

## *Original Paper*

# Economic Issues in Budgeting Genetic Test in Israel and in the World

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### ***Abstract***

*Promotion and performance of hereditary screening tests is known by the world health organizations as one of the economically most efficient processes, i.e., investing resources in screening tests in a process, which has increasing efficiency every year to locate an increasing number of known hereditary diseases in order to advice in preventing pregnancies with risk to have a child with incurable hereditary diseases and that will shorten his life expectancy. However, besides the economic success discussion, the other side must be examined, the side of the tests' target population. For this population the screening tests' economic aspect is both the tests cost and the illness's influence on the family. The discussion in these two aspects is separate, with only few researches examining the mutual influence of these economic considerations. Therefore, an integrated examination of the considerations must be taken to increase the hereditary screening tests and continue to reduce the incidence of hereditary disease in the world.*

### ***Keywords***

*Economic, Budgeting, Genetic test, Hereditary diseases, Cost-benefit*

### **1. Introduction**

Usually, when discussing about the decision to perform hereditary screening test in a specific population, it is done by the economic aspect. An article which discussed the issue of performing hereditary screening tests criteria shown that since the Wilson and Junger criteria presented in 1968 until today, the hereditary screening tests criteria has been changed, but one aspect did not change—the cost-benefit balance. On the other hand, in the early criteria, even before the cost-benefit, there is the criterion of acceptance by the target patient. In the late version of the criteria was also included the aspect of screening tests accessibility to the patient (Andermann, Blancquaert, Beauchamp, & Déry, 2008). A common accessibility form is the economic accessibility. It may be concluded that the

discussion in the economic aspect of performing screening tests must deal with cost-benefit aspects and economic feasibility for both sides, whereas most of the existing literature deals with only one side of the equation. The meeting point between these two economic sides and their mutual influence and connection must be examined.

## **2. The Economic Aspects of the Health System**

The national expenditure on health services was 7.9% of gross national income (GNI) in 2012. One third of it was funded by the state, about a quarter by health tax and additional 39% by the Israeli health customers. This expenditure is generally (9.3%) lower than the OECD average. It is a disorganized budget which tends to grow along the year. Parts of it are discussed and argued and changed even a month prior to the budget decision (State comptroller, 2015). However, there is a demand to the system's economic efficiency. One of the mechanisms that are expected to efficient is the health basket, i.e., treatments budgeted by the state that will not be directly paid by the patients. For example, the demands presented to the Israeli Knesset basket committee were about 2 billion shekels, while the budget set to the committee was only 300 million shekels. The debate may consider high unproven medical efficiency or low and proven efficiency, the target population size, what diseases may be prioritize etc. these budgets were up to different limitations and until 2010 could be routed to the Health Maintenance Organizations and other sources while the basket's budget itself was only 200 million shekels. The deductible the health organizations collect for medicines and treatments included in the basket is about 7% of the basket cost. On the other hand, the law limited patients' participation to 6.45%. The half-percent gap in the health organizations' overpayment is 2.36 billion shekels a year are passed on the end consumers (Koch Davidovich, 2015). The impression is that health services expansion is mainly related to passing the expense to end consumers. And, on the other hand, the health system cannot function without economic efficiency. However, there is a type of treatment in which the economic discussion concerns the possibility of saving in health system expenses. This treatment refers to hereditary screening tests.

## **3. The Policy of Screening Tests in Israel**

Hundreds of hereditary diseases carriers' cases are detected in Israel every year. According to the Ministry of Health publication (2015), after starting an intensive screening program to populations at risk, were found more than 5000 carriers of 65,000 subjects, i.e., a total prevalence of 1:13 of diseases carriers as fragile X. it seems to be positive and desirable behavior. However, in the report published on this intensive screening program, the following sentence appeared: "the number of carriers found meets the expected results and justify continuing the screening tests". This sentence implies profitability consideration, which is less referring public health, and more to justification of expenditure, economic considerations, and existing policy.

The policy in Israel regarding the implementation of hereditary screening tests is Opt-in after marriage,

i.e., there is no promoting knowledge policy of hereditary screening tests, even in risk populations, until a woman who is already pregnant comes to follow-up tests and the health organization clinic nurse tells her, as one of many pregnancy information, about the need for genetic counseling, which is actually part of the medicine basket (the ministry of health, 2014). At this stage the woman is already pregnant and has no way to know whether her current pregnancy is at risk. The result is a worrisome phenomenon in which an action known to be economically beneficial is not carried out due to a policy of inaccessibility of prior information. Research has shown that there is a positive correlation between knowledge availability regarding screening tests and its performance (Romano-Zelekha & Shohat, 2012; Ahmed, Green, & Hewison, 2005). Maybe this approach is the result of the deficient conduct of the health organizations as wrote the State comptroller (State comptroller, 2015). For example, screening tests' budgeting in the medicines basket is about 6,000 tests per year, while between 2013 and 2014, over 300,000 tests were performed among 65,000 patients (Ministry of Health, 2015). And while the deficit situation shapes the hereditary screening testing policy in Israel, it is worthwhile to examine the real economic balance of these tests, and not only by the health organizations' point of view.

#### **4. Hereditary Screening Tests—Cost Considerations**

##### *4.1 System Cost Considerations—Supplier*

Cost-benefit considerations influenced the screening tests performing policy in Israel since the first tests were performed in 1978. At first the focus was on two most common diseases in the population—Tay-Sachs among Ashkenazi Jews, and later also—Thalassemia among many risk populations. Even then, additional screening tests were known, as CF detection and fragile X syndrome, but only for cost considerations these tests were not included in the basket. In 2002, it was decided to expand the offered tests, expecting that the required number of tests would be no more than 6000 per year (Ministry of Health, 2005). However, between 1.2.2013-31.01.2014, as part of the Ministry of Health's intensive program for detecting hereditary disease, approximately 60,000 genetic screening tests were performed, 10 times the budget allocated by the health basket (Ministry of Health, 2015). Approximately 5,000 carriers were found in these tests. The Ministry of Health declared the carrier prevalence is 1:60, but in practice, were found carrier of 1: 149 in diseases as the fragile X syndrome, and still this test is included in the medicines basket. Additional criticism on this budget may be presented due to research performed in the United States among a representative sample of 1,000,000 residents. This research examined the efficacy of next-generation DNA sequencing in the study population. Over 80,000 carriers were found to have inherited mutations. It was also found that 223 births at risk were prevented comparing to not performing screening tests at all, and 21 births known to be affected by genetic changes due to this specific test. This intervention saved the health system about US \$ 13 million (Azimi, Schmaus, Greger, Neitzel, Rochelle, & Dinh, 2016). Hence, it can be concluded that performing large-scale hereditary tests enables more significant savings for the health

system. Therefore, the basket restrictions and the use of comprehensive tests instead of single-disease tests can bring significant economic benefits to the health system.

Despite the basket restrictions, the economic efficiency of screening tests and hereditary counseling has been conclusively demonstrated. A British publication calculated the cost of a genetic counseling and testing (about £ 1,000), compared to a one-year cost of £ 11,000 for Tai Sachs treatment. It should be mentioned that life expectancy of Tai Sachs patient depends on the age the disease appears, from 6 month old, and continue, with proper care, to a healthy person's life expectancy, i.e., dozens of treatment years (Ghosh, Griffiths, & Griffiths, 2016) This is a cold but unequivocal calculation, considering that this is a disease that is common in some populations, as the Ashkenazi Jews, can reach 1:46 carriers (Ministry of Health, 2005), this is significant savings, and genetic testing and training has been found to be effective. In 1990 it was published that Tai Sachs screening tests reduced Tai Sachs incidence among risk populations in the world (Ashkenazi Jews, Irish native born, French Canadians, etc.) in about 90% (Trics-Raine et al., 1990). Since screening tests performing became more effective and the price of a single test has decreased, the efficiency of long-term screening tests is unequivocal. The economic efficiency of the hereditary screening tests for the system has been unequivocally demonstrated, but the question arises as to the economic efficiency of these tests for the target population.

#### *4.2 Patient Cost Considerations—Customer*

The share of Israeli citizens in health expenditure is relatively high compared to other OECD countries. 24% of the health system's budget in Israel is financed by direct taxation on health, and another 39% is paid by the private consumers in direct payments (State comptroller, 2015). Passing on these expenditures to the consumer cause a situation where treatment or the test costs are related to the patient performing the tests. A survey of 768 women in Israel showed that among Jewish women there was a significant correlation between income and performing genetic screening tests (Romano-Zelekha et al., 2012). A more recent research among 414 Arab women in Israel showed more frequent use of genetic counseling (OR 3.44, 95% CI, 1.8-6.5,  $p < 0.001$ ) among higher-income women comparing to women with low income (Sharkia, Tarabeia, Zalan, Atamany, Athamna, & Allon-Shalev, 2015). While this research deals with addressing genetic counseling and not to the screening tests, we may conclude higher interest in hereditary morbidity among women with higher income. Maybe this tests' cost influences women's willingness to find out about hereditary morbidity in their family. A research of 50 women in Israel, of which 27 had hereditary screening tests, and 23 did not had hereditary screening tests showed that among women who had screening tests, only 20% included economic considerations as a possible barrier to perform the tests. But among women who did not perform the tests, 70% noted the economic barrier, a rejection level equal to that of moral or religious resistance to abortion (Remennick, 2006). Hence the screening tests' cost affects the tests' performance. For example, Clalit Health Services offers patients with supplementary insurance, i.e., patients who already pay tens of shekels a month beyond basic insurance, an option to perform hereditary screening tests that are not

included in the basket, at a cost of 80 shekels per test. These tests include common diseases that have not yet been entered the medicines basket, as the hereditary test for Bloom syndrome, a diagnosis to be a carrier is 1 in every 100 Ashkenazi Jews or Fanconi anemia in which 1 in 90 Ashkenazi Jews is a carrier (Alon Shalev, 2015). On the other hand, there are situations where the tests' cost is not a deterrent. For example, in the Dor Yeshurim project in the ultra-Orthodox community, there is a preference to private test in additional cost of \$ 180 per person, thanks to which 9-10 common hereditary diseases in this community are located and its occurrence is prevented by discouraging matchmaking between a pair of carriers (Burton, Levene, Alberg, & Stewart, 2009). Therefore, the deterrence of cost compared to the damage of known hereditary diseases should be discussed.

On the other hand, considering only cost benefit calculation, by Ghosh et al. (2016), earning ability loss of a parent whose child has Tay Sachs symptoms is about £27,000. In addition, the need treat the child and additional harm in daily life results a decrease of about 11% in the parent's functioning, and another 18% due to the birth of a child with Tay Sachs, i.e., it is not only a one-time cost, but the loss of parental potential, emotional distress and commitment to treatment.

In other words, on one hand it is known that there is a correlation between performing hereditary tests and their additional cost, but on the other hand, there are researches that show that not performing the tests can lead to a birth that will harm even more the parents' economic situation. However, there is no much literature that deals with the question of "cost-benefit" for family members, and it is not clear whether the family is informed of the economic outcome of performing or not performing the tests.

## **5. Discussion—The Economic Balance of Hereditary Screening Tests**

The screening tests are poorly budgeted by the health system. Despite the update, the medicine basket covers only about 6,000 hereditary screening test per year (the ministry of health, 2005), while the ministry of health promotes a 5 times performance of screening tests in focused programs (ministry of health, 2015). This creates a deficit policy and these may be the circumstances that shaped the existing policy of late and poor knowledge accessibility to hereditary screening tests to women in Israel. The result is that the knowledge became a barrier to performing hereditary screening tests (Romano-Zelekha, 2012).

This approach represents only the health system resources point of view, calculating the hundreds of dollars/shekels expenses per test, and rolling the costs on the patients' population as much as possible (State Comptroller, 2015; Alon Shalev, 2015). In other words, in an effort to reduce the screening tests' costs, the health system adds an economic barrier to the knowledge barrier.

This system saving policy has two problems. The first problem is that in practice the screening tests are a medical process that saves the health system money. Ghosh et al. (2016) showed a calculation by which any case of preventing a birth of a child with Tai Sachs is a case of savings 10-15 times a year compared the cost of performing a single genetic test or consultation. As for the intervention effectiveness, it has been known for over 20 years that intensive screening can reduce the incidence of

hereditary disease as Tay Sachs by about 90% (Triggs-Raine et al., 1990), i.e., reduction and specific savings in performing screening tests prevents significant savings in the future.

The second fault is not referring the patient himself. Not preventing the birth of a child with hereditary disease results in parental expenses, harms his productivity before calculating the emotional damage caused to a parent seeing his child suffer and die of hereditary disease (Ghosh et al., 2016). Maybe parents would have higher response if not the policy of non-accessibility of information and economic barriers. Even here the state suffers significant economic damage, just because they try to save in costs of tests that have already proved to be effective.

We may see that the one-sided discussion only on the cost of performing hereditary screening test, the focus on budget lag rather than budgetary efficiency and streamlining the consumer side that prevents effective implementation of tests among those already aware to its existence, actually means an increase in health expenditure.

## 6. Summary

The existing literature always focuses on one side of screening tests. It may be the effectiveness of tests already performed, it may be the economic deficit of the health system and the cost of each screening test. Some of the literature deals with the target audience, the barriers they face and even less deal with the negative consequences of not performing screening test of families.

The budgeting policy and screening tests in Israel are a result of this lack of knowledge balance. On one hand, there is a focus on health care spending and the health basket restrictions. On the other hand, there is a presentation of screening tests' effectiveness, the large number of located carriers that were sent to genetic counseling. But there is little reference to the inaccessibility of information policy on one hand, and to the inefficiency of performing hereditary screening tests, which can prevent expenditures to the health system on one hand, and economic damage and suffer of families on the other.

Therefore, more researches are needed to examine the effectiveness of the number of tests performed in comparison with the economic implications of preventing the birth of hereditary patients on one hand, and many researches on the human side of performing screening tests, the families, the communities, the considerations and the harm of the patients.

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