

# Ethical implications of predictive DNA testing for hereditary breast cancer

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Predictive medicine offers the possibility of detecting many common diseases that have a genetic basis, such as cancer; however, a genetic alteration might only indicate susceptibility to, not certainty of, disease. Whereas means for identifying a greater susceptibility to disease have been developed, effective interventions have progressed much more slowly. Awareness of one's susceptibility to disease without an actual possibility of intervention can lead to an unacceptable use of such information, or have a dramatic psychological impact on the person involved. Are the risks connected with the knowledge of susceptibility to genetic disease proportional to the benefits that such knowledge may provide? Does the knowledge of one's genetic condition constitute a service to the individual and society, or is this predominantly harmful for the person involved? The problem is vast, and involves medical, psychological, social, political and ethical dilemmas. These dilemmas, common to all predictive medicine, are most evident in predictive DNA testing for hereditary breast cancer. In our analysis, we will first examine the ethical values involved in genetic testing, highlighting the special ethical issues raised by predictive DNA testing for hereditary breast cancer. Next we will deal with genetic counseling, which, in our opinion, is the 'ethos' for ethically justifying predictive DNA testing.

**Key words:** breast cancer, counseling, ethics, familiarity

## Introduction

Predictive DNA testing offers the possibility of detecting many common diseases that have a genetic basis, such as cancer; however, a genetic alteration might only indicate susceptibility to or a high risk of developing a disease, but not the certainty of having it. Whereas means for identifying a greater susceptibility to disease have been developed over the last few years, effective interventions (both preventive and therapeutic) have progressed much more slowly.

Awareness of one's susceptibility to disease without an actual possibility of intervention can lead to an unacceptable use of such information (discrimination or social instrumentalization), or might have a dramatic psychological impact on the person involved. In fact, as more genes are identified, there is growing pressure to broaden existing screening programs and increase both the number of DNA tests available and the volume of genetic information they generate.

Are the risks connected with the knowledge of susceptibility to genetic disease proportional to the benefits that such knowledge may provide? Does the knowledge of one's genetic condition constitute a service to the individual and subsequently to

society? Or, conversely, is this predominantly harmful for the person involved because of the psychological impact that such knowledge occasions and/or the illicit use that can be made of it?

The problem is vast, and involves medical, psychological, social and ethical dilemmas. These dilemmas, common to all predictive medicine, are most evident in predictive DNA testing for hereditary breast cancer.

*BRCA1* and *BRCA2* (*BRCA1/2*) mutations have been identified that account for up to 15% of all breast cancer cases [1, 2]; in healthy women they are associated with a 55–85% lifetime risk of breast cancer and an increased risk of ovarian cancer [3]. Breast cancer is a common disease with a high incidence at earlier age; women fear this illness and the suffering engendered by metastases. With regard to effective intervention strategies in *BRCA1/2* mutations carriers, follow-up and life-style changes are important, but not definitive, chemoprevention is under investigation and bilateral prophylactic mastectomy does not completely protect from breast cancer [4, 5]. In such a case, is the use of predictive DNA testing ethically justified?

In our analysis we will start by examining the relevant ethical values involved in DNA testing with a focus on the special ethical issues this raises [6], and then proceed to deal with genetic counseling.

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## The relevant values involved in DNA testing

Genes are a fundamental element of a person's biology. Being informed through DNA testing of a disease an individual may acquire influence factors that belong to the personal sphere of that individual (including disease, physical development, suffering and death). Some relevant values are involved in this matter that give rise to ethical problems.

The personal dimension of DNA testing implies respect for an individual's autonomy, that is, the right to make autonomous decisions about one's health care and to voluntarily pursue DNA testing having possible consequences on that person's life. This value has priority in all the national and international bodies that have proposed guidelines on this matter [7–9], but it should not be considered as the sole basic norm guiding the use of genetic information.

Respect for an individual's autonomy requires that that person authorizes DNA testing intentionally, freely and based on understanding. It is also important that there not be pressure from the family, the professionals involved or other persons, because control by third parties would invalidate the consent given. The choice of whether to pursue DNA testing belongs to the individual.

Respect for an individual's autonomy is ensured by obtaining adequate informed consent from that person, and this means more than just a signature on a piece of paper. Thus, it is essential to offer pre-test counseling, both to evaluate the individual's capacity for autonomous decision-making and to provide a realistic view of the risks and benefits, the efficacy and alternatives, the seriousness and potential treatment of disorders, as well as the social and ethical implications involved. It is necessary to explain that genetic knowledge has an individual, predictive and probabilistic nature, and that the results of DNA testing have implications not only for the patients, but also for their biological kin. Genetic counseling should be carried out before submitting the individual to the test, as well as after the test when the results are disclosed.

Finally, respect for an individual's autonomy also entails that all information acquired through DNA testing should be considered in a confidential setting, and should not be disclosed without the individual's consent. There could be, however, some valid reasons to breach confidentiality and inform relatives or third parties (for example, when there is high probability of irreversible harm that disclosure will prevent, and there is no other reasonable way to avoid the harm).

On the other hand, genes are in the 'public domain', shared with others (parents, children, siblings, etc.), and it is possible to have a genetic disease or susceptibility in common with others without any of the parties knowing it. Thus a person's autonomy cannot be appreciated in its full sense if it does not encompass that person's responsibility toward others who are somehow involved in his/her decisions. This concept, which is valid for all bioethical issues, is particularly crucial in the area of genetics. In fact, an individual's awareness of his/her own genetic disease or susceptibility may entail the knowledge that relatives (including future children) may also have the disease

or a great likelihood of developing it. Similarly, a relative's wish to know whether they carry a genetic disease or susceptibility to disease may lead that individual to obtain knowledge of his/her own genetic disease or susceptibility.

Besides the above-mentioned values, there are also values linked to the social dimension of the problem. In the field of genetic diseases, the individual is exposed so that the primary duty of public authorities is to help and protect that person. This translates into society's making use of every means to identify diseases for which preventive interventions can be anticipated. Maximum care should be taken so that acquired information is suitably safeguarded and not used to stigmatize individuals or discriminate against them (for example, in employment or insurance coverage).

However, regarding the duty to help, there are arguments suggesting that such a duty is less stringent or urgent than the duty to avoid harm [10, 11]. DNA testing, in fact, may potentially harm people by raising anxiety, changing their self-image and paving the way for genetic discrimination [12].

Another societal duty is to ensure equal access to genetic services and an equal allocation of health-care resources. To the extent that DNA testing is considered of value because it contributes to human well-being and to the satisfaction of human needs, access to such procedures and to other health services will become a matter of justice. To the extent that such tests and services are linked to human well-being but are made available for reasons other than need, for example, to those who can afford them, injustice will arise. Genetic services should be treated like other health-care services.

## The special ethical features of DNA testing

Alongside the ethical aspects considered above, there are some factors inherent in genetics, and especially in predictive DNA testing, that should heighten our awareness of the human values involved [13]. These factors are: (i) that prophecy precedes the cure; (ii) the ambiguities in the concept of genetic disease; (iii) the poor understanding of probability and risk in genetics; (iv) the emphasis on genetic differences; (v) the influence of genetics on personal identity; and (vi) the fact that genetic information is also information about others.

That DNA testing may predict diseases long before we are able to prevent, treat or cure them has already been discussed above, and this is what we mean by 'the prophecy precedes the cure'. This disproportion between diagnostic and preventive/therapeutic measures often places the persons involved in a difficult or even a tragic situation, and raises doubts about the very legitimacy of diagnosing a future disease when effective preventive/therapeutic measures are not available, or are highly speculative. Should there be consensus about whether DNA testing be limited to pathological entities for which preventive or therapeutic measures exist?

The second factor concerns the ambiguities in the concept of genetic disease. DNA testing, which can reveal incipient genetic diseases before the occurrence of any symptom or susceptibility, challenges our notions of disease. How should

we consider a person with positive test results—ill, healthy, ‘asymptomatic but ill’ or as an ‘unpatient’—since he/she may develop symptomatic disease in the future? The Danish Council of Ethics has considered the risk of a sort of ‘morbidity’ involved in DNA testing. The detection of a diathesis, or predisposition, to a genetic disease can promote the view that a person ‘in actual fact’ is already sick, with an adverse affect on that person’s zest for life and general behavior as a result [14]. Genes are only one of the causal factors contributing to health, which, in a more holistic approach, is seen as the product of an interaction among somatic, psychological and spiritual elements, and as the result of the interaction between the body–mind system and the environment.

Especially in this area, there is a poor understanding of the basics of genetics both among the general public and, sometimes, health professionals. Because so many of the putative benefits that may derive from genetic information depend on a clear understanding of basic genetics and risk probabilities, it is imperative to ensure that the public and the experts have the knowledge they need. This means that screening programs cannot fulfill their aims unless the public is aware of the purpose of the test, its availability, its benefits to individuals, its limitations and the disease it intends to detect [15].

The fourth factor is the emphasis on genetic differences, which is tantamount to underscoring the differences among ethnic groups. Detecting certain genetic traits can form the basis for discriminating persons and groups within the population, with the possibility of outright discrimination as a result. It would be very easy to fall into the temptation of maintaining that there are differences among groups, and that those differences are genetic in nature. When such differences are used as reasons for treating people differently or as explanations for enduring inequalities, the potential for injustice is great. So the more important risk is ‘geneticization’, which identifies persons with their genes and overemphasizes the role of genes in disease etiology, in medical practice and in social attitudes toward disease [16].

The fifth factor regards the influence of genetics on personal identity. Our genetic makeup affects our identity by influencing our physical attributes and traits, and our propensities toward disease. Genetics also ties us to our ancestors and our descendants and makes us the people we are. This is why genetic inheritance is intimately connected with our personal identity.

The sixth factor to be considered is that genetic information is also information about others. Information that a subject is a carrier of, or is affected by, a genetic disease is relevant to the person’s biological relations, who may also be carriers of, or at risk for, the same disease. A sister may find out without wanting to that she and her children are at high risk for a serious genetic disease because a DNA test revealed that her brother is at risk for the same disease. This confirms that confidentiality, a value belonging to the personal sphere, can be difficult to maintain within a family, especially with certain types of DNA tests that entail obtaining blood samples from biological relatives of the index person.

In addition to these factors, we should consider other ethical issues that relate specifically to the predictive DNA testing for hereditary breast cancer context, namely the safety and availability of DNA tests.

A DNA test should safeguard the welfare of the person tested. The conditions for a good test are: simplicity, accuracy, precision or repeatability, sensitivity, and specificity. Full gene *BRCA1/2* sequencing is considered to be the most specific and informative method of detecting these mutations [17], but it is very expensive [18]. For this reason, some centers opt for less expensive tests using, amongst others, the protein truncation test, which can identify approximately 60% of *BCRA* mutations, without identifying a substantial number of carriers among those tested.

With regard to availability, does each man and woman have a right to DNA testing for hereditary breast cancer, or do only high-risk families have this right? There are no indications for mass screening for *BRCA1/2* mutations, because at present the information available comes entirely from very high-risk families, and there is no information on the possible gene penetrance in different contexts. For these reasons the first person tested is usually the breast cancer patient, and this approach maximizes the information obtained from DNA testing; if this patient carries a pathogenic mutation, any blood relative can then be presymptomatically tested for family specific mutation.

## Pre- and post-testing counseling for hereditary breast cancer DNA testing

The special ethical features raised by DNA testing indicate that counseling should be an integral part of this procedure. Anyone who is offering (or referring for) DNA testing must provide (or refer for) appropriate genetic counseling before and after testing.

This principle has been adopted by the American Society of Clinical Oncology, which supports the role of clinical oncologists in providing counseling for familial cancer risk and options for prevention [19]. The Convention on Human Rights and Biomedicine has a specific chapter regarding the problems of genetics, and states that DNA testing may be performed only for health purposes or for scientific research linked to health purposes, and subjected to appropriate genetic counseling [20].

Treatment of the theory and the ethical principles of counseling would be beyond the scope of this paper, but we wish to underscore how genetic counseling is the only context in which to help people correctly cope with such health issues. For this reason, it is essential that primary care practitioners and allied health professionals have a minimal basic understanding of medical genetics and counseling [21].

One of the principles underlying the methodology of counseling is non-directiveness, that is, professionals should not present any decision as more correct or advantageous for a person or society [6]. However, is it acceptable in the name of non-directiveness to place all the options on the same level,

leaving the choice solely to the individual? Is this really what individuals expect? Should the counselor engage in non-directive counseling and only present all the alternatives, without advising for or against any choice? Or does the counselor have the responsibility of presenting his/her moral view?

The response to these questions derives from the consideration of the normativity of medicine. Medicine regards itself ultimately as a helping and healing profession, and in such a concept, value-neutrality is not an appropriate position to guide medical activities. According to this view, physicians adhere to professional norms that go beyond the neutrality of values. The norm of non-directiveness in clinical human genetics, therefore, is inadequate also from a medical point of view, and the normative attitude of clinical geneticists should shift from neutrality to prescriptivity. Thus, if there are options that do not ensure respect for human life, health and dignity, the counselor has the duty to make them known, since this constitutes part of the truth, not only scientific truth, that he/she is called to bear witness to as a professional and as a person. Moreover, studies on the practice of clinical genetics show that health professionals who offer DNA testing services do not always act in conformity with the theoretical neutrality of values [22].

There are two phases in genetic counseling: pre- and post-test counseling. An adequate understanding of the implications of predictive DNA testing for hereditary breast cancer is a prerequisite, given the need to evaluate a woman's capacity for autonomous decision-making and, in cases where there are significant doubts concerning her competence, to postpone the test.

Pre-test counseling for *BRCA1/2* breast cancer susceptibility mutations should include: (i) exploration of all pros and cons of testing; (ii) the elucidation of a woman's motives for the testing; (iii) identification of areas in which the woman's expectations may be unrealistic; (iv) understanding that the predictive value of finding a pathological gene mutation has not been established; (v) avoiding the so called 'therapeutic illusion', namely the belief that predictive DNA testing guarantees early detection and/or prevention of disease; and (vi) information about psychological, familial, social, ethical aspects and economic consequences [23].

Sometimes, *BRCA1/2* mutation tests will not be informative and the counselor should help women face the uncertainty regarding the potentially hereditary nature of their cancer and their genetic status. At the same time, a counselor can prevent false reassurance, since a negative test result does not exclude the hereditary nature of cancer in a family or the possibility of having breast cancer.

Since information on testing for *BRCA1/2* mutations associated with increased risk of breast cancer may be very complicated, it should be correct, complete and communicated in a comprehensible way. In signing the consent form, the women are asked to state that they fully understand the terms and have had adequate opportunity to ask questions. According to the results of a Gribble analysis, the consent forms that are used for *BRCA1/2* testing are often written for advanced-level readers,

and the reading abilities of many women are substantially lower than the level of the consent form, resulting in a readability gap [24]. This disparity suggests that women may not fully understand the documents they are asked to sign. The readability gap poses serious issues about informed consent, which becomes more effective if it is built on women's own knowledge base, rather than someone else's.

Finally, an important issue is whether healthy minors can be tested for mutations in *BRCA1/2*. It is true that since *BRCA1/2* gene alterations are dominantly inherited, children of parents with mutations have a 50% chance of acquiring the same mutation. However, unlike adult members of high-risk families, children themselves are not eligible for *BRCA1/2* mutation analysis. Predictive DNA testing for *BRCA1/2* in children is contraindicated owing to a variety of medical, ethical and psychological concerns. Research shows that DNA testing of children has deep psychological repercussions on family dynamics and is often not to the advantage of the child at risk [25]. For the same reasons, and for important consequences with respect to abortion and eugenics, prenatal DNA testing for *BRCA1/2* is also contraindicated [16].

In post-test counseling for *BRCA1/2* breast cancer susceptibility mutations, the counselor should communicate test results and help women understand them. First of all, the women tested have the right to decide not to be told what the test results are. The great majority of people think that DNA testing would be a good idea and, asked hypothetically, they would want to be tested themselves. However, when really offered DNA testing, the uptake is considerably lower. Even among families at high risk for genetic disorder, many individuals choose not to know.

The right to know is of value especially for women themselves, so that they may know what their own genetic constitution is and thence make responsible choices concerning their future lives. There are also issues stemming from the (parental, social) responsibilities that engender the right to know the genetic makeup of another person. In contrast, the right not to know is sustained by various arguments: (i) knowledge can cause distress, even if it has been observed that the benefits of knowledge could outweigh the disadvantages, and that uncertainty can also cause anguish; and (ii) since the human condition is by nature one of limited knowledge, it does not make sense to say that we ought to know or that there is a duty to know. It would thus seem more 'human' to assert a right to hope versus a right to certainty. Nevertheless, an apparent contradiction remains: how could a person decide not to know without knowing what there is to know? The moral problem, in conclusion, lies not so much at the level of wanting or having a duty to know or not to know, but rather concerns how to make meaningful use of the available genetic information [6]. This points to the importance of adequate counseling, at the end of which the subject may even decide not to take the test if the information to be obtained were so inconclusive and probabilistic that the person involved would be unable to take any subsequent measures.



If a woman has decided to know, she is the object of information. In fact, confidentiality and privacy are important in DNA testing, and not only because of the possibility of discrimination, but also because they are crucial to preserving a person's autonomy. In some cases, there could be others who may be interested in information for other reasons; in these cases, there is a conflict between autonomy and responsibility toward others. For example, blood relatives or other family members have every right to be informed, since genetic information is information about biological kin. Friends may also be altruistically interested in the patient's well-being. Finally, requests for information made by the health-care system, an insurance company or employers for utilitarian reasons becomes more problematic.

We think there could be some good reasons to breach confidentiality only to inform relatives. In fact, high-risk family members' access to predictive DNA testing is usually dependent on relatives who have already had breast/ovarian cancer undergoing mutation testing: the predictive DNA testing can be offered to relatives at risk only after the confirmation of an affected *BRCA1/2* mutation carrier relative. Thus, testing individuals plays an important role in generating genetic information for their biological kin. Counselors usually invite tested women to disclose this information to biological kin who could benefit from that information. According to Hallowell et al. [26], the ethical dilemma faced by women is not whether they should disclose genetic information to their relatives, but how and when they should effect this in practice.

What if the patient refuses to disclose? The choice whether to inform relatives at high genetic risk against a woman's wish (or without her consent) is ethically difficult. The duty to preserve confidentiality is in conflict with the responsibility to warn third parties of harm if there is no preventive intervention that can effectively reduce mortality and morbidity among carriers.

In concrete cases it is necessary to weigh the risks against the harms. The US President's Commission's recommendation can be helpful in this and disclosure is possible if there are four conditions: "a. reasonable efforts to elicit voluntary consent to disclosure have failed; b. there is a high probability both that harm will occur if the information is withheld and that the disclosed information will actually be used to avert harm; c. the harm that identifiable individuals would suffer if the information is not disclosed would be serious; d. appropriate precautions are taken to ensure that only the genetic information needed for diagnosis and/or treatment of the disease in question is disclosed" [27].

The second aim in post-test counseling is medical management [23]. Many women take *BRCA1/2* tests in order to make more informed decisions about cancer surveillance, prophylactic surgery, chemoprevention or life-style modifications. In this phase, such information is essential because of individual differences in the perception of risk and the consequences of the choices made.

## The importance of education

The identification of *BRCA1/2* mutations involved in hereditary breast cancer is an important scientific discovery and it is at the service of women and their lives. For discovery of such mutations not to engender stigmatization of or discrimination against the women carrying them, ethical analysis founded on the value and centrality of the human being is essential, together with efforts directed at educating people.

It is important not only to help people understand the differences between mutation and disease, risk assessment and susceptibility penetrance, polygenicity and the interaction between genes and environment, and the possibility of false-negatives and -positives in DNA testing, but also to help people responsibly make choices. For this reason, education should focus on scientific facts, but it should encompass psychological, social and ethical aspects. Education of patients lies in the hands of family physicians, who should act as intermediaries between patients and genetic services.

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