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HOW ARE JEWISH WOMEN DIFFERENT FROM ALL OTHER WOMEN?

Anthropological Perspectives on Genetic Susceptibility Testing for Breast Cancer

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IN 1994, WHEN THE FIRST GENE was found whose mutations predispose some women to breast and ovarian cancer, researchers stressed that mutations in this BRCA1 gene probably accounted for no more than five percent of all breast cancers[1] and that these were cancers in women from very high-risk families.[2] Yet, the idea of population-based testing is implicit in much of the media coverage of this discovery and has been kept alive by reports that commercial enterprises are gearing up to make testing available in the near future directly to women or through their primary care providers.[3] Policy

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1. *See* Yoshio Miki et al., *A Strong Candidate for the Breast and Ovarian Cancer Susceptibility Gene BRCA1*, 266 SCIENCE 66, 66 (1994) (explaining the positional cloning methods used to discover the BRCA1 gene).

2. *See generally* D.F. Easton et al., *Genetic Linkage Analysis in Familial Breast and Ovarian Cancer: Results from 214 Families*, 52 AM. J. HUM. GENETICS 678, 678 (1993) (analyzing the inherited component of breast and ovarian cancer in a study of families); Kevin Davies, *Further Enigmatic Variations*, 378 NATURE 762, 762 (1995).

3. *See generally* Natalie Angier, *Scientists Identify a Mutant Gene Tied to Hereditary Breast Cancer*, N.Y. TIMES, Sept. 15, 1994, at A1 (announcing the discovery of BRCA1 gene); Elyse Tanouye, *Gene Testing for Cancer to be Widely Available, Raising Thorny Questions*,

statements in response to the idea of broad-based testing have been issued by many professional and consumer groups.[4] These statements raise concerns about unanswered scientific questions, such as the penetrance and incidence of the various BRCA1 mutations and the efficacy of potential prevention and detection options following a positive test result. They also point to the need to thoroughly investigate the psychosocial effects of testing. These may include anxiety, depression, family disruption following both positive and negative results, and potential employment and insurance discrimination. Some authors have posited dangers of a more global nature, including stigmatization, the potential of genetic information to seem unalterable and inevitable, and the difficulty physicians and test consumers may have in understanding the probabilistic nature of genetic test results.[5] While considerable research is currently underway to address many of these issues,[6] most of the

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WALL ST. J., Dec. 14, 1993, at B1 (describing commercial efforts to make BRCA1 testing available to the public). *Cf.* Jean Marx, *Gene Defect Identified in Common Hereditary Colon Cancer*, 262 SCIENCE 1645, 1645 (1993) (discussing the discovery of the gene that causes an inherited form of colon cancer and genetic screening for susceptible individuals in the population at large).

4. *See* American Society of Clinical Oncology, *Statement of the American Society of Clinical Oncology: Genetic Testing for Cancer Susceptibility*, 14 J. CLINICAL ONCOLOGY 1730, 1730-36 (1996) (setting forth one professional organization's policy statement regarding genetic testing for cancer susceptibility); Hereditary Susceptibility Working Group, National Action Plan on Breast Cancer, *Commentary on the ASCO Statement on Genetic Testing for Cancer Susceptibility*, 14 J. CLINICAL ONCOLOGY 1738, 1738 (1996) (documenting concerns that genetic testing without the requisite scientific knowledge makes clinical use of tests premature); Neil A. Holtzman, *From Discovery to Delivery: Are We Ready to Screen for Inherited Susceptibility to Cancer?*, ONCOLOGY (forthcoming 1996); Ruth Hubbard & R.C. Lewontin, *Pitfalls of Genetic Testing*, 334 NEW ENG. J. MED. 1192, 1193 (1996) (stating opposition of two groups to testing outside of controlled clinical trials); Francis S. Collins, *BRCA1-Lots of Mutations, Lots of Dilemmas*, 334 NEW ENG. J. MED. 186, 187-88 (1996) (noting that several organizations are calling for testing to remain a research activity due to uncertainties), National Advisory Council for Human Genome Research, *Statement on Use of DNA Testing for Presymptomatic Identification of Cancer Risk*, 271 JAMA 785, 785 (1994) (stating that many questions must be addressed prior to making broad-based genetic testing available).

5. *See* Barbara Koenig, *Gene Tests: What You Know Can Hurt You*, N.Y. TIMES, Apr. 6, 1991, at A23 (suggesting reasons why extreme caution should be used when testing for breast cancer genes in women).

6. The most notable set of research projects into the psychosocial and ethical implications of genetic susceptibility testing for cancer are fifteen projects being funded by a four-agency, NIH Cancer Genetics Studies Consortium. These projects are distributed throughout the United States and Canada. The majority are investigating the psychosocial impact of undergoing genetic testing for cancer risk, some among ethnically diverse populations. A small number of studies are also investigating issues such as the ideal informed consent process for genetic testing and physician, as well as test consumer attitudes.

policy statements counsel caution and recommend that genetic susceptibility testing for breast cancer remain within research protocols for the present time.

However, the concern that population-based mutation testing might precipitously become a reality increased when it was reported in 1995 that one BRCA1 mutation, described as 185delAG, was particularly common among women of Ashkenazi-Jewish descent.[7] Results from the first, small-scale studies indicate that Ashkenazi-Jewish women, those of Eastern-European descent who comprise close to ninety-five percent of the Jewish population in the United States, might have rates of deleterious mutations in the BRCA1 gene several times greater than other women.[8] In addition, it has been suggested that the 185delAG mutation is particularly likely to be a cause of breast cancer diagnosed in young Jewish women.[9] Furthermore, having even a mild family history of breast cancer might particularly predispose Jewish women to breast cancer.[10]

None of these findings indicate that a Jewish woman is necessarily more likely to get breast cancer than a non-Jewish woman. Yet, when a commercial biotechnology firm announced that it was interested in offering 185delAG testing to all interested Ashkenazi-Jewish women,[11] concern was expressed that women would not understand that this offer was based primarily on the greater technical feasibility and reasonable costs involved in looking for only one mutation. It was

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7. *See* David E. Golgar & Philip R. Reilly, *A Common BRCA1 Mutation in the Ashkenazim*, 11 NATURE GENETICS 113, 113-14 (1995) (describing the implications of a survey which found unexpectedly high frequency of the 185delAG BRCA1 mutation in Ashkenazi-Jewish women).

8. *See* Jeffery P. Struewing et al., *The Carrier Frequency of the BRCA1 185delAG Mutation is Approximately 1 Percent in Ashkenazi Jewish Individuals*, 11 NATURE GENETICS 198, 198 (1995) (noting that this group's test study of DNA determined a 0.9% frequency of the 185delAG mutation in Ashkenazi individuals and none in the reference group).

9. *See* Michael G. FitzGerald et al., *Germ-line BRCA1 Mutations in Jewish and Non-Jewish Women with Early-Onset Breast Cancer*, 334 NEW ENG. J. MED. 143, 148-49 (1996) (describing research methodology and findings in a study exploring the incidence of the 185delAG mutation in Jewish and non-Jewish women and the correlation with early-onset breast disease).

10. *See* Kathleen M. Egan et al., *Jewish Religion and Risk of Breast Cancer*, 347 LANCET 1645, 1646 (1996) (finding a correlation of family history of breast cancer to the disposition towards cancer in Jewish women).

11. *See* Gina Kolata, *Breaking Ranks, Lab Offers Test to Assess Risk of Cancer*, N.Y. TIMES, Apr. 1, 1996, at A1 (identifying a commercial firm that is making the BRCA1 test available and exploring the rationale for the decision).

feared that women might instead assume that they were at particular risk for breast cancer on the basis of their ethnicity alone, and therefore, they should be tested. Although it has been pointed out by many concerned parties that almost all the unanswered questions that pertain to BRCA1 testing in general remain relevant to the case of 185delAG testing, a public dialogue rapidly emerged which suggests that to *refuse* testing to any Jewish woman who wants it is paternalism rather than good public policy.[12]

Presently, only one company is offering 185delAG testing. However, concerns about the possibility of a large demand for 185delAG testing stem from a belief that Jewish women will be different from other women in their response to an offer of testing. Specifically, their enthusiasm and demand for testing will be much greater. This belief is based on a particular set of assumptions about Jewish culture. First, that Jewish culture places particular value on science and medicine. Second, that there is a great sense of community among Jews and that, linked with the positive predisposition to science, this will translate into a perceived responsibility to take part in any sort of research endeavor that has the potential to help the community. A corollary assumption is that in Jewish culture scientific knowledge is always thought to be useful. Finally, there is an assumption that Jewish doctrine,[13] and more generalized cultural leanings, coalesce to create a particular attentiveness among Jews to issues of health. The fear is that these aspects of Jewish culture will combine to make this group particularly vulnerable to any offer of genetic susceptibility testing.

We would argue instead that this set of assumptions about Jewish culture can be completely accurate without necessarily indicating that Jewish women will react differently from other

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12. *See* Joseph D. Shulman et al., *Genetic Predisposition Testing for Breast Cancer*, CANCER J. SCI. AM. (forthcoming Sept. 1996); Walter Gilbert & Barbara Biesecker, *Pro Con: Should the Breast Cancer Gene Test be Available to Any Woman Who Wants It?*, HEALTH July-Aug. 1996, at 32 (offering a breakdown of the reasons for and against offering testing for the BRCA1 gene); Wylie Burke et al., *First Do No Harm Applies to Cancer Susceptibility Testing Too*, CANCER J. SCI. AM. (forthcoming Sept. 1996).

13. *See generally* Elliot N. Dorff, *Jewish Theological and Moral Reflections on Genetic Screening: The Case of BRCA1*, 7 HEALTH MATRIX 65 (1997); Fred Rosner, *Principles of Practice Concerning the Jewish Patient*, 11 J. GEN. INTERNAL MED. 486, 486 (1996) (relating the relevance of Judaism to the Jewish patient).

women with regard to interest in genetic testing for breast cancer risk. In fact, when news of the 185delAG mutation was first announced, there was an assumption at the National Institutes of Health, (NIH) and elsewhere, that a flood of requests for testing would follow. This did not, however, prove to be the case.[14] It *is* true that the synagogue-affiliated Jewish community (about fifty percent of Jews) in the Baltimore-Washington area has been extremely cooperative with those conducting epidemiological studies on the occurrence of the 185delAG mutation in a population-based sample.[15] This may be explained by a positive view among Jews about the value of scientific research. Furthermore, the Jewish community in this area had a positive experience with Tay-Sachs researchers in the 1970s. But whatever factors explain Jewish cooperation with this research effort, one cannot generalize from this support for an epidemiological study demand by the average Jewish woman for susceptibility testing.

In fact, we would suggest that at the current time there is simply a lack of data on which to base projections about the attitudes and interest of most women, Jewish or non-Jewish, in susceptibility testing. The majority of research studies currently underway to address these issues involve women in very high-risk families. Many of these families were participants in the long-term research which helped locate the BRCA1 gene and its mutations. Families selected to participate in these "gene-hunting" studies were atypical in the particularly heavy burden of disease they carried through several generations — a burden which may also have motivated their participation as research subjects. This very special history limits the generalization of data from these studies to other women. Similarly, lessons learned from studies of families at risk for Huntington Disease, a fully penetrant, incurable neurodegenerative disorder, have limited applicability to issues of how women in the general population, even those with a mother or sister with breast

14. *See* Bob Kuska, *BRCA1 Discovery Aftermath: No Rush for Genetic Testing*, 87 J. NAT'L CANCER INST. 1578, 1578 (1995) (discussing the relatively small number of calls received by the National Cancer Institute after the announcement of the BRCA1 gene and its link to cancer in European Jews).

15. Gail Geller, Ph.D., Personal Communication (Aug. 1996).

cancer, will respond to an offer of genetic testing for breast cancer risk.

The purpose of this Article is to suggest a different framework within which to think about these questions. We propose that a cultural context, larger than genetic disease, needs to be considered. Specifically, we will explore cultural attitudes toward three issues which we believe comprise much of the context into which genetic susceptibility testing for breast cancer will emerge: (1) The cultural construction of cancer, and, specifically, breast cancer as an illness; (2) attitudes of potential test consumers toward medical information, including genetic information, provided through technology; and (3) the use of risk information within contemporary biomedicine for prediction of future disease. We intend to show why the specific illness for which genetic testing is offered has a profound effect on the degree of interest that testing evokes. Conversely, we will demonstrate that genetic testing is a less novel enterprise than traditionally thought. Rather, it is a very logical extension of the on-going trend to assess and quantify risk of disease far in advance of the presentation of symptoms. The Article is, therefore, divided into three sections, each focusing on different parts of the phrase *genetic testing for breast cancer risk.*

Part I, which is the longest section, focuses on the disease for which testing is offered. It discusses the social construction of cancer and cancer phobia. It draws upon the historical work of James T. Patterson to demonstrate the development of the themes which define the relationship of the individual to cancer risk in the United States today. It then examines the applicability of these themes to contemporary images of breast cancer, especially the way risk for breast cancer has been constructed and is perceived by women in the United States today. Data for this section come largely from an analysis of recent popular literature undertaken by the authors.

Part II explores attitudes toward science in general and genetic testing in particular. Preliminary data are presented on the knowledge about, and attitudes toward, genetic susceptibility testing of potential test consumers. These data come from interviews conducted with one hundred European-American and African-American women recruited from the general popu-

lation to represent varying levels of breast cancer risk and socioeconomic background.[16]

Part III specifically focuses on the concept of risk and risk management within contemporary biomedicine. The purpose of this section is to suggest how genetic testing fits within an already existing trend within medicine for predicting and quantifying distant risks of disease.

Finally, at the conclusion of this Article, we will return to the issue of whether there is any reason to believe that anything in Jewish culture is likely to outweigh the general cultural forces we have discussed in predicting the demand for and response to genetic susceptibility testing for breast cancer risk by Ashkenazi-Jewish women.

I. THE SOCIAL CONSTRUCTION OF CANCER PHOBIA

Medical anthropologists draw a distinction between the concepts of *disease* and *illness*.[17] The term *disease* is used to demarcate and delimit those things which are commonly seen in Western biomedicine as constituting the entirety of being unwell — abnormalities in the structure and function of bodily systems. Diseases can conceptually exist apart from the sick person who is sick. In contrast, *illness* refers to the embodied experience of disease. Particularly, illness encompasses the physical sensations, the search for causes, cures, and meaning, and the complex interaction of the experience of illness within the web of interpersonal relationships and activities which constitute daily life.

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16. This research was funded as part of the Cancer Genetics Studies Consortium. It is a qualitative study of the understandings and attitudes about health, breast cancer, and genetic testing of women at varying risk for breast cancer. It includes women of varying socioeconomic levels and four ethnic groups (African-American, European-American, Native-American, and Ashkenazi-Jewish). *See* Wylie Burke, Genetic Testing for Breast Cancer Susceptibility (grant proposal) (on file with author and the National Center for Human Genome Research of the National Institutes of Health).

17. *See* ARTHUR KLEINMAN, THE ILLNESS NARRATIVES: SUFFERING, HEALING AND THE HUMAN CONDITION 3-6 (1988) (defining illness and diseases as fundamentally different concepts); Arthur Kleinman et al., *Culture, Illness, and Care: Clinical Lessons from Anthropologic and Cross-Cultural Research*, 88 ANNALS INTERNAL MED. 251, 251 (1978) (discussing concepts derived from anthropologic and cross-cultural research which may provide an alternative framework for identifying health care issues that require resolution).

The usefulness of this distinction is that it forces us to consider as problematic, and thus requiring examination and explanation, issues which might not seem problematic if looked at through a biomedical model of disease alone. For example, this distinction leads us to consider which diseases are considered to bear the heaviest burdens by particular societies at specific times. Cancer is the quintessential feared illness in twentieth century America. Since it is also a frequently fatal disease for which attempted cures are often arduous, disfiguring, and unpleasant, the fear surrounding it might appear to be a result of the characteristics of the disease itself. Yet, once the distinction between disease and illness is embraced, the very intensity of dread that cancer evokes, and the way it crowds from view other common, often fatal, and equally debilitating diseases, becomes problematic and demands a careful examination.

James T. Patterson, in his book, *The Dread Disease: Cancer and American Culture*,[18] traces the history of cancer *phobia* as a phenomenon that is distinct from the actual disease. Patterson believes that while cancer had been long known and feared, cancer *phobia* did not exist in the United States until the end of the nineteenth century. His thesis states that the development of cancer as *the* dread disease awaited the creation of a prosperous business and professional class whose lives were marked by a new longevity, comfort, and affluence. This very comfort, according to Patterson, had the paradoxical effect of leading to an increased fear of illness and, more particularly, of early death. Although this was a time in which tuberculosis was epidemic while cancer was not considered a particularly common disease, tuberculosis was associated largely with conditions of poverty. It was, therefore, somewhat predictable in its occurrence and remote from the burgeoning middle class. Cancer, on the other hand, was believed to often attack precisely those whose lives were seen by some social critics as very "comfortable" and overly "civilized."[19] Thus, in addition to an objective and reasonable fear of cancer, this illness may have served a metaphoric function both as a symbol of the remain-

18. JAMES T. PATTERSON, THE DREAD DISEASE: CANCER AND MODERN AMERICAN CULTURE (1987).

19. *Id.* at 31-33.

ing kernel of risk within increasing safety, and of the distrust with which a culture shaped by the Protestant Ethic viewed a life of ease and luxury.[20]

Several themes came to define the discourse of cancer phobia in the first decades of the twentieth century and they continue to be central in contemporary discussions of cancer. We believe they have great relevance for potential consumer interest in genetic susceptibility testing for breast cancer as well. One of these themes was the belief that cancer rates were increasing precipitously. Although countered by the same scientific cautions that greet today's discussion of a breast cancer "epidemic," cancer in the early part of the century was described by the American Society for the Control of Cancer,[21] as existing in epidemic proportions and being "a menace to the welfare of mankind"[22]

Also of interest is the striking continuity between espoused causes of cancer then and now. Specifically criticized were the "softness," excessive consumption, and "luxurious living" of modern life.[23] One writer proposed, in a theme which would be commonly repeated, that cancer most frequently afflicted " . . . well-nourished persons who live well and do not work off their waste products."[24] An improper, too generous diet was hypothesized again and again as causing the disease.[25] Yet, paradoxically, the stresses of contemporary, competitive, industrial existence were also cited as a cause for cancer's increase. Most intriguing in its prefiguring of today's more psychologically minded era, was a view that not only tension but, specifically, emotional repression could also lead to cancer.[26]

It is worth noting that all of these criticisms, while aimed globally at a changing and dangerous society, carry implicit

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20. For a more in-depth discussion of this concept, refer to Susan Sontag, *Illness as Metaphor, in* HEALTH AND DISEASE: A READER, 33, 33-37 (Basiro Davey et al. eds., 1995) (discussing the attitudes and metaphors associated with tuberculosis and cancer).

21. This organization later changed its name to the American Cancer Society. PATTERSON, *supra* note 18, at 72.

22. *Id.* at 78-82.

23. *Id.* at 43.

24. *Id.* at 44.

25. *See id.* at 103.

26. *See id.* at 103.

correctives which are the responsibility of the individual. Society might be getting "soft," but individuals could eat differently, live more in accord with the Protestant Ethic, and even lead less emotionally repressed lives. This theme of individual responsibility for cancer prevention grew and strengthened throughout the twentieth century.

One surprising viewpoint about cancer in the beginning of this century has particular relevance to current attitudes toward breast cancer. At the beginning of the century, when cancer of internal organs often metastasized and led to death without a specific diagnosis, and before the mass production and marketing of cigarettes made lung cancer common among men,[27] women's breast and reproductive disease were the most frequently diagnosed cancers. In fact, cancer was seen as a woman's disease.[28] Thus, when statistics first appeared which demonstrated that cancer had increased among men, it was suggested that this was another proof of the link between cancer and a soft, overly indulgent, contemporary life which was now even making men vulnerable to a woman's disease.[29] It seems possible that this perceived link between cancer and women may have contributed to the impression that cancer was particularly private and especially shameful. It is also interesting to note that the American Society for the Control of Cancer used this perception of the special connection between women and cancer to begin an auxiliary of prominent and wealthy women who succeeded in raising both awareness in and money for cancer. This was an interesting forerunner of the immensely effective National Breast Cancer Coalition of today.

A. "The Magic Bullet" and "Early Detection"

The final thread of the cancer discourse, which can also be traced back to the beginning of this century, involves the search for a cure and the dogma of early detection. James T. Patterson wrote that one aspect of the ethos of the new, grow-

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27. *See id at* 203. *See also* ELIZABETH WHELAN, A SMOKING GUN: HOW THE TOBACCO INDUSTRY GETS AWAY WITH MURDER 72-80 (1984) (relating the increased marketing and production of cigarettes to the beginning of the investigation into the link with lung cancer).

28. *See* PATTERSON, *supra* note 18, at 43.

29. *See id.* at 43.

ing middle class which so feared cancer was an optimistic assumption that all problems could be solved. The middle class also had extreme faith in "expert, scientific solutions."[30] By the middle of the twentieth century, this faith was spectacularly rewarded as science and medicine provided a remarkable series of successes. These successes ranged from the discovery of antibiotics and vaccines, to air flight, and ultimately, to the creation and use of "the bomb." Yet, despite these successes in subduing nature through science, a cure for cancer remained elusive. Although articles appeared in the popular press heralding a "breakthrough" just around the corner, the repeated fizzling of such hopeful rhetoric required a different approach to "beating cancer." From the beginning of the century until now, that approach has been the lifesaving potential of "early detection."

Although what the American Society for the Control of Cancer saw as "early detection" when it began its public education campaign in the 1920s would be considered detection at a late disease stage now, the message that they presented has changed very little if at all. From their very inception, the American Society for the Control of Cancer emphasized that individuals had to be vigilant for signs of cancer and had to get medical attention immediately. This was a grave responsibility to others, as well as to oneself. Thus, a public service advertisement from 1921 depicted a widow and two small children sitting sadly around a table reading an information brochure under the heading "*If Daddy had only known this!*" Daddy, it is clear, is gone because he did not follow the advice of the advertisement to "attack cancer the right way," by attending to cancer's "warning signs," and by immediately seeking competent medical help.[31] A 1932 advertisement exhorts the reader to "*Fight Cancer with Knowledge.*"[32] Yet another advertisement from the same year counsels, "*Don't Fear Cancer, Fight It.*" This particular advertisement, suggestive of the goddess

30. *Id.* at 71-74.
31. *See id.* at 77.
32. *Id.* at 71-74.

Athena holding up a sword, is strikingly reminiscent of the current campaigns for breast cancer awareness.[33]

Throughout the early twentieth century, methods of cancer detection improved. By the 1970s it was possible to detect some cancers at a largely asymptomatic stage. In an odd way, this advance presented a new problem. No longer were people being asked simply not to ignore obvious signs of potential cancer; they were now being asked to go to a doctor on a regular basis so that an occult disease might be detected. This led to a new theme in the advertisements: mainly that *feeling* well did not necessarily mean you *were* well. Thus, a 1970 American Cancer Society advertisement promoting regular physical examinations, shows an ostrich with its head in the sand and asks rhetorically, "If you're feeling great, why bother?" It answers that "[m]any cancers are curable if detected early . . . . An annual checkup helps your doctor . . . make sure you are really as fine as you feel." The advertisement ends by again stressing the personal level of responsibility involved in fighting cancer with the line "It's up to you. . .". If advertisements in the 1920s were sympathetic to the father who simply did not know enough about cancer, in later periods, more severe censure was attached to those who should have known better, but chose to avoid the actions that could have detected early disease.

Currently, the most common public service announcements for early detection focus on mammography and reiterate the theme of responsibility to self and others. In fact, all of the general themes involved with cancer and cancer phobia discussed above coalesce in the fight against what has become the quintessential cancer, and most women's ultimate dread disease, breast cancer.

B. Deconstructing Breast Cancer

One of the assumptions underlying our research is that women's beliefs and attitudes about breast cancer will strongly shape their actions in regard to genetic susceptibility testing. Breast cancer today is a major source of story lines for wom-

33. *See id.* at 77.

en's and general news magazines. Therefore, in order to find out what images of breast cancer might be shaping the understandings and opinions of the women we were interviewing, we began an analysis of the current coverage of breast cancer in popular literature. Our preliminary effort consisted of a single search on the word "breast cancer" in the General Periodicals Index in the Seattle Public Library. We confined this initial search to three years. This period, 1993-1995, included the year when the BRCA1 gene was sequenced.

Our first finding was that the number of articles discussing breast cancer appeared to increase steadily throughout the period. In 1993, we located thirty-one articles; we located fifty in 1994; and in 1995, we located sixty-four.[34] More striking than the increasing number of articles that we located was the tone and emphasis of the articles, in particular, how this tone reflected the elements of the cancer phobia discussed above. The primary themes apparent in these articles were the following: the presentation of breast cancer as a particularly dreaded disease of epidemic proportions; and, breast cancer as a disease largely attributable to various elements of modern lifestyle. A new theme, but one prefigured by Patterson's discussion of the genesis of cancer phobia, was of breast cancer as a disease of affluent, professional, and *young* women.

Breast cancer is presented in these articles as vividly frightening. Typical of the tone are the following headlines: "The Terrifying Statistic — That One in Nine Women Will Get Breast Cancer . . . ," "How Safe Are Your Breasts?," and, "Cancer Stalks the Women in Anna Fisher's Family . . . ." [35] We found that articles frequently used the familiar one in nine, or one in eight, breast cancer risk number, but very rarely clarified that this number is only relevant to women who live well into their eighties or nineties. Often stories begin with an alarming array of statistics to support a claim of epidemic

34. These articles and the numerical analysis are on file with the author.

35. *Surviving Breast Cancer: Seven Extraordinary Women Talk About Going On*, MCCALLS, Oct. 1993, at 110 (illustrating that frightening statistics can be misleading); Malcolm Gladwell, *How Safe Are Your Breasts?*, NEW REPUBLIC, Oct. 24, 1994, at 22 (discussing how the revised guidelines for a mammography may be more cost-conscious than health-conscious); Larry Thompson, *The Breast Cancer Gene: A Woman's Dilemma*, TIME, Jan. 17, 1994, at 52 (discussing the fear provoked in one woman by her family's history of breast cancer).

incidence and increase in breast cancer. In some articles, the tone made it seem as though getting breast cancer were inevitable. For example, a story in *Vogue*, a leading women's magazine, begins with these poignant sentences: "Throughout the ages, the breast has been associated with beauty, sensuality, and fecundity. But today when we think of the breast, we think of cancer."[36] This sentiment is particularly striking since words like these appear in a number of our preliminary interviews with young, professional women who repeatedly describe their breasts as "time bombs." We would argue that the articles found in popular literature, such as this one in *Vogue*, create, as well as reflect, the atmosphere of fear and desperation which some women today feel about their risk for this disease.

As in the past, the only hope offered by many of these articles is personal vigilance which leads to early detection; such vigilance continues to be presented as not only an opportunity, but also as a responsibility. However, the standards of what constitutes vigilance have become much stricter than they were in the past. Thus, an abstract for an article in *Redbook* magazine reads: "A woman describes how she reacted when she discovered a lump in her breast . . . . She went into denial and delayed seeing a doctor. . . ." Yet, a careful reading of the article reveals that she "delayed" seeking medical advice from Saturday afternoon until "late Monday morning!"

C. "I am Stunned . . . I Have No Risk Factors"

Another aspect of the paradigm of vigilance, and one which can be expected to have great significance for women's response to the availability of genetic testing for cancer susceptibility, has to do with the elaboration of "risk factors" in the scientific literature and the popular press. The theme of delineating "your risk factors" for breast cancer was an extremely common one in the articles we collected. Breast cancer risk factors mentioned in these articles include the following: family history of breast cancer; reproductive history including age at menarche and menopause, age at first pregnancy, and breast

36. Noelle Oxenhandler, *Fruits of the Body*, VOGUE, June 1995, at 56 (describing the paradox of different views of the breast and the effect of breast cancer on those views).

feeding practices, as well as spontaneous and induced abortion; elements of "life style" such as diet, especially fat and alcohol intake, lack of physical exercise, and stress; and finally, an astonishing array of other potential risks including being single, having a mother who was older than average when you were born, the use of electric blankets, being of above average height, and being highly educated.

The usefulness of knowing about a risk factor like height, about which nothing can be done, or educational level, which of logical necessity must be merely a marker for something else, is highly questionable. It raises an issue of why it seems necessary to report every epidemiological risk association as though it is a factor relevant to the lives and practices of individual women. We would suggest that there are two implicit assumptions that underlie this relentless delineation of risk factors. The first is a view that the risk of breast cancer is so high that almost anything that *could* be done by a woman *should* be done. The second is a belief that the obverse of anything that creates risk can reduce risk. Thus, if a high-fat diet increases risk, women can and should eat a low-fat diet to protect themselves. So fervent is this belief among some scientists that one recent book, written by a physician, actually promises that eating a low-fat diet will "save" you from breast cancer.[37] Or, if late age at childbearing increases risk, then teenage pregnancy can be protective and should be undertaken, as one prominent woman scientist recently recommended.[38] To a large extent, however, information is such an undisputed good in U.S. culture[39] that little overt justification seems necessary to keep women informed about even the most speculative breast cancer risk findings. We believe that this discourse of risk factors will help pave the way for an acceptance of genetic

37. *See* ROBERT M. KRADJIAN, SAVE YOURSELF FROM BREAST CANCER 85 (1994).

38. *See* Maureen Henderson, *Current Approaches to Breast Cancer Prevention*, 259 SCIENCE 630, 631 (1993) (considering the viability of social and health policies that encourage and support younger women to bear children to prevent breast cancer).

39. *See* Nancy Press et al., *Why Women Say Yes to Prenatal Screening*, SOC. SCI. & MED. (forthcoming 1996); C.H. Browner & Nancy Press, *The Production of Authoritative Knowledge in American Prenatal Care*, 10 MED. ANTHROPOLOGY Q. 141, 153 (1996) (describing the concept of authoritative knowledge and reviewing study results, which explore the role of individual patients in facilitating the dominance of biomedical authoritative knowledge).

information, which is perhaps the most powerful risk information of all.

Despite the very broad range of risk factors discussed in these articles, there is one kind of woman who appears in these magazines to be especially at risk — the young woman. Approximately one-third of the articles we analyzed used a personal vignette to focus or anchor the story. This is a common journalistic technique and, therefore, it is not particularly surprising to find it employed so frequently. Nevertheless, we believe that these stories are particularly effective in making breast cancer seem like every (*young*) woman's problem. Indeed, stories often focus on young women who state that they never expected this to happen to them. These women often are presented as being caught especially unaware and vulnerable. Thus, a young woman whose breast cancer is diagnosed during a routine mammogram begins her personal story with the following words: "I am stunned. There must be a mistake. I have no risk factors. Maybe my name was mistakenly placed on someone else's mammogram. I can't stay here anyway, my parking meter is about to expire. And I have a luncheon appointment."[40] But so many stories begin in this same way, with a shocked, baffled woman who has had the mundane dailiness of her life torn apart, so sentences about how sunny and happy things were *before* function like the sinister music in a horror movie: One suspects that the savvy reader is supposed to respond, "How could you *not* have expected this?"

In fact, in one of the most instructive of these personal vignette stories, the woman explicitly expresses the idea that her false sense of security may have somehow been connected to the bad outcome of finding a breast lump. It is entitled, *"I thought I couldn't get breast cancer at 31. Then I found a lump!"*

> I knew the moment I felt it. I knew . . . . [and] my mind automatically registered the awful inevitability of what lay ahead. Breast cancer . . . .surgery . . . .chemotherapy . . . .hair

40. Robbie Lyons, *It's Probably Nothing, This Lump in My Breast, But . . . .*, GOOD HOUSEKEEPING, Mar. 1993, at 58 (tracing the author's emotional reactions from the time her mammogram revealed a lump through the time she received a mastectomy).

> loss . . . .death. I couldn't believe it . . . .[h]alf praying, half pleading, I asked it to go away, suddenly filled with remorse. I wanted to say I was sorry. To somehow make things right. I kept thinking that maybe this was some sort of divine punishment for being such a frivolous person. Because just a minute ago, the only thing I had been worrying about was my tan lines.[41]

One of the most striking aspects of this story is that it is revealed, although not until the final paragraph, that this woman did not have breast cancer. Rather, she was diagnosed with a benign breast lump. The first person narrative presents this as a miraculous reprieve. Because of the tone the woman takes, the moral of the story is not that in the future she (and by extension other women her age) should check, but not panic about breast lumps. Rather, she is somehow chastened; she can no longer hide in a world of parties and tan lines. She now gives generously to her hospital's cancer drive as though she must be thankful to medicine itself for saving her. What makes this article particularly worrisome from a public health viewpoint is that, although for this thirty-one year old, the likelihood that a breast lump will be benign is overwhelming, the story does not provide any statistical framework so that the reader can understand that this woman's extreme degree of distress was, if understandable, nevertheless unnecessary.

The fact that this woman was thirty-one is also representative of the universe of these media presentations of breast cancer. *Glamour* magazine, whose readership hovers in the eighteen to twenty-five year old range, has had two cover stories on breast cancer in the past thirteen months. It is worth wondering why it seemed appropriate to the editors to run two major stories on this topic within a year of each other given the age of their readership. Nevertheless, one of the stories is based on a personal vignette. It is about a friendship between two women, one with now-metastasized breast cancer. The picture of the two of them together show that they are both wrenchingly young; the article informs us that the woman with breast cancer was diagnosed, six weeks before her wedding, at

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41. Jennet Conant, *"Not Me!"* REDBOOK, June 1993, at 96 (relating the author's personal reaction to her discovery of a lump on her breast).

the age of thirty-one.[42] It is almost as though this article is creating a universe in which the thirty-one year old woman from the *Redbook* article is living in a world in which one *should* expect breast cancer at this age.[43]

In aggregate terms, we found twenty newspaper and magazine articles in 1994 which used personal vignettes and gave the ages of the women profiled. Of these, sixteen described women diagnosed with breast cancer between the ages of twenty-nine and thirty-nine. Of the remaining four stories, only one was about a woman over fifty. She was, in fact, precisely fifty, the oldest woman in the group. Thus, if you live in the world of these stories and you are diagnosed with breast cancer you have an eighty percent chance of being in your twenties or thirties. In reality, the chances of a woman developing breast cancer by the time she is thirty-one is less than two in one thousand.[44] Likewise, the modal age of a breast cancer diagnosis is sixty-four.

The fact that women are hearing and believing these message is supported by a variety of findings. One is the perception of clinicians, such as prominent breast surgeon, Susan Love, who observes that the women who are expressing the most interest in mammography are educated women under age fifty.[45] This occurs despite the fact that the usefulness of mammography for this age group is unproven. Research supports her impression. In one study, European-American women age forty to forty-nine were actually *more* likely than older women to undergo regular mammographic screening.[46]

Additional support for the view that breast cancer is becoming regarded as a young woman's disease comes from a survey conducted by one of the authors with 450 Californian

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42. Kate Manning & Wendy Morse, *Wendy has Breast Cancer. Kate Doesn't. The Story of Two Friends*, GLAMOUR, Aug. 1996, at 186.

43. *See supra* footnote 41 and accompanying text.

44. *See* Eric J. Feuer et al., *The Lifetime Risk of Developing Breast Cancer*, 85 J. NAT'L CANCER INST. 892, 894 (1993) (citing statistical evidence for the probability of developing invasive breast cancer for various age groups).

45. Susan Love, Personal Communication (June 1996).

46. *See* John P. Fulton et al., *Determinants of Breast Cancer Screening Among Inner-City Hispanic Women in Comparison With Other Inner-City Women*, 110 PUB. HEALTH REPORT 476, 478 (documenting the differences between Hispanic and white and black Non-Hispanic women in obtaining screening breast examinations and mammograms).

women of diverse ethnic backgrounds.[47] When asked to indicate what they thought was the most common age for women to develop breast cancer, more than ninety-five percent incorrectly chose under sixty, and three-quarters felt that younger than fifty was the most common age to get breast cancer.

In sum, we have women, especially young, educated women, who are terrified of breast cancer and overestimate their own vulnerability to the disease. Their sense of risk is created and reinforced by media presentations of breast cancer which also accustom them to thinking in terms of "risk factors." Since many of the most frightened women also may be those with the best access to health care services, we would suggest that a highly motivated set of consumers exists for anything which they believe may reduce their risk of breast cancer. The question that we will turn to now is whether we have any reason to believe that these women will think that genetic susceptibility testing will, in fact, help them with risk reduction.

II. GENETIC TESTING — ANGER AT SCIENTISTS/FAITH IN SCIENCE

In the late 1940s and 1950s, Americans firmly believed that the science which had split the atom and made "the bomb" could certainly cure the problem of cancer.[48] However, after close to 150 years of journalistic reports of cancer "breakthroughs" about to occur, the contemporary versions of this faith in science evidence somewhat more frustration. Thus, the frequently heard phrase, "if they can put a man on the moon, then why can't they find a cure for cancer?" Our interviews also uncovered a skepticism about certain aspects of science. The most succinct expression of this was a phrase used with surprising regularity by women from families at high-risk for breast cancer: "If men got this disease there'd be a cure by now." Yet, what is most interesting about this statement is not the explicit anger expressed toward the scientific establishment,

47. *See* Nancy Press, Survey Conducted for the California State Breast Cancer Early Detection Partnership Program (BCEDP), Orange County Region 10 (1995) (on file with the State of California and author).

48. *See* PATTERSON, *supra* note 18, at 140.

which is believed to be underfunding research on women's health issues, nor at scientists, who are accused, in essence of just not doing their job, but the implicit, and unshaken, faith expressed in the scientific enterprise itself: If only scientists cared enough and targeted the right issues there *would* be a cure. This underlying faith in science was evident in the magazine articles we analyzed as well. Even those which reported contradictory scientific findings, continued to respectfully cite an array of scientific experts under headlines such as: "What Doctors Wish You Knew About Breast Cancer" and "If You're Under 40, These New [Scientific] Facts Could Save Your Life."[49] While American women clearly express fatigue at waiting for the "magic bullet" of a cure, cancer remains now, as James Patterson saw it to be in the late nineteenth century, a social, and ultimately a political, "problem" to be solved. Science was the place to look for that solution in the past, and it apparently still is. In fact, what may be the clearest and most public expression of this tension between anger at scientists and faith in science is perfectly expressed in the official slogan of the highly influential National Breast Cancer Coalition: "Breast Cancer. Say It. Fight It. Cure It. Damn It."

Given this enthusiasm about science and scientific findings, we were surprised by the small number of articles which discussed the discovery of BRCA1. Based on this lack of coverage, however, it is perhaps not surprising that only a small proportion of the women we interviewed were knowledgeable about this topic. Only about one-third recognized the term BRCA1 or the phrase "a breast cancer gene." Of that third, only half could actually produce any information on this topic. It is interesting to note that there was no statistically significant difference in the knowledge base of women with or without a family history of breast cancer.

Participants' interest in testing was assessed through a series of seven-point Likert scales. Each scale was a response to a question which always began the same way: "Imagine that your doctor asked you if you wanted to take a genetic test for

49. Linda Heller, *What Doctors Wish You Knew About Breast Cancer*, REDBOOK, Apr. 1993, at 38 (quoting statistics from the National Cancer Institute to clarify misconceptions about the risk of cancer).

breast cancer risk and you said to the doctor, 'I don't know if I want it; let's say I took the test and . . . . '" The end of the sentence was varied fourteen times, each time with a change in some essential feature of the test. For example, one question suggested that a positive test result would mean that the risk of developing breast cancer was fifty percent, while another question asked if the woman's interest would be different if a positive result meant a ninety percent chance of breast cancer. Other questions assessed interest in testing given the existence of different possible interventions, such as prophylactic surgery, gene therapy, or just the existing regimen of early detection. Participants were asked to indicate their degree of interest on the Likert scale, as well as to explain their thought process with regard to each answer. The purpose of these scales was to see what types of uncertainty women found most troubling *and* to expose women to the idea that this test would present many complexities.

Below are the results from our first one hundred participants from the first and the last questions asked to assess hypothetical interest in testing. The first question was intended to establish a baseline level of interest predicated only on the small amount of information we had imparted, plus whatever underlying assumptions the participant might have had about the usefulness of medical tests in general. The final question asked women for an overall, gut-level assessment of their interest in testing now that they had completed all the scales and had had the opportunity to learn and think about the test. Therefore, to the greatest degree possible, these could be considered "before-thought" and "after-thought" responses.

In answer to the first question, over seventy-seven percent of our participants indicated they would want to take such a test. There was no significant difference between the responses of women with and without a family history of breast cancer. Thus, it would appear that neither a great deal of knowledge, nor even much exposure to information about genetic susceptibility testing for breast cancer is necessary in order for women, hypothetically, to accept an offer of testing. Even more interesting, however, is our finding that following thirteen more Likert scales and much discussion of what a test might or might not be able to do, an almost identical percentage of par-

ticipants (seventy-seven percent) indicated that they were still *somewhat likely* to *definitely interested* in testing.

One of the most interesting explanations women gave for their interest in testing came in response to out Likert scale about prophylactic mastectomy. The idea of mastectomy to *avoid* disease appeared repellent and even bizarre to many women. Yet, many of those who rejected this opinion still professed a strong desire to take the test *in response to this specific Likert scale.* The most common explanation given was that just knowing about their increased risk would be helpful because it would motivate them to be more vigilant about early detection and make lifestyle modifications, especially consuming a lower-fat diet and increasing exercise.

Further, detailed analysis of these data is necessary to be certain of the meaning of these results. It would appear, however, that women's belief in the value of a medical test offered by their physician is extremely robust. Such a result would be in keeping with findings from research on the routinization of other medical technologies which involve little physical risk and can be seen as part of standard medical care. That such easy routinization can take place even when bioethicists or other social theorists see significant ethical dilemmas in a technology is borne out by the rapid routinization of prenatal screenings, such as maternal serum alpha-fetoprotein blood screening for neural tube defects.[50] These data would also suggest that unless some very specific and in-depth educational efforts accompany an offer of testing, women are not likely to see this testing in the way bioethicists do -- as a new order of medical tests replete with scientific uncertainty and bioethical conundrums. Indeed, susceptibility testing for breast cancer will be viewed under a rubric that is already well-established in medicine -- fairly "simple tests that tell you about your future risks."

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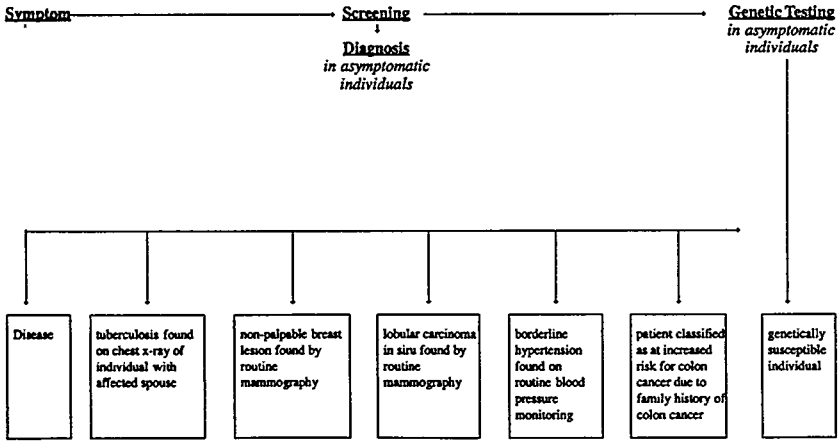
50. *See* Nancy Press & C.H. Browner, *'Collective Fictions': Similarities in Reasons for Accepting Maternal Serum Alpha-Fetoprotein Screening among Women of Diverse Ethnic and Social Class Backgrounds*, 8 FETAL DIAGNOSIS & THERAPY 97, 105 (1993) (analyzing the decisions of a diverse group of women and what factors affected their decisions to accept or refuse a prenatal test); Nancy Press et al., *Why Women Say Yes to Prenatal Screening*, SOC. SCI. & MED. (forthcoming 1996).

III. BEING "AT-RISK" — THE PURPOSE OF PROPHECY

Sociologists, such as Leo Baric and, more recently, Regina Kenen, have discussed the creation of a new social role for patients: that of being "at-risk" for disease rather than actively sick.[51] But this new social role is dependent upon prior changes in biomedicine. Figure 1 below is a representation of this conceptual and historical change within biomedicine in the United States as it affects the distance between symptom and diagnosis.

The Historical and Conceptual Progression from Diagnostic to Predictive Testing



51. *See* Leo Baric, *Recognition of the "At-Risk" Role: A Means to Influence Health Behaviour*, 12 INT'L J. HEALTH EDUC. 24, 31-32 (1969) (describing a system within which an individual moves while experiencing different degrees of health or illness); Regina H. Kene, *The At-Risk Health Status and Technology: A Diagnostic Invitation and the 'Gift' of Knowing*, 42 SOC. SCI. & MED. 1545, 1545 (1996) (identifying the creation of the at-risk health status along with possible risks of the status and the need for standards).

Movement along this continuum of risk from left to right can be conceptualized as a change both in the relationship of patient to physician and as a change in the role of biomedicine itself. At the left end of the continuum, a patient initiates contact with a physician following the appearance of symptoms that cause discomfort or interfere with daily functioning. As one moves toward the right, the patient goes to the physician, sometimes in response to a "warning sign" of disease, such as a painless breast lump, and sometimes simply for a periodic examination. In each case, the patient feels well, but has the possibility of being told that some disease exists. As one continues toward the right along the continuum, less is known about the natural history of the disease detected or the efficacy, or even necessity, of medical interventions. It is not yet known, for example, how much latent prostate cancer would ever progress to life-threatening disease.[52] Thus, it is difficult to work the equation which balances iatrogenic harm and needless anxiety against reduction in morbidity and mortality. Further still to the right, yet conceptually prior to actual genetic testing, a patient can be classified according to *risk* of disease on the basis of family history. Although the risk prediction is very imperfect, such classification raises the issue that a person without any disease may, because of a risk classification, begin to consider him or herself not quite well. These are the stages which have set the background for genetic testing. Represented at the furthest right pole of the continuum, genetic testing presents a situation in which an individual, or even a fetus, can undergo a "simple blood test," and be given a specific number which indicates their quantitative risk for a disease which may not occur until decades in the future.

Our purpose in proposing this framework is not to debate the usefulness of a preventive health paradigm in reducing morbidity and mortality in various situations. Rather, we are interested in presenting the idea that there is a cultural belief

52. *See* Barnett S. Kramer et al., *Prostrate Cancer Screening: What We Know and What We Need to Know*, 119 ANNALS INTERNAL MED. 914, 918 (1993) (critically evaluating evidence for the implementation of screening of asymptomatic men for prostate cancer using the prostate-specific antigen (PSA) blood test).

which, distinct from advances in science, drives the constant expansion of this continuum in the direction of future disease prediction. We suggest that there is an implicit belief in the contemporary United States that a probability statistic, accurately calculated and named, can eliminate its own most essential element — uncertainty. This belief makes Americans see risk information as inherently useful and may be one of the reasons there is often insufficient attention paid to gaps between diagnostic sophistication and treatment options. This is particularly relevant in the case of genetic susceptibility testing for breast cancer because this belief may drive both clinicians and test consumers to opt for genetic testing even in the absence of proven efficacy of treatment sequelae. To support this point we would like to present data related to the current use of risk calculations for breast cancer.

There are several models which are used to estimate a woman's risk for developing breast cancer. Each one uses a somewhat different set of factors in its calculations.[53] The model created by Stephen Taplin, et al. is of particular interest for the way it illuminates issues in the use of risk calculations.[54]

Stephen Taplin, et al. establishes four levels of risk for women aged forty and over. Risk factors calculated in this model include personal and family history of breast cancer, and "minor risk factors" which refer primarily to hormonal and reproductive history. The model also implicitly includes age as a risk factor, since a woman over fifty can be assigned to a particular risk level with a smaller number of risk factors than can a woman under fifty.

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53. *See* Mitchell H. Gail et al., *Projecting Individualized Probabilities of Developing Breast Cancer for White Females Who Are Being Examined Annually*, 81 J. NAT'L CANCER INST. 1879, 1880-82 (describing a relative risk model for predicting the probability of breast cancer); Elizabeth B. Claus et al., *Autosomal Dominant Inheritance of Early-Onset Breast Cancer: Implications for Risk Prediction*, 73 CANCER 643, 643 (1994) (describing a study which provides age-specific risk estimates for women with family histories of breast cancer); Stephen H. Taplin et al., *Revisions in the Risk-Based Breast Cancer Screening Program at Group Health Cooperative*, 66 CANCER 812, 812 (1990) (describing one health maintenance organization's development of a risk-based selective approach to recommending cancer screenings).

54. Taplin et al., *supra* note 53, at 813 (identifying the strengths and limitations of the risk classification system).

TABLE 1

Risk Category	Risk Factors		Relative Risk
	Women 40-49	Women 50+	
Level 1 (highest)	Prior breast cancer, two first degree relatives with breast cancer	Same	4-14
Level 2	One first-degree relative with breast cancer	One first degree relative or two minor risk factors*	1.9 - 3.5
Level 3	One or more minor risk factors*	All other women	1.2 - 1.9
Level 4 (lowest)	All other women	Not applicable	1.0

* Minor risk factors: Second degree relative with breast cancer, early menarche (age 10), late menopause (age 55), first birth after age 30 or nulliparity, previous breast biopsy for benign disease.

The highest risk category, Level I, contains women with personal or significant family history of breast cancer. These women are calculated to have a relative risk of breast cancer four to fourteen times greater than the average woman. Level II contains those women with less marked family histories of breast cancer; women over fifty can be assigned to this level if they have two or more minor risk factors alone. This level is considered to be associated with a relative breast cancer risk of 1.9 to 3.5 years. Women under fifty with one or more minor risk factors are assigned to Level III, as are all remaining women over fifty; the relative risk of breast cancer at this level is calculated to be 1.2 to 1.9. This leaves Level IV, the lowest risk level. In this risk model only women under fifty are considered to have a relative risk of 1.

The most interesting aspect of this careful, if somewhat controversial, model is that it was devised specifically to aid in establishing clinical practice guidelines for breast cancer screening. It is therefore stunning to note that there are no differences between risk Levels III and IV in terms of the

recommended mammography screening guidelines. What then is the purpose of distinguishing Level III from Level IV?

Level III is the level of "minor risk" factors. It contains many of the factors discussed in women's magazine articles on breast cancer. While geneticists probably would not consider a relative risk of 1.2 to 1.9 particularly significant, the reaction to reported risks in exactly this range among the women we have interviewed suggest that they do find it significant, and worrisome. When even a model intended to guide clinical practice cannot distinguish interventions according to all the risk levels delineated, it strongly suggests that there are questionable, but unquestioned, assumptions underlying the elaboration of risk.

It is not possible to know to what extent health care organizations or providers in private practice are using these sorts of risk calculations. Further, there are no data on how frequently women who are patients in such practices are being told about their risk status. We suspect, however, that both of these trends are increasing. An indication of just how widespread such an approach may become was recently found in an announcement on the Internet. An insurance company in New York State is offering a 1-800 phone number for women to call. Women can use the telephone keypad to respond to computer-generated questions about various risk factors and immediately receive their breast cancer risk number plus follow-up written information on "risk management."[55] However, as we have seen, the parsing of risk that is possible has far outstripped the targeting of interventions, or even the demonstrable efficacy of those interventions that are available. Thus, it is completely unclear whether enhanced "risk management" can possibly occur. What seems likely, however, is that this road will be the one more traveled, since it began long before the advent of genetic susceptibility testing for breast cancer.

55. Anne Leininger, genetic counselor, Personal Communication (July 8, 1996).

IV. CONCLUSION

To return to the original question, we can ask whether Ashkenazi-Jewish women are more susceptible than others to the lure of the sort of risk information genetic susceptibility testing will provide. Perhaps some of them will be. But we would suggest that this difference is likely to be marginal because the forces that converge around BRCA1 testing are likely to be so powerful for many women. These forces include the following: (1) the construction of cancer as an especially dread disease; (2) the feeling of extreme vulnerability to breast cancer that many American women have, especially those with the most access to cutting-edge medical services; (3) the fact that the popular media have accustomed women to thinking about risk and risk factors for disease; (4) the general movement of medicine in the direction of prediction of future risk; and, finally (5) the cultural belief that risk named is risk that can be averted. Thus, it seems possible that Ashkenazi-Jewish women may become the first group who, believing like most other Americans, that knowledge is power and that all information is knowledge, will trustingly hold out their arms for a blood test while asking rhetorically, "how can it hurt to know?" Sadly, the way that Jewish women may be different from all other women is simply that they will be the first to find the answers to this question. The problem, then, is not that Ashkenazi-Jewish women are different from all other American women. The problem is that they are probably not.