The Effect of Genetic Counseling on Knowledge and Perceptions Regarding Risks for Breast Cancer

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In 1994, a clinic for cancer risk counseling was opened at Hadassah University Hospital in Jerusalem. Most of the counselees have been women who had breast cancer and/or a relative with breast cancer. In order to evaluate the effect of this counseling on women's knowledge and perceptions regarding the risks for breast cancer, a questionnaire was given before and after the counseling session to 60 healthy women who came to the clinic because they have relatives with breast cancer. According to the genetic counselors' estimations, most of these women had a significantly increased risk (compared to the general population) of developing cancer. Before counseling, the women overestimated the population risk for breast cancer, the contribution of heredity to morbidity of cancer, and their own risks to get cancer. After counseling session, they gave reduced estimates, closer to the "real" ones. The subjective perceptions regarding these risks were reduced after counseling, except for the perceptions regarding their relative risks which have not changed after the counseling. About 90% of the women who came to the clinic wanted to be tested for genetic predisposition to cancer. For most of these women, the expectations that the test can rule out a genetic predisposition to cancer became more realistic after the counseling. The option to first test an affected relative was offered to all families, and a test was actually conducted in 75% of the families.

KEY WORDS: breast cancer; cancer risk counseling; risk estimate; risk perception.

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INTRODUCTION

About 5-10% of breast cancer cases are considered to be hereditary (Newman et al., 1988; Claus et al., 1991), and in recent years, it was shown that mutations in two genes, BRCA1 and BRCA2, are responsible for most of the hereditary susceptibility to breast cancer (Hall et al., 1990; Easton et al., 1993; Miki et al., 1994; Wooster et al., 1995). Soon after the BRCA1 and BRCA2 genes were cloned, it became reasonable to assume that in the near future women would be offered a test for mutations in these genes. Since then, many mutations in BRCA1 and BRCA2 have been identified (Collins, 1996; Couch et al., 1996; Phelan et al., 1996). In many populations studied so far, no common mutations were found, and therefore, carriers detection cannot be done using simple methods. Sequencing the entire coding regions of these genes may identify most of the mutations, but this is a laborious method, and even this method may miss part of the mutations.

In Israel, the situation is different, since two mutations in BRCA1 (185delAG and 5382insC) and one mutation in BRCA2 (6174delT), account for as many as 60% of ovarian cancer and 30% of early onset breast cancer in the Ashkenazi population (Abeliovich et al., 1997). Recently, it was reported that about 2.5% of the Ashkenazi Jews are carriers of one of these mutations (Struweing et al., 1995; Oddoux et al., 1996; Roa et al., 1996). Therefore, the test for Ashkenazi women has a higher sensitivity than the test for women from other origins (Ashkenazi Jews comprise about 40% of the population of Israel).

Together with significant advances in research which led to growing possibilities of genetic testing, problems and dilemmas connected to these tests were raised. These include the uncertainties that remain among women for whom no mutation is found (which is the case for a large part of the women tested), and the risk that women who have been given negative results will drop from early detection programs because of wrong subjective interpretation of the results. In addition, there are still disagreements about some of the preventive recommendations for carriers while there are indications that mental distress may dominate the lives of some women who receive a positive result (Lerman and Croyle, 1994; Lerman et al., 1996; Struweing et al., 1995).

As a result of these problems, some clinicians are skeptical about the value of genetic testing (Hubbard and Lewontin, 1996), and even of cancer risk counseling, and express concern about the possible emotional harm to women who receive positive results. Geller et al. (1995) claimed that from their experience, many women who wished to be tested changed their mind after discussing the issue with specialists. On the other hand, recent studies have shown a strong interest in testing for genetic susceptibility both in