

The functioning of the Israeli healthcare system management is limited by many laws, such as the National Health Insurance Law - 5754-1994 and the Genetic Information Law - 5761-2000 (Ministry of Health, 2019). It is also influenced by frequent changes of management procedures, regulations, additional laws, and standardization requirements. The prevalence of hereditary diseases among Israel's general population is high. In some population groups, such as the Bedouin in the Negev, the prevalence of carriers of hereditary diseases can in some cases reach 1 in 9 (For example, osteoporosis) or even 1 in 5 (Carmi syndrome). The result of such a high prevalence includes, among other things, high infant mortality. For example, in the same Bedouin population, the prevalence of birth defects is 10 times higher than among the Jewish population, and infant mortality is 11.4 per 1000 live births, 3 times the rate of the Jewish population (Ministry of Health, 2014). The Arabs, including Bedouins, in Israel belong to lower income group, and have a traditional culture characterized by paternalism, authoritarianism, and 99% are Muslims.

Genetic screening is a costly process both in terms of human life and in financial terms. Israel has a policy of performing genetic screening tests, which have unequivocal criteria and targeted populations. The operational and the economic responsibility for conducting screening tests belong to the health funds. According to the Ministry of Health's 10/2018 Medical Division Circular, the condition for

eligibility for coverage of the cost of tests by health funds requires proof that the test has a sensitivity of more than 50% of the disease in question, is executed in a laboratory recognized by the Ministry of Health and that there is an expert's approval for conducting the tests. In conclusion, apparently, the policy of the Ministry of Health for dealing with screening seems adequate - focusing on at-risk populations, adding complete genome tests. However, in practice, the situation is different, since the performance of screening tests is largely lacking, mostly in Arab population. For example, the introduction of complete genome tests is in addition to specially targeted tests (Ministry of Health, 2018), thus creating a waste of resources. Also, the health system is transferring more costs to health consumers on one hand and looking for ways to streamline the treatments it provides, on the other.

However, there are certain groups among whom the performance of genetic screening tests is more complex and the responsiveness to testing in these groups is low. In Israel these are members of the Arab community, while the Muslim community is less responsive than the rest of the population. However, it is very important to increase the responsiveness of Israeli Arabs to screening tests, due to the high incidence of certain types of hereditary diseases, such as *Thalassemia*, in their society (Ministry of Health, 2014).

This paper will deal with the subject of genetic testing among the Arab population at an administrative level, considering the theoretical framework in the field of health systems management and existing diagnostic methods, the importance of conducting screening tests, theoretical, social, and religious aspects that affect the importance of the response to screening, and examination of possible solutions at the policy level and the knowledge level. The purpose of the paper is to present the complexity of the issue of genetic screening tests among the Arab population in Israel and the wide range of changes that can be made to increase the response of Arab women to genetic tests on a national and community level, in order to reduce hereditary morbidity in Israel.

2. The research methodology

Within the quantitative phase, 381 questionnaires were distributed among Arab women and 120 questionnaires among stakeholders, to examine their positions and opinions on the current situation and on their willingness to introduce a new change regarding the conducting of genetic testing in the country.

The pilot sample consisted of 20 Arab women aged 18-44, of childbearing age. All the questionnaires were returned fully completed. This is a convenience sample collected from among family health centers in Arabic-speaking communities in northern and central regions of Israel. All the participants were women (20, 100%), all were Muslim (20, 100%), most had a high school education or higher, most were traditional (16, 73%), most were married (13, 59%) and most had an average of 2-3 children (11, 55%).

Once the results of the pilot study showed that the questionnaire is a trusted, valid, and reliable tool, 381 questionnaires were distributed among Arab women in Israel.

288 completed questionnaires (75.66%) were received from the Arab women and were included in the research analysis. The research population is approximately 9.1 million people, of which 40,427 are Arab women aged 17-44. To calculate the appropriate sample size, the following main factors were used: Threshold probability for rejecting the null hypothesis. Type I error rate = 0.05, power of 80%, or in other words the probability of failing to reject the null hypothesis under the alternative hypothesis. Type II error rate = 0.2, and the expected correlation coefficient (r) is equal to 0.25. The minimum sample size is 381 participants.

The inclusion criteria for Arab women were the following: to be literate, aged between 18-44 years, and being of childbearing age. The survey included 228 women of childbearing age. The demographic characteristics of the ample are presented in Table 1, below.

Table 1: The demographic characteristics of the Arab women sample

Variable		Number of Respondents	Percent of the Sample (%)
Marital status	Married	168	73.68
	Single	53	23.25
	Divorced	7	3.07
Religion	Muslim	225	98.7
	Other	3	1.3
Degree of religiosity	Secular	7	3.07
	Traditional	197	86.4
	Very religious	24	10.53
Number of Children	0-2	121	53.07
	3-4	85	37.28
	5 or more	22	9.65

Table 2, below, presents numerical demographic characteristics of the sample.

Table 2. The numerical demographic characteristics of Arab women sample

Variable	Minimum	Maximum	Average	Standard deviation
Age	20	56	34.23	7.702
Years of education	2	26	14.72	10.85

One can see that this is a sample of relatively young women with a wide age distribution. The most common education was a Bachelor's degree (42.5%), the average number of years of education was 14.7 (matriculation certificate and above). A random sample questionnaire was distributed between November 2019 and January 2020 among Arab women from the Arab sector in central and northern Israel.

The pilot questionnaire, completed by 20 subjects, as well as the research questionnaire 228 responses from women, were developed, written, and based on the

first, qualitative part of this research. The themes and categories that emerged from the first part of the research and were supported by the literature, enabled the creation of this questionnaire. The questionnaire was designed specifically for this research. Each section of the questionnaire underwent Cronbach's alpha testing in order to examine the questionnaire's internal consistency level. It was validated by three content experts.

A Likert scale was used in this research: This is a scaling technique designed to allow the possibility of classifying variables for which there is no fixed and agreed unit of measure. In the Likert scale, the subjects are asked to evaluate a statement by giving it a quantitative value on any kind of subjective or objective dimension, thus stating their level of agreement/disagreement (Derrick & White, 2017). All responses to statements range from 1 ('strongly disagree') to 6 ('strongly agree'). Questionnaire results were analyzed statistically, and the findings either confirmed or refuted the research hypotheses.

The questionnaire used for Arab women included 56 questions in 5 parts.

The first part dealt with the socio-demographic part. For all parts of the questionnaire, Cronbach's alpha tests were conducted to test the internal reliability level of the questionnaire.

The second part included questions 1-14 on the subject of "genetic screening tests". They refer to the tests performed, the timing of the tests prior to or during pregnancy, the type of tests the women underwent, the referring parties, training on the subject and when they received the training, existing family diseases, who the patients are, what types of diseases, "willingness to care for a sick child" and awareness of the dangers involved, and a question about the means that can help women perform the tests. The questionnaire was compiled by the researcher specifically for the purpose of this study as part of factor analysis.

The third part included questions 1-21 on the subject of "assessing positions and awareness towards genetic screening tests." This part consisted of 15 statements describing attitudes towards performing the tests. The answers to the statements range from 1 ('strongly disagree') to 5 ('strongly agree'). The Cronbach's alpha internal reliability test found a good enough internal reliability level, $\alpha = 0.705$.

For the purpose of constructing the index, the average of answers to the 5 statements was calculated, such that a high score indicated the great importance of performing the tests in the practical aspect and the timing of the tests prior/after pregnancy, the emotional, cultural and religious aspect, knowledge and awareness of the tests, influence of the emotional and economic situation on the family, the most suitable location for training, and support for a law that would mandate testing.

The Cronbach's alpha internal reliability test found the Alpha Cronbach $\alpha = 0.790$. For constructing the index, the average of the responses to the statements is calculated so that a high score indicates that there is a high level of awareness and a great willingness to perform screening tests, and a low score will indicate a lack of responsiveness to performing the genetic tests.

The fourth part consists of 8 statements and includes 8 questions describing the following factors influencing the participants' decision to perform or not to perform hereditary screening tests. The answers to the statements range from 1 ('strongly disagree') to 5 ('strongly agree'). The Alpha Cronbach internal reliability test found a high internal reliability level $\alpha = 0.919$. For processing the data, an average index of the answers of all 8 statements was constructed. The high score of the questionnaire will indicate decisive factors that influence women not to perform the tests. A low score will indicate low importance of the set of factors that influence the decision to perform genetic tests.

The fifth part consisted of 2 statements and included two questions. The part examined level of knowledge about the incidence of genetic diseases in the Arab population and the type of diseases examined by genetic screening tests.

The sixth part consisted of 2 statements and included two questions. The questions refer to the existence of an intervention program on the subject, and if so, which programs do women consider important and which should be carried out in the general population, $\alpha = 0.922$.

Statistical analysis was performed using the SPSS version 24 software for quantitative analysis.

3. Findings

The findings of the survey of a representative sample of 228 women of fertility age are discussed further. Table 3 below summarizes the demographic characteristics of the sample. One can see that most of the subjects were married (73.68%) and Muslim (98.7%).

Table 3. Demographic characteristics of the women respondents

Variable		Number of Respondents	Percentage of the Sample
Marital Status	Married	168	73.68
	Single	53	23.25
	Divorced	7	3.07
Religion	Muslim	225	98.7
	Other	3	1.3
Religiosity Level	Secular	7	3.07
	Traditional	197	86.4
	Very religious	24	10.53
Number of Children	0-2	121	53.07
	3-4	85	37.28
	5 or more	22	9.65

Table 4 below presents numerical demographic characteristics. One can see that this is a sample of relatively young women with a wide age distribution. The common

level of education is a bachelor's degree (42.5%), 34.2% had a matriculation certificate, approximately 19% hold a master's degree, 3% hold a doctoral degree, and the rest had no formal education, while the average number of years of education is 14.7 years (matriculation or higher).

Table 4. Numerical demographic variables of the women sample

Variable	Minimum	Maximum	Mean	Standard Deviation
Age	20	56	34.23	7.02
Years of Education	2	26	14.72	1085

The higher the education, the less subjects agree with the claim that genetic testing affects a family's financial state. Half of all women strongly disagree with marrying a husband with a genetic disease in the family. The lower the education, the more variance in the answers. Almost everyone disagrees with the argument "it's better for parents not to know", except those who have no education - they are mostly neutral. Most of the respondents (especially those with a PhD) agreed with the claim that the state authorities must require genetic testing. The majority agree that information on genetic testing should be provided in school. Regarding religious centers there are differences of opinion (that most likely depend on the religion). There is a great variance in replies regarding information at health funds and regarding predicating marriage on the performance of the tests.

The respondents identified the following factors that could have influenced women to perform genetic tests, by education level of respondents: a) the vast majority *disagree* that the financial factor is the most influential factor; b) religion is the most influential factor among the group of women with no education; c) parents' positions also affect women without consequences, but less when the women are more educated; d) there is more variance regarding the partner's position; e) the more educated women are, the more influential is the factor of women's health; f) there is a positive link between knowledge of the various tests and women's level of education. Knowledge about the existence of tests plays an important role when women are more educated; g) this is also true of availability at health funds.

When asked about the need for a compulsory law there is not much difference. Most women agree that this is a very important consideration. Regarding the behaviour of the Israeli Ministry of Health in this regard, 42.2% women answered that is insufficient, 35.6% acceptable, quite a few assessed the functioning of the Ministry of Health as very good 10.5% and 11.4% considered it excellent, and 5 not replying. In conclusion, the more than three quarters of women respondents were not satisfied with the quality of the activity of the government about the existing situation.

Since women, as citizens are also clients of the health system, this result indicates that there is an urgent need to improve the policy and the management of the genetic screening system.

Related to the proposals for actions to improve the system, the largest percentage (39.9%) suggested organizing additional lectures on genetic testing, 36.4% supported providing information at schools and health funds, 10.5% were in favour of campaigns on social networks and in newspapers, 9.6% proposed mandating

testing prior to marriage, 7.9% - advertising in the Arab sector, 2.2% - free tests for everyone, and only 0.4% - identifying inbreeding.

4. Discussion

This part discusses the findings about the subject of responsiveness and opinions on performing genetic tests in Arab society in Israel and attitudes to this practice as evidenced by the analysis of the findings in the quantitative part that emerged from statistical analysis of questionnaires distributed among stakeholders and Arab women of childbearing age in the State of Israel.

This study examined factors influencing the management of the public health system on the performance of genetic screening tests and their impact on the level of responsiveness to performing screening tests by women in the Arab sector, according to by the Arab women themselves.

The conclusion that emerges from the discussion is that in the literature review, this connects to the importance of content delivery by professionals and their unwillingness to invest the training time in a population that is less exposed to the whole issue. The literature reinforces the opinion that the knowledge component of the medical sector and its transmission to the population is necessary to raise awareness. According to Siani and Assaraf (2017), the issue of content adaptation and training methods, as well as genetic counselling per se, is a significant theme in interviews conducted among genetic experts. There is room for a change in policy from uniform training for the entire population in Israel to training medical staff to examine content and conduct training in a culturally appropriate manner, in order to increase the responsiveness of performing genetic screening tests.

Israel does not recommend a binding law; this allows for a lack of responsiveness due to personal considerations and the result can be grave. The literature shows that one of the reasons for the lack of testing is "unwillingness" among Arab women.

However, the quantitative findings regarding a binding law revealed that among women there is a great deal of support for enforcing such a law and mandating the performance of tests as well as the requirement to predicate marriage on tests, in comparison to the opinion among stakeholders.

The findings of the present study indicate the influence of religion on the willingness to perform tests among the population. A special and important contribution of the current study is a change in religious policy by the Chairman of the Muslim Court in Israel, who issued a fatwa (religious order) that commands and directs the population to perform the tests.

Moreover, the issue of the importance of screening tests has been examined in countries around Israel, and in some of them it has been implemented on the legal level as part of promoting public health in light of religious policy.

The researcher is proposing the development of a national program that promotes genetic health and directly influences responsiveness to pre-pregnancy tests aimed towards the main stakeholder group that is Arab women in Israel. The efficacy of the program is expressed by predicting the behaviour of the target population towards

the issue of genetic diseases and performing preliminary screening tests, and according to the data obtained, carrying out an appropriate culturally sensitive intervention. The expectation after the intervention is for a decrease in the incidence of genetic diseases among the target population, while addressing all the factors and barriers that can affect it and treating them accordingly in order to promote the issue of testing. Moreover, building a future training program for Imams and clergymen that are active in society, that will provide them with knowledge on the subject and the ability to provide extensive guidance and leadership on the subject, the so-called "health trustees".

Another contribution is a proposal for a managerial change in the policy of performing genetic screening tests in the health funds, by inserting the tests into health quality indices determined each year by the Ministry of Health and marking performed/not performed in the medical file of any patient arriving at the health fund and referring him or her for testing, if necessary. Also, a proposal for a secondary change in the school system that prepares the younger generation and the beginning of exposure to the subject and its study in high school. Instruction will be structured and adapted from tenth to twelfth grade.

The management of the national level genetic health program constitutes an important layer in preventive medicine, through the placement of the patient(s) health and wellbeing at its center. Today the patient-centred approach is one of the pillars of Israel's health system, and the patient is surrounded by a multi-professional team and active and influential key people in the community who are harnessed to understanding the patient's perceived and expressed needs and thus help the public system to promote his health and prevent the onset or reduction of diseases.

The study emphasized that Israeli policymakers play a key role in directing and harnessing promotion of the issue of pre-pregnancy genetic screening tests due to their significant importance in preventing and reducing genetic morbidity and raising a healthy lifestyle among the general population. However, our study revealed that there is a lack of knowledge about the nature, the causes the factors and the barriers facing the system for genetic screening among Arab women in Israel, as shown by the findings of the study among Arab women. One possible explanation is that in Israel, policy on conducting screening tests is in the hands of those who do not necessarily have a direct say in conducting the tests in the field or in health, although the health of the population is the main issue and is thought to be on the policymakers' agenda.

There is also a significant connection between religion, decision making to the responsiveness and performance of genetic tests, even among policymakers, stakeholders, and women. The lack of contact with the field in decision making can certainly explain the lack of knowledge on the subject even among policymakers. It is quite possible that if in Israel there was a link between religion and decision making on heredity tests, similar to certain countries in the Middle East (Cousens, Gaff, Metcalfe, & Delatycki, 2010), at least among Arab religious policymakers there would be more awareness of the phenomenon.

The findings revealed a significant link between reasons related to culture and high belief in God and the environment and lack of adherence and restrictions on performing the tests. A very important practical result of the current study is that there has been a significant change on the religious-cultural level based on the fatwa of the Mufti, Dr. Mashhor Fuaz.

In addition, the current study revealed the influence of family and spouses in terms of resistance to testing. This identification is important and culturally sensitive. Therefore, it is highly important to involve the husband in the decision making through the national plan proposed by the present study. Among women there is a positive link regarding the effect of performing the tests on the emotional state of the family. The literature addressed the religious cultural context at an inadequate level, so there is room for further research to gain an in-depth understanding of the full picture of family influence on decision-making.

In addition, the current study identified that the transfer of information and accessibility of genetic screening tests has a mediating effect on the level of adherence and performance of tests. The findings revealed that in the three groups, among policymakers, stakeholders, and women, this creates immediate gaps in decision making. It should be noted that in the existing policy, based on the delivery of leaflets to a small part of the population, the study findings indicate the importance of identifying populations where there is a lower incidence of using information and existing tests. The findings of policymakers in the first part of the study emphasized the importance of collaborating with professionals, opening additional clinics and training additional staff, as well as collaborating with organizations available to Arab women, clergymen, media, and Internet personnel that will provide intensive training on the subject.

An important bias, thus a limitation, is that the researcher, being both a nurse and a nursing teacher, having the experience and knowledge gained over many years of practice might have created a subjective point of view.

5. Conclusions

The study findings emphasize the importance of raising awareness about pre-pregnancy genetic tests among the population through collaboration with key figures in addition to the medical staff (Ministry of Health), clergymen and the Ministry of Education. The findings revealed a great need for first-line information from physicians and nurses, which highlighted a lack of necessary information. Future research is needed about availability of professionals for the Arab population and the Arab population's perception about it, about factors that influence the performance of hereditary screening tests among Israeli Arabs. Another important future research is to examine the effects of the new fatwa on the willingness and level of responsiveness to pre-pregnancy screening tests among the Muslim Arab population in Israel.

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