Abstract

Clinical Services for Familial Breast and Ovarian Cancer in Germany

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Multiple hereditary cancer syndromes have been defined including the hereditary non-polyposis colon cancer (HNPCC) and the familial breast and ovarian cancer (HBOC) syndromes. Germline mutations of the cancer susceptibility genes BRCA1 and BRCA2 seem to be a major part of the HBOC syndrome. Gynaecological cancers like breast, ovarian and endometrial cancer are the most abundant cancer types. Public awareness and interest about predictive genetic testing for “late-onset” diseases are substantial due to scientific efforts (human genome project) and permanent publicity in the mass media. Personal expectations are focussed towards the specific cancer syndrome, asking for detailed information about the risk and nature of the disease as well as the — underlying and unspoken — wish for the information that the individual enquirer is not at genetic risk of the disease.

Furthermore, there is the individual demand

for specific actions including matters of prevention (i.e. medication, life style, surgery), early disease detection (i.e. ultrasound, mammography, magnetic resonance tomography), and therapeutic options (i.e. surgery, gene therapy). All this is affected by personal experiences with close relatives having the disease. To fulfil these public expectations, since 1994 “cancer genetic clinics” with an interdisciplinary counselling approach (gynaecological oncology, human genetics, psychotherapy, molecular biology) have been established at various universities. Since December 1996 the German Cancer Aid (DKH) has coordinated these individual efforts in a prospective multi-center study “Familial breast and ovarian cancer”. Clinical and genetic counselling is performed, high-risk families are identified, and (1) the effect of counselling, (2) the participation in an early cancer detection program, (3) the information about prophylactic medication or surgery, (4) the individualized psychological support and (5) different analytical strategies are tested. Results from this study are expected in the year 2000.

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