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Jewish Theological and Moral Reflections on Genetic Screening: The Case of BRCA1

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JEWISH THEOLOGICAL AND MORAL REFLECTIONS ON GENETIC SCREENING: THE CASE OF BRCA1[1]

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INTRODUCTION

WITH THE ADVANCE OF GENETIC screening procedures, it has become possible to identify genes responsible for a number of diseases. Although it is hoped that one day it will be possible to cure such diseases through genetic engineering applied *in utero*, that is not yet a reality. As a result, the only possibilities we have are the following: 1) to abort the affected fetus; 2) to allow the fetus to go to term and then deal with the disease in whatever ways we can (which, of course, varies with the disease); or 3) not to do such screenings altogether so as not to tempt those involved to abort.

The responses to these three possibilities vary not only among religions, but in fact, within any given religion authorities may and do differ. Furthermore, how a particular authority

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1. I would like to thank Professor Thomas Murray, Professor and Director of the Center for Biomedical Ethics of Case Western University for involving me in this project and for supplying me with articles on the BRCA1 mutation associated with cancer.

The following Judaic scholarly and biblical sources were utilized by the author: Mishnah (version edited c. 200 C.E.); Tosefta (version edited c. 200 C.E.); Jerusalem Talmud (version edited c. 400 C.E.); Babylonian Talmud (version edited c. 500 C.E.); MAIMONIDES' MISHNEH TORAH (completed 1177 C.E.); and JOSEPH KARO'S SHULHAM ARUKH (completed 1565 C.E.). Note on sources with no published English translation available: All sources that were unavailable in English were individually translated by the author, a scholar in Judaic Studies. While opiniens may differ as to exact translation of such texts, Rabbi Dorff's interpretations and translations are deferred to for purposes of this Article.

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responds to a given disease or condition may not be the same as how it would respond to another. For example, how one responds to the information that a fetus has a debilitating but non-fatal condition like Down's Syndrome may or may not differ from the way in which one responds to news of a fatal genetic disease like Tay-Sachs. Some religious authorities would not give a general answer as to how to respond to a given condition. Instead, they would only answer on a case-by-case basis, reasoning that the couple's personal situation and values and their psychological, economic, familial, and other resources may all affect the decision as to what is appropriate in a given case.

In recent years, research has suggested that a mutation on the BRCA1 gene appears in Ashkenazic-Jewish women more frequently than it does in the general population and that those who have this mutation are more likely to suffer from breast or ovarian cancer than those who do not. Those findings make the questions surrounding screening for this disease, and possibly aborting because of it, of particular interest to Jews. This Article, then, will present and focus the Jewish discussion of the issues surrounding the BRCA1 mutation.

First, it is helpful to put the questions raised by this finding into the larger context of how Judaism understands medicine in general, and abortion more specifically. I shall then review and evaluate rabbinic responses to those genetic diseases which have been discussed in the past, such as Downs Syndrome and Tay-Sachs, and then, based on this foundation, I shall formulate a Jewish response to the new information about BRCA1.

A. Medical Care in Jewish Theology and Law

Judaism's positions on issues in health care generally, and on genetic screening in particular, stem from two of its underlying principles: (1) that the body belongs to God; and (2) that human beings have both the permission and the obligation to heal.

1. The Body Belongs to God

In Judaism, God owns everything, including our bodies.[2] God loans them to us for the duration of our lives, and they are returned to God when we die. The immediate implication of this principle is that neither men nor women have the right to govern their bodies in any manner they please. Rather, since God created our bodies and owns them, God can and does assert the right to restrict the use of our bodies according to the rules articulated in Jewish law.

One set of rules requires us to take reasonable care of our bodies. The analogy can be made to the loaning of an apartment: just as one would have the obligation to take reasonable care of the apartment while using it, so too one has the duty to take care of one's body. Thus, in Jewish sources, rules of good hygiene, sleep, exercise, and diet are not just words to the wise designed for our comfort, but commanded acts that we owe God.[3] Ultimately, the duty to save one's own life and that of others (*pikkuah nefesh*) supersedes all other commandments except three.[4]

Just as Jews are commanded to take positive steps to maintain good health, likewise, we are obligated to avoid danger and injury.[5] Indeed, Jewish law views endangering one's health as worse than violating a ritual prohibition.[6] For example, anyone who cannot subsist except by taking charity but refuses to do so out of pride is shedding blood and is guilty of a mortal offense.[7] Similarly, Conservative, Reform, and some

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2. *See, e.g.*, *Torah*, Deuteronomy 10:14; *Writings*, Psalms 24:1. *See also Torah*, Genesis 14:19, 23 (using the Hebrew word for "Creator" [*koneh*] which also means "Possessor" and where "heaven and earth" is a merism for those and everything in between). *Cf. Torah*, Exodus 20:11; *Torah*, Leviticus 25:23, 42, 55; *Torah*, Deuteronomy 4:35, 39; 32:6.

3. *Leviticus Rabbah*, 34:3 (describing Hillel's reasoning as to why bathing is a commandment). Maimonides' codified rules requiring proper care of the body: MAIMONIDES' MISHNEH TORAH, Laws of Ethics (De'ot), chs. 3-5.

4. *Babylonian Talmud*, Shabbat 132a; *Babylonian Talmud*, Yoma 85b; *Babylonian Talmud*, Avodah Zarah 28b; MAIMONIDES' MISHNEH TORAH, Laws of the Foundations of the Torah ch. 5:2 & 5:7; MAIMONIDES' MISHNEH TORAH, Laws of the Sabbath ch. 2; JOSEPH KARO, SHULHAN ARUKH *Orah Hayyim* 328:1.

5. *Babylonian Talmud*, Shabbat 32a; *Babylonian Talmud*, Bava Kamma 80a & 91b; MAIMONIDES' MISHNEH TORAH, Laws of Murder 11:4-5; JOSEPH KARO, SHULHAN ARUKH *Yoreh De'ah* 116:5; JOSEPH KARO, SHULHAN ARUKH *Hoshen Mishpat* 427:8-10.

6. *Babylonian Talmud*, Hullin 10a; JOSEPH KARO, SHULHAN ARUKH *Orah Hayyim* 173:2; JOSEPH KARO, SHULHAN ARUKH *Yoreh De'ah* 116:5.

7. JOSEPH KARO, SHULHAN ARUKH *Yoreh De'ah* 255:2.

Orthodox authorities have prohibited smoking as an unacceptable risk to our God-owned bodies.[8] Ultimately, human beings do not, according to Judaism, have the right to murder someone else or even the right to dispose of their own bodies at will (i.e., commit suicide). Rather, both murder and suicide would be a total obliteration of that which does not belong to us but rather to God.[9]

2. The Permission and Obligation to Heal

God's ownership of our bodies is the foundation behind our obligation to help other people escape sickness, injury, and death.[10] This obligation is not for some general (and often vague) humanitarian reason or for reasons of anticipated reciprocity. Even the duty of physicians to heal the sick is not a function of a special oath that they take, an obligation of reciprocity to the society that trained them, or a contractual promise that they make in return for remuneration. Rather, a physician has his duty because all creatures of God are under the divine imperative to help God preserve and protect what is His.

The duty to heal is neither the sole, nor an obvious, conclusion from the Bible. According to the Bible, God inflicts illness as a punishment for sin and since God announces Himself as our healer,[11] perhaps medicine is an improper human intervention in God's decisions to inflict or cure illness.

The rabbis were aware of this line of reasoning, but they countered it by pointing out that God Himself authorizes us to heal. In fact, He requires us to heal. They found that authoriza-

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8. *See* ELLIOT N. DORFF & ARTHUR ROSETT, A LIVING TREE: THE ROOTS AND GROWTH OF JEWISH LAW 337-362 (1988) (discussing various Judaic authorities that prohibit smoking).

9. *Torah*, Genesis 9:5-6; *Mishnah*, Semahot 2:2; *Babylonian Talmud*, Bava Kamma 91b; *Midrah Rabbah*, Genesis 34:13 stating that the ban against suicide includes not only cases where blood was shed, but also self-inflicted death through strangulation and the like; MAIMONIDES' MISHNEH TORAH, Laws of Murder 2:3; MAIMONIDES' MISHNEH TORAH, Laws of Injury and Damage 5:1; JOSEPH KARO, SHULHAN ARAKH *Yoreh De'ah* 345:1-3. *See also* J. DAVID BLEICH, JUDAISM AND HEALING: HALAKHIC PERSPECTIVES 158-161 (1981) (discussing Jewish teaching with regard to suicide).

10. *Sifra* on *Leviticus* 19:16; *Babylonian Talmud*, Sanhedrin 73a; MAIMONIDES' MISHNEH TORAH, Laws of Murder 1:14; JOSEPH KARO, SHULHAN ARUKH Hoshen Mishpat 426.

11. God inflicts illness as punishment for sin, *see, e.g.*, Torah, Leviticus 26:16; *Torah*, Deuteronomy 28:59-61. God as our healer, *see, e.g.*, *Torah*, Exodus 15:26; *Deuteronomy* 32:39; *Prophets*, Isaiah 19:22, 57:18-19; *Prophets*, Jeremiah 30:17, 33:6; *Prophets*, Hosea 6:1; *Writings*, Psalms 103:2-3, 107:20; *Writings*, Job 5:18.

tion and imperative in two Biblical verses. First, Exodus 21:19-20, which states that if one assaults another he must provide for his victim until he is "thoroughly healed," presumably by paying for his medical care. The second duty to heal is found in Deuteronomy 22:2 which states "you shall restore the lost property to him." The Talmud understands the Exodus verse as giving *permission* for the physician to cure, whether hired by an assailant, as in the Bible's case, or not. On the basis of an extra letter in the Hebrew text of the Deuteronomy passage, the Talmud declares that this verse includes the *obligation* to restore another person's body as well as his property. Hence, there is an obligation to come to the aid of someone else in a life-threatening situation. On the basis of Leviticus 19:16 which states, "Nor shall you stand idly by the blood of your fellow," the Talmud expands the obligation to provide medical aid to encompass expenditure of financial resources for this purpose. Finally, Nahmanides, a fourteenth century rabbi, understands the obligation to care for others through medicine as one of many applications of the Torah's principle, "And you shall love your neighbor as yourself" (Leviticus 19:18).[12]

While each Jew must come to the aid of a person in distress, and while the assailant has the direct duty to cure his victim, Jewish law recognizes the expertise involved in proper medical care. Thus, as in other similar cases, the layman may hire the expert to carry out his obligations. The Talmud reflects some ambivalence about the level of expertise of physicians of its time (most explicitly in comments like "The best of physicians deserves to go to Hell!").[13] Furthermore, some later Jewish authorities were particularly wary of physicians' abilities to practice internal medicine (as contrasted with surgery and healing external wounds and diseases). However, in the end, the Talmud prohibits Jews from living in a community

12. *Babylonian Talmud*, Bava Kamma 85a, 81b; *Babylonian Talmud*, Sanhedrin 73a, 84b. *See also Sifrei Deuteronomy on Deuteronomy* 22:2; *Leviticus Rabbah* 34:3 (explaining that the soul is a guest in the body and a man who bestows kindness on his body does good to his soul); NAHMANIDES, KITVEI HA-RAMBAN [WRITINGS OF NAHMANIDES] 2:43 (Bernard Chavel, ed., Mosad Harav Kook 1963 [Hebrew]). This passage comes from NAHMANIDES' TORAT HA-ADAM [THE INSTRUCTION OF MAN], *Sh'ar Sakkanah (Section on Danger) discussing Babylonian Talmud*, Bava Kamma, ch. 8; JOSEPH KARO, BET YOSEF on the *Tur, Yoreh De'ah* 336. Nahmanides bases himself on similar reasoning in *Babylonian Talmud*, Sanhedrin 84b.

13. *Babylonian Talmud*, Kiddushin 82a.

where no physician is present. This conclusion returns us to the first principle described above: for only if a physician is available can one carry out one's duty to preserve that part of God's property which is our bodies.[14]

The expert, in turn, has special obligations because of his expertise. Thus, Rabbi Joseph Karo (1488-1575), the author of one of the most important Jewish codes, states the following:

> The Torah gave permission to the physician to heal; moreover, this is a religious precept and is included in the category of saving life, and if the physician withholds his services, it is considered as shedding blood.[15]

Similarly, the following rabbinic story indicates that the rabbis recognized the theological issue involved in medical care. Furthermore, it also indicates the clear assertion of the Jewish tradition that the physician's work is legitimate and, in fact, obligatory:

> It once happened that Rabbi Ishmael and Rabbi Akiva were strolling in the streets of Jerusalem accompanied by another person. They were met by a sick person. He said to them, 'My masters, tell me by what means I may be cured.' They told him, 'Do thus and so until you are cured.' The sick man asked them, 'And who afflicted me?' They replied, 'The Holy One, blessed be He.' The sick man responded, 'You have entered into a matter which does not pertain to you. God has afflicted, and you seek to cure! Are you not transgressing His will?'
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> Rabbi Akiva and Rabbi Ishmael asked him, 'What is your occupation?' The sick man answered, 'I am a tiller of the soil, and here is the sickle in my hand.' They asked him, 'Who created the vineyard?' 'The Holy One, blessed be He,' he answered. Rabbi Akiva and Rabbi Ishmael said to him, 'You enter into a matter which does not pertain to you! God created the vineyard,

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14. Abraham ibn Ezra, Bahya ibn Pakuda, and Jonathan Eybescheutz all restricted the physician's mandate to external injuries: *See* Ibn Ezra's commentary on *Exodus* 21:19 and *cf.* his comments on *Exodus* 15:26 and *Exodus* 23:25, and *see also* where he cites *Job* 5:18 and *II Chronicles* 16:12-13 in support of his view; Bahya's commentary on *Exodus* 21:19; JONATHAN EYBESCHEUTZ, KERETI U'PLETI (analyzing JOSEPH KARO, SHULHAN ARAKH Yoreh De'ah 188:5). *See* IMMANUEL JAKOBOVITS, JEWISH MEDICAL ETHICS 5-6 (1959, 1972) (discussing historical views on medicine and stating that Jewish practice teaches people to seek out doctors). *Jerusalem Talmud*, J. Kiddushin 66d (stating that a Jew may not live in a city without a physician). *Cf. Babylonian Talmud*, Sanhedrin 17b, where this requirement is applied only to "the students of the Sages."

15. JOSEPH KARO, SHULHAN ARUKH *Yoreh De'ah* 336:1.

> and you cut fruits from it.'
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> He said to them, 'Do you not see the sickle in my hand? If I did not plow, sow, fertilize, and weed, nothing would sprout.'
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> Rabbi Akiva and Rabbi Ishmael said to him, 'Foolish man! . . . Just as if one does not weed, fertilize, and plow, the trees will not produce fruit, and if fruit is produced but is not watered or fertilized, it will not live but die, so with regard to the body. Drugs and medicaments are the fertilizer, and the physician is the tiller of the soil.'[16]

This is a remarkable concept, for it declares that God does not bring about all healing or creativity on His own, but rather depends upon human beings to aid in the process. Thus, God commands us to try. We are, in the Talmudic phrase, God's partners in the ongoing act of creation.[17]

3. Implications for genetic screening

In the case of genetic screening, the permission and obligation to heal means several things. First, a child born with a genetic disease is God's creation just as much as any "normal" human being is. Therefore, we clearly do not have the right to take that child's life. Quite the contrary, we have the duty to provide for the special needs of the child and later the adult, to make him or her as much a part of society as possible, and even to bless God for creating His human creatures to be different from one another.[18]

Second, we have not only the right, but the obligation, to do our best to cure the disease, and, failing that, to ameliorate its effects. In other words, however much support there is in

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16. *See* OTZAR MIDRASHIM 2:580-581 (J.D. Eisenstein ed. 1915) (citing *Midrash Temurrah*). *Cf. Babylonian Talmud*, Avodah Zarah 40b. This is a story in which Rabbi [Yehudah, the President of the Sanhedrin] expresses appreciation for foods that can cure. Although circumcision is not justified in the Jewish tradition in medical terms, it is instructive that the Rabbis maintained that Jewish boys were not born circumcised specifically because God created the world such that it would need human fixing. A similar idea is articulated here on behalf a of physicians' activity despite God's rule. *See also Midrash Rabbah*, Genesis 11:6; *Pesikta Rabbati* 22:4.

17. *Babylonian Talmud*, Shabbat 10a, 119b. *Cf. Torah*, Genesis 2:1-3 (participating in God's ongoing act of creation when reciting this passage on the Sabbath); *Babylonian Talmud*, Sanhedrin 38a (wanting the Sadducees *not* to be able to say that angels or any being other than humans participate with God in creation).

18. *See generally* CARL ASTOR, . . . WHO MAKES PEOPLE DIFFERENT: JEWISH PERSPECTIVES ON THE DISABLED (Stephen Garfinkel ed. 1985).

the tradition to see sickness as the consequence of sin, that theological perspective, which itself is strongly challenged as early as the biblical Book of Job, in any case does not limit our attempts to find and give cure and comfort. Thus, in accordance with Judaism's usual rules governing dying, we may withhold or withdraw life support mechanisms if they are not effective in curing a fatal disease, and we must do everything we can to make the sufferer comfortable.[19] In the meantime, we must seek to develop means to prevent or cure the disease.

Third, while few would doubt the Jewish legitimacy of seeking to cure disease through genetic engineering, at some point our efforts in that direction may come into conflict with the principle of God's creative prerogative and God's ownership of our bodies. When the conflict occurs will depend upon how broadly "disease" is defined. For example, should we, if we can, change genes for height or intelligence to "cure" undesirable results and "improve" the species? The very possibility of using genetic engineering in that way has immediate implications for the treatment and even the conception of the value of the disabled in our society. Additionally, it also effects those who are considered "normal" now, but who would not be deemed so under some formula for genetic eugenics. Theologically, the dilemma is to define when we cease legitimately to be God's partners in creation and become instead God's substitute, "playing God," as it were, in changing the nature of the species. While that line of questioning will be critical in years to come, I will only note it here and not treat it. Rather, I take

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19. Two long rabbinic rulings were passed by the Conservative Movement's Committee on Jewish Law and Standards on the process of dying. *See* Elliot N. Dorff, *A Jewish Approach to End-Stage Medical Care*, CONSERVATIVE JUDAISM, Spring 1991, at 3-51; Avram Israel Reisner, *A Halakhic Ethic of Care for the Terminally Ill*, CONSERVATIVE JUDAISM, Spring 1991, at 52-89 (permitting withdrawal of machines and medications, but not artificial nutrition and hydration). I permit the withdrawal or withholding of artificial nutrition and hydration as well. In a subsequent ruling, however, Rabbi Reisner agreed that in the case of neonates born prematurely, even artificial nutrition and hydration may be withheld or removed.

My ruling would permit administering as much pain medication as necessary to make the child feel comfortable, even if, in the last stages of life, the amount of morphine required to alleviate the child's pain is also the amount which will hasten his or her death. Intent is the critical factor here: we may not do anything with the intent of bringing about the child's death more speedily, but we may and should do whatever is necessary to make the child feel comfortable, even if that has the secondary effect of advancing the child's death. Rabbi Reisner, however, does not accept the double-effect argument, and so for him morphine may be used only to the extent that it will not shorten the patient's life.

refuge that the condition caused by the BRCA1 gene mutation is, on all accounts, a disease and that genetic engineering to cure it is not currently possible. I therefore focus on genetic screening for the BRCA1 mutation and the responses to it that are now available.

B. The Status of Abortion in Jewish Law

If a couple elects to test for the BRCA1 gene mutation or for any other genetic disease, and if repeated tests are positive, the couple currently has two options. They can, first, let the fetus go to term and then deal with the consequences of the disease, whether that be raising the child while all involved endure the effects of the disease, or, if the illness is fatal, making the afflicted child as comfortable as possible during the dying process. A couple's second alternative is to abort. It is thus important to review Jewish sources on abortion in formulating a Jewish response to the couple's dilemma.

The Jewish tradition has a clear bias for life. Indeed, life is considered sacred. Consequently, although abortion is permitted in some circumstances and actually required in others, in most cases Jewish law forbids abortion. The decision to abort is certainly *not* viewed as a morally neutral matter of individual desire or as an acceptable form of *post facto* birth control.

On the other hand, Judaism does not see abortion as murder, as Catholicism does, because biblical and rabbinic sources understand the process of gestation developmentally. The fertilized egg cell and the later-term fetus are potential life and, therefore, may not be destroyed without reason, but they do not have the same legal status as a person after birth.

This view of the fetus begins with the biblical law that if a pregnant woman miscarries as a result of being struck by two men fighting, the one who hit her is not guilty of murder and therefore subject to the death penalty, but rather of assault and therefore subject to monetary compensation and fines for the injury.[20] This indicates that, according to the Bible, the fetus does not constitute a full-fledged human being with all of the

20. *Torah*, Exodus 21:22-25.

protections attaining to that status. (Note that Christian interpretations of that passage depend on the Septuagint translation of the Hebrew Bible, which, in this case, is erroneous or at best misleading.)

Following this biblical lead, the Talmud distinguishes two stages in pregnancy, but in both, the status of the fetus does not rise to that of a human being, which comes only with birth. Specifically, the Talmud rules that within the first forty days after conception the zygote is "simply water."[21] Another Talmudic source distinguishes the first trimester from the remainder of gestation.[22] From one or the other of those points in the gestational process to the moment of birth, the fetus is, according to rabbinic sources, "like the thigh of its mother."[23]

These marking points are not based on a theory of ensoulment at a particular moment in the uterus; the physical development of the fetus determines them. The effect of these demarcations is to make abortion during the early periods permitted for more reasons than during the rest of pregnancy while making abortion generally prohibited.

Specifically, because the body belongs to God, no man or woman may decide one day to cut off his or her thigh on a whim. That would be to destroy that which does not belong to you. Similarly, since the fetus is "like the thigh of its mother," one may not abort simply as a matter of choice. Indeed, *abortion is generally prohibited.*[24]

On the other hand, if the thigh is gangrenous, the person not only may, but must, have the thigh amputated in order to save his or her life. Similarly, if the fetus a woman is carrying threatens her life or health, then even if she deeply wants to have the child, she *must* have it aborted.[25] This is because the

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21. *Babylonian Talmud*, Yevamot 69b. *Cf. Mishnah*, Niddah 3:7 (30b); JAKOBOVITS, *supra* note 14, at 275 (noting that "forty days" in Talmudic terms may mean just under two months in our modern way of calculating gestation due to improved methods of determining the date of conception).

22. *Babylonian Talmud*, Niddah 17a.

23. *Babylonian Talmud*, Hullin 58a. *See also Babylonian Talmud*, Gittin 23b which states "the fetus is regarded as one of her limbs."

24. *See* DAVID M. FELDMAN, BIRTH CONTROL IN JEWISH LAW 265-66, 268-94 (1968) (explaining why abortion is generally prohibited by Jewish law).

25. *See* JAKOBOVITS, supra note 14, at 186-87, 378-79 n.173 (concluding that the life of the fetus must be set aside to save the life of the mother).

fetus does not attain the full rights and protections of a human being until birth — specifically when the forehead emerges or, if it is a breech birth, when most of the body emerges.[26] The mother, of course, has full human status. Consequently, if the fetus threatens the mother's life or health, it must be aborted. The following Mishnah graphically stipulates this premise:

> If a woman has (life-threatening) difficulty in childbirth, one dismembers the embryo in her, limb by limb, because her life takes precedence over its life. Once its head (or its "greater part") has emerged, it may not be touched, for we do not set aside one life for another.[27]

Only in a narrow band of cases does the woman have a choice in the matter. This choice occurs if the fetus does not clearly and directly endanger her life and health but does increase her risks beyond those of normal pregnancy. Under such circumstances, the woman, in consultation with her physician, *may* abort, but she may also choose to accept the elevated risks and carry to term. It is not surprising that authorities differ widely on how much of a threat to a woman's health the fetus must pose to justify or require an abortion.

Based on a responsum by Rabbi Israel Meir Mizrahi in the late seventeenth century,[28] many modern authorities also permit an abortion to preserve the mother's mental health. This premise has been variously construed in narrow or lenient terms in modern times.[29] To the extent that Jewish law makes a special provision for an unusually young or old mother, an unmarried mother, the victim of a rape, or the participant in an adulterous or incestuous union, abortion is usually justified as a measure necessary to preserve the mother's mental health.[30]

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26. *Mishnah*, Niddah 3:5.

27. *Mishnah*, Oholot 7:6. There are variant versions of this. *See, e.g., Jerusalem Talmud*, Shabbat 14:4 (stating that a neonate may not be touched when "its greater part has emerged"); T. *Yevamot* 9:9 and *Babylonian Talmud, Sanhedrin* 72b (stating "its head"); *Jerusalem Talmud*, Sanhedrin 8 (stating "its head or its greater part"). The later codes follow suit: MAIMONIDES' MISHNEH TORAH, Laws of Murder and Protection of Life 1:1; JOSEPH KARO, SHULHAN ARUKH *Hoshen Mishpat* 425:2.

28. ISRAEL MEIR MIZRAHI, RESPONSA PRI HA-ARETZ (1899) (commenting in Volume III, number 2 on the *Yoreh De'ah*).

29. *See* FELDMAN, *supra* note 24, at 284-94 (describing different situations for which permission to abort is granted). MOSHE HALEVI SPERO, JUDAISM AND PSYCHOLOGY: HALAKHIC PERSPECTIVES 168-80 (1980) (discussing abortion rationales).

30. *See* FELDMAN, *supra* note 24, at 284-94; SPERO, *supra* note 29, at 173; JAKOBOVITS,

Mental health reasons for an abortion are not, however, construed so broadly in contemporary rabbinic opinions as to condone an abortion for economic reasons, or because the couple wanted a child of a specific gender and the fetus is of the opposite gender, or simply because the woman did not want to bear a child.

There is no justification in the traditional sources for aborting a fetus for reasons having to do with the health of the fetus; only the mother's health is a consideration. As a result, some people object to performing an amniocentesis at all for fear that the information which is gained through such a procedure may tempt those involved to abort.[31] Supporters of amniocentesis argue the opposite premise; where it is clear that the mother is not able to cope with the prospect of bearing or raising a child afflicted with a given genetic disease, they justify aborting the fetus on the basis of preserving the mother's mental health. Supporters consequently permit the prenatal diagnostic procedure to determine whether the fetus has the disease in the first place, especially when the mother or father for any reason falls within a group particularly at risk for begetting such a child.[32]

Many Conservative and Reform rabbis, and even a few contemporary Orthodox rabbis, approach the matter in a completely different way. They reason that traditional sources recognize only threats to the mother's health as grounds for abortion because until recently it was impossible to know anything about the genetic or medical make-up of the fetus before birth. Our new medical knowledge, they say, should establish the fetus' health as an independent consideration.[33]

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supra note 14, at 189-90 (concluding that abortion is justified for moral or other grave reasons).

31. *See, e.g.*, J. DAVID BLEICH, CONTEMPORARY HALAKHIC PROBLEMS 112-15 (1977) (discussing various Judaic views of abortion); J. David Bleich, *Abortion in Halakhic Literature*, *in* JEWISH BIOETHICS 134, 175 n.97 (Fred Rosner & J. David Bleich eds., 1979) (analyzing Halakhic literature which discusses abortion).

32. *See generally* FELDMAN, *supra* note 24, at 284-94 (describing when abortion is permitted under Jewish law).

33. *See generally* ALEX J. GOLDMAN, JUDAISM CONFRONTS CONTEMPORARY ISSUES 35-62 (1978) (summarizing positions within all three movements).

The Conservative Movement's Committee on Jewish Law and Standards has adopted an official position stating that "[A]bortion is justifiable if a continuation of pregnancy might cause the mother severe physical of psychological damage, or if the fetus is judged by competent medical opinion to be severely defective." *See* Ben Zion Bokser & Kassel Abelson, *Statement on*

Although I personally agree with this approach, there are problems with it. Aside from the fact that it would represent an innovation in Jewish law, it raises the extremely difficult issue of determining what constitutes a sufficient defect which warrants abortion. The "easy" cases are those in which the fetus has minimal neurological function, as in cases of anencephaly, or a terminal, degenerative disease like Tay-Sachs. The more difficult cases involve diseases such as Huntington's Chorea in which the degeneration does not begin until age thirty-five or forty. I believe that abortion is not justified in the case of Huntington's Chorea since the person will live an extended period of time without suffering from the disease's debilitating effects. Furthermore, there is reasonable hope that the person may have children of his or her own and that a cure may be developed in that time. But, where do we draw the line? Is it appropriate at a life expectancy of twenty-five years? Fifteen years? Ten years? What constitutes a defect which justifies abortion in the first place? Mental retardation? If so, how much? Blindness or deafness? Answers to these questions pose the risk of dehumanizing people with disabilities and defining qualifications for a master race.

The difficulty of making these decisions does not mean that we can or should shrink from them. Human life requires decisions throughout, and the essence of morality is not only the will to do the right and the good, but additionally the ability to recognize them. The latter requires one to develop the sensitivity to analyze the moral issues in specific cases and to

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the Permissibility of Abortion, 37 PROCEEDINGS OF THE COMMITTEE ON JEWISH LAW AND STANDARDS OF THE CONSERVATIVE MOVEMENT 1980-85, at 37 (1988). *See also id.* at 3-35 (providing the rabbinic opinions of Rabbis Kassel Abelson, David M. Feldman, Robert Gordis and Issac Klein which justify this joint position).

Orthodox rabbis who take this position: ELIEZER WALDENBERG, RESPONSA TZITZ ELIEZER 9:51 (1967); ELIEZER WALDENBERG, RESPONSA TZITZ ELIEZER 13:102 (1978); SAUL ISRAELI, AMUD HAYEMINI, no. 35 cited in NO'AM 16 (K.H.) 27 (note); L. GROSSNASS, RESPONSA LEV ARYEH 2:205.

For the Reform position, refer to WALTER JACOB, CONTEMPORARY AMERICAN REFORM RESPONSA 23-27 (1987) [hereinafter JACOB, CONTEMPORARY RESPONSA]. Here, Jacob states that "[w]e do not encourage abortion, nor favor it for trivial reasons, or sanction it 'on demand,'" but he would sanction it for the physical or psychological health of the mother (including cases of incest and rape, if the mother wishes it). Moreover, "[s]uch problems, as those caused by Tay-Sachs and other degenerative or permanent conditions which seriously endanger the life of the child and potentially the mental health of the mother, are indications for permitting an abortion." *Id.* at 27.

distinguish among them in determining their moral valence. Unlike Christian Science, Judaism has taken the stand that one does not need to accept whatever nature serves us. Rather, one has the right, and indeed the duty, to intervene medically as an agent or partner of God. The advances of modern medical science have created a whole new spectrum of decisions that we may prefer not to make, but there is no escaping our duty to confront these issues as responsibly as we can.

With regard to abortion, in some cases an abortion will be clearly justifiable or clearly unjustifiable according to the criteria established by Jewish law. In other cases, the matter will be more clouded. In the latter group the traditional method of judging the issue on the basis of the mother's mental reaction to the defect may be the wisest choice. For some mothers, raising a mentally retarded child is manageable and possibly even fulfilling. However, for others, it is beyond their psychological competence to handle.

This of course means that only the people who are psychologically the strongest and the most stable would have the responsibility to raise such children. That is unfair. Moreover, if most families abort "defective" children, one wonders about the degree to which society, in the long run, will tolerate imperfections and provide for people who have them. Thus, the very sensitivity of society to the sanctity of life is at stake.

Even so, these decisions must be made, and rabbis are gradually developing a series of precedents which will ultimately provide guidelines for making them. In addition, medical, religious, and mental health professionals must be trained to help families facing these excruciating decisions.

In practice much of this discussion is moot. Jews engage in abortion almost indiscriminately. Indeed, before the law in Israel was changed recently to make abortion less readily available, there were some years when there were more abortions than live births among Jews. American Jews are no less apt to abort. That is a particularly problematic phenomenon for the contemporary Jewish community because Jews are barely reproducing themselves in Israel. Likewise, they are falling far short of reproduction in North America. The Jewish reproduc-

tive rate is approximately 1.6 or 1.7 children per couple.[34] Consequently, even those rabbis who are liberal in their interpretation of Jewish abortion law are also calling for Jews to marry and to have three or four children so that the Jewish people and Judaism can continue for more than another generation or two.[35]

This is just one instance of a larger phenomenon — namely, the relationship of Jews to Jewish law. According to the 1990 Jewish Population Study conducted by the Council of Jewish Federations, 6.6% of those born Jewish see themselves as Orthodox, 37.8% Conservative, and 42.4% Reform. The remaining 13.2% see their Jewish connection in a variety of different ways.[36] Orthodox Jews, at least in theory, see themselves as bound to Jewish law. Conservative Jews do too, but they understand Jewish law historically and therefore are more apt to change it. Members of both movements who are committed to their ideologies would be likely to take the legal duties and limitations described above seriously. Reform Jews have adopted Enlightenment notions of personal autonomy in their understanding of what Judaism should be today. As a result, American Reform Jews, in living out their movement's ideology, and, in practice, many American Orthodox and Conservative Jews, influenced by the heavy American emphasis on individual liberty, would all undoubtedly understand the legal duties and limitations delineated above as the lessons of their tradition which they then need to evaluate on their own in deciding what they themselves will do.[37]

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34. BARRY A. KOSMIN ET AL., COUNCIL OF JEWISH FOUNDATIONS, HIGHLIGHTS OF THE CJF 1990 NATIONAL JEWISH POPULATION SURVEY 15 (1991) (charting the number of children born per woman by age and Jewish identity). I am rounding out the figures presented there for the various age groups. The most important (and the most threatening) statistics are those for women now in their child-bearing years: 0.12 for women between 18 and 24 years of age, 0.87 for women between 25 and 34, and 1.57 for women between 35 and 44. Compare these figures with that of the general, white population in the United States: 0.35, 1.29, and 2.00, respectively. *See id.*

35. This was the clear and repeated message in the rabbinic letter which I wrote for and with the Rabbinical Assembly's Commission on Human Sexuality. That letter, after extensive discussion and revision, was approved and published by the Rabbinical Assembly as a whole, and it thus represents the opinion of the Conservative rabbinate. *See generally* ELLIOT N. DORFF, "THIS IS MY BELOVED, THIS IS MY FRIEND:" A RABBINIC LETTER ON INTIMATE RELATIONS (1996). On this issue, the Orthodox would undoubtedly agree, and most of the Reform rabbinate would as well.

36. *See* KOSMIN ET AL., *supra* note 34, at 32 (charting the denominational preferences of adult Jews by religion).

37. For a description and explanation of the ideologies of American Jewish movements and

C. Genetic Screening for Tay-Sachs

Many of the rabbinic opinions written to date that have been analogous to our case of the BRCA1 mutation concern genetic screening for Tay-Sachs Disease. Using these precedents for the BRCA1 case will require both an evaluation of their soundness with regard to Tay-Sachs itself, and then an analysis of the similarities and differences between Tay-Sachs and BRCA1. It will thus be helpful to review the nature of Tay-Sachs and the precedents with regard to screening.

Tay-Sachs is a genetic disease which causes deterioration five or six months after birth and death by the third or fourth year of life. While approximately one in three hundred of the general population is a carrier, among Ashkenazic Jews (that is, those descended from Jews living in Central and Eastern Europe) it is one in thirty, that is, ten times as frequent. Since both parents must have the disease for their child to have it, statistically one in nine hundred Jewish couples may have a Tay-Sachs child. For those couples, who are themselves normal physically and mentally, each time they conceive a child they have a twenty-five percent chance of bearing a child with the disease, a fifty percent chance of producing a normal child who is a carrier, and a twenty-five percent chance of producing a child who is completely free of the disease. The statistical probability among Ashkenazic Jews of bearing a child afflicted with Tay-Sachs is one in 3600. Those who inherit the Tay-Sachs mutation from both parents have virtually a one-hundred-percent chance of suffering and ultimately dying from the disease.

For purposes of comparison, the carrier frequency of Tay-Sachs among Ashkenazim is three to four percent, Gaucher's Disease is four to six percent, Canavan 1.7 to two percent, and Niemann-Pick one to two percent. The reported carrier frequency among Ashkenazic women of the BRCA1 mutation connected with breast and ovarian cancer, the subject of this Article, is approximately one percent.[38] While Tay-Sachs and the

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their implications for Jewish law, refer to ELLIOT N. DORFF, CONSERVATIVE JUDAISM: OUR ANCESTORS TO OUR DESCENDANTS 110-57 (1977); ELLIOT N. DORFF, CONSERVATIVE JUDAISM: OUR ANCESTORS TO OUR DESCENDANTS 96-149 (1996).

38. *See* Jeffrey P. Struewing et al., *The Carrier Frequency of the BRCA1 185delAG*

other diseases mentioned are all carried on recessive genes, BRCA1 is carried on the dominant gene. Therefore, while the other diseases can only infect those who inherit the particular recessive gene from both parents, only one parent needs to pass on the BRCA1 gene for the child to be affected by it. Assuming that approximately half of the children born are female and one percent of all children born to Ashkenazic women have the BRCA1 mutation, half that percentage, or one of every two hundred children, born to Ashkenazic women will, as a result of this gene, be at substantial risk for breast cancer. (It may also be true that male children born with this gene have an increased risk for prostate or colon cancers, but the available data, as far as I know, does not show nearly as strong a linkage between the presence of the gene and these forms of cancer in males.) Keep this higher frequency in mind as I review the concerns with the less frequent Tay-Sachs disease and seek to apply them appropriately to BRCA1.

Screening for Tay-Sachs, which has become common among Ashkenazic Jews, will in the vast majority of cases indicate that neither partner is a carrier. Therefore, in those situations, nothing should be done. In those cases where only one of the partners is a carrier, there are no implications for the reproductive plans for the couple themselves, but their children and their respective spouses need to be tested when they are thinking of having children. If both partners are carriers, the usual procedure followed by physicians and genetics counselors is to warn the couple of the one-in-four risks of bearing a Tay-Sachs child, counsel them about the alternatives to having their own children (including adoption and now the use of donor gametes), and admonish them that if they do proceed to have their own children, they should have the cells of the fetus tested.

This regimen poses two sorts of problems which must be addressed: (1) the advice given the couple to consider not having children of their own; and (2) the abortion following a diagnosis of Tay-Sachs. Rabbi J. David Bleich has been most forceful in opposing the usual regimen on these grounds. He

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Mutation is Approximately 1 Percent in Ashkenazi Jewish Individuals, 11 NATURE GENETICS 198, 199 (1995).

maintains the following:

> The obligation with regard to procreation is not suspended simply because of the statistical probability that some children of the union may be deformed or abnormal. While the couple may quite properly be counseled with regard to the risks of having a Tay-Sachs child, it should be stressed that failure to bear natural children is not a halakhically viable alternative. As has been indicated earlier, artificial insemination using donor semen is not an acceptable solution.[39]

"Of at least equal, if not graver concern," he writes, "is the possibility that the couple will abort the child if it proves to have Tay-Sachs. The fear that a child may be born physically malformed or mentally deficient does not in itself justify recourse to abortion."[40] He is especially concerned with this alternative because if amniocentesis is used to determine the Tay-Sachs status of the child, that procedure is normally performed in the sixteenth week of gestation. Therefore, any abortion performed in response to the information learned from the amniocentesis is commonly done in the eighteenth week of pregnancy. The eighteenth week of pregnancy is long past the stage when the child is "simply water." By hypothesis, no risk to the mother is involved, and therefore such an abortion would not be legitimate in Bleich's view. Bleich would, therefore, restrict the use of amniocentesis to cases where there is a medical remedy for the disease. The amniocentesis would indicate as, for example, a blood-group incompatibility which can be treated by exchange transfusion. Where there is no therapeutic option aside from abortion, amniocentesis should not, in his opinion, be performed in the first place because it would tempt those involved to perform an illegitimate abortion. Furthermore, it "poses a pointless medical risk to both the mother and the fetus and also constitutes an act of *chavalah* — an unwarranted assault upon the mother."[41] (Presumably, if chorionic villus sampling is used to test the fetal genetic structure, since that is usually done in approximately the sixth week of gestation, this concern would be less weighty for Rabbi

39. BLEICH, *supra* note 9, at 105.
40. *Id.*
41. *Id.* at 106.

Bleich, but I frankly doubt that he would permit the abortion even then, given that the mother's life or health is not endangered.)

On the other hand, Rabbi Bleich does countenance screening for Tay-Sachs through blood tests before marriage, preferably in the teenage years. He notes that a person found to be a carrier may suffer anxiety and depression as a result and that others may see such a person as a pariah, but both reactions would be unfounded and contrary to Jewish law. The Jewish community, in fact, would be duty-bound in such cases to make sure that carriers are *not* stigmatized that way.

Carriers should, though, try to marry people who are not themselves carriers to avoid any possibility of producing a child with the disease. This is in conformity with "what is historically perhaps the oldest recorded item of genetic counseling," namely, that the Talmud advises a man not to marry into a family where leprosy or epilepsy has appeared in at least three people.[42] A person who is not a carrier need not fear marrying a carrier, as long as their children are also tested and counseled. It must be emphasized, however, Rabbi Bleich says, that "when Tay-Sachs screening is carried out before marriage and both prospective bride and groom have been identified as Tay-Sachs carriers they must be counseled that Judaism does not sanction a sterile union."[43]

Other rabbis who have written on this issue share Rabbi Bleich's concern with the duty to procreate, but permit some of the procedures which he prohibits. Specifically, as noted above, Conservative, Reform, and some Orthodox rabbis would permit an abortion when the fetus suffers from an untreatable genetic disease. Such rabbis, therefore, would certainly permit, and maybe even advise, prenatal testing to determine whether the fetus has such a disease. Given the risks of amniocentesis itself, the procedure should only be done when the child is in special "at-risk" categories. Thus, if both parents are carriers of Tay-Sachs, that certainly qualifies. If the results indicate that the child will be a carrier but will not have the disease, the child certainly should not be aborted. However, if the child

42. *Babylonian Talmud*, Yevamot 64b.
43. BLEICH, *supra* note 9, at 106.

will suffer from the disease, most rabbis would allow an abortion.

Even those rabbis who take this stance would agree with Rabbi Bleich that genetic screening for Tay-Sachs should be done in the teenage years. The same holds true for the other diseases mentioned above which effect Jews in disproportionate numbers. People informed of their carrier or non-carrier status would probably not make marital decisions on that basis, and their refusal to do that is appropriate. If both are carriers for any of these diseases, however, they should use prenatal testing to determine whether their fetus has the disease so that they can determine whether they want to abort. In such cases, the abortion would be justified as a measure to preserve the mother's mental health or, in the alternative theory in contemporary Jewish legal rulings, as a direct result of the child's disease.

The couple in which both people are carriers for one of these diseases may, however, engage in other approaches as well. According to my own rabbinic ruling, which was approved by the Conservative Movement's Committee on Jewish Law and Standards, the couple may, with some restrictions, use donor semen or eggs as a way of avoiding the possibility that the child will suffer from the disease. That alternative would make an abortion unnecessary. The couple also has the option of adoption.

Even though procreation requires the contributions of both male and female genetic materials, for both exegetical and economic reasons, Jewish law interprets the commandment to procreate to devolve upon the man.[44] Thus if donor sperm or

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44. Both the Mishnah and the Talmud have difficulty finding a biblical verse to support the ruling. *See Mishnah*, Yevamot 6:6 (61b), where the ruling is recorded as the majority opinion (that is, without ascription) but without textual support. *See also* where Rabbi Yohanan ben Beroka immediately objects: "With regard to both of them [i.e., the male and female God first created] the Torah says, "And God blessed them and said to them . . . 'Be fruitful and multiply.'" (*Torah*, Genesis 1:28). *But see Babylonian Talmud*, Yevamot 65b-66a (bringing conflicting evidence as to whether a woman is legally responsible for procreation and ultimately does not decide the matter). *Cf.* MAIMONIDES' MISHNEH TORAH, Laws of Marriage 15:2; JOSEPH KARO, SHULHAN ARUKH *Even Haezer* 1:1, 13.

The Talmud there also brings conflicting exegetical grounds for the Mishnah's ruling, basing it alternatively on "Replenish the earth and subdue it" (*Torah*, Genesis 1:28) or "I am God Almighty, be fruitful and multiply" (*Torah*, Genesis 35:11). There are problems in using both texts, however. The traditional pronunciation of the first is in the plural, making propagation a

adoption is used, the man will technically not fulfill the commandment of procreation. Even so, because of the documented threat of disease in his offspring, the Conservative Movement would see the man *as if* he were infertile and therefore incapable of fulfilling the commandment. Thus he is not at fault for failing to procreate. That is, while the Conservative Movement would certainly assert that disabled or diseased people are as much God's creation as anyone else, it would not say, as Rabbi Bleich does, that a couple who is at substantial risk for bringing a diseased child into the world must nevertheless procreate. Moreover, if a child is born through donor gametes or is adopted, Conservative rabbis would, according to my ruling, recognize the parents who raise the child as the child's "real" parents in the many and important ways that they function as such.[45]

D. Applying These Principles and Precedents to BRCA1

1. Present and Future Research on BRCA1

We are now prepared to deal with the case at hand. It is estimated that ten percent of the women diagnosed each year with breast cancer have a family history of the disease. Likewise, BRCA1 mutations are estimated to account for about half of inherited breast cancer and over three-quarters of the cases

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commandment for both the man and the woman. It is only the written form of the text which is in the masculine singular (and even that can apply, according to the rules of Hebrew grammar, to either men alone or to both men and women). The second text is indeed in the masculine singular, but that may be only because God is there talking to Jacob. The fact that Jacob is subject to the commandment proves nothing in regard to whether his wives were. These problems prove that the real reason for limiting the commandment of procreation to men is not exegetical at all, and we have to look elsewhere for what motivated the rabbis to limit it in that way.

The real reason may have been economic: since a man was legally responsible to support his children, it was against his financial interests to have them in the first place, and so the law had to command him to do so. Alternatively, since the man has to offer to have conjugal relations with his wife for procreation to take place, it may be that anatomical factor which prompted the rabbis to impose the commandment on men. Conversely, some argue that the rabbis would not have imposed the commandment on a woman since they would not have legally obligated her to undertake the risks of pregnancy and childbirth, risks which were considerably greater in times past than they are now. Whatever the reason, Jewish law ultimately places legal responsibility for procreation on the man.

45. *See* Elliot N. Dorff, *Artificial Insemination, Egg Donation, and Adoption*, CONSERVATIVE JUDAISM, Fall 1996, at 3-61 (discussing why parents who raise the child are deemed to be the child's parents in some respects but not others). *See specifically id.* at 23-30, 50-54.

of inherited breast and ovarian cancer combined. Samples originally taken to test for cystic fibrosis and Tay-Sachs in 858 Ashkenazic-Jewish women in the United States and Israel revealed that the carrier frequency among them of the 185delAG mutation alone is approximately one percent. It is estimated that among Ashkenazi women, the BRCA1 mutation accounts for sixteen percent of breast cancers and thirty-nine percent of ovarian cancers diagnosed before age fifty. By contrast, in the non-Ashkenazi population, the estimated contribution of *all* BRCA1 mutations is 4.1% of breast cancer cases (approximately a fourth the rate of Ashkenazi-Jewish women for the 185delAG mutation alone) and twelve percent of ovarian cancer cases (less than a third the rate of Ashkenazi-Jewish women for that one mutation). In families with a history of breast or ovarian cancer, the female inheritors of BRCA1 mutations have an eighty to ninety percent lifetime risk of breast cancer and a forty to fifty percent risk of ovarian cancer. This finding of the link between this mutation and cancer is especially important to Ashkenazi Jews.[46] While the results are not as pronounced, the researchers also note that males with BRCA1 mutations show an increased risk of contracting prostrate and colon cancer.[47]

What should be done with these results? The researchers note that, on the one hand, "the observed 0.9% prevalence of the 185delAG mutation is higher than the prevalence of many genetic diseases for which routine screening is conducted." They do not as yet recommend widespread genetic screening, however, because it is not clear that people being tested for being carriers of Tay-Sachs and cystic fibrosis are representative of all Ashkenazi Jews. Therefore, more random testing of that population is necessary to determine whether all Ashkenazi Jews are part of the at-risk population identified in this study, or only a subset of them, namely, those at risk for Tay-Sachs or cystic fibrosis. This further research should, in their view, also collect personal and family histories of cancer to deter-

46. *See* Struewing et al., *supra* note 38, at 198.

47. *See* Deborah Ford, et al., *Risks of Cancer in BRCA1-Mutation Carriers*, 343 LANCET 692, 694 (1994) (stating that BRCA1 carriers also experience moderately increased risks of colon and prostate cancer).

mine the predictive value of a long family history of such cancers. Likewise, research should collect information on males as well as females in light of the "modestly elevated" levels of prostate and colon cancer among those who inherit this BRCA1 mutation.[48]

The Jewish tradition certainly would not object to such research. Rather, it would actually push Jews to do as much as we can to learn about this linkage so that hopefully one day soon we can help people avoid cancer or, failing that, cure it. This comes from the fundamental principle discussed previously regarding the Jewish attitude toward medicine, namely, that human medical research and practice are not violations of God's prerogatives but, on the contrary, some of the ways in which we fulfill our obligations to be God's partners in the ongoing act of creation. We must, of course, insure that respect for persons, honesty, disclosure of risks, balance of risks and benefits, and the other moral canons of medical research are upheld in the process of conducting this study. Since we have initial evidence that this line of inquiry may be fruitful in attaining our medical goals of preventing or curing some kinds of cancer, however, we have, from a Jewish perspective, not only the right, but the duty to pursue this investigation to the extent that we can.

Determining exactly what that extent is requires that we balance our expenditure of time, money, and energy on this type of research with other medical efforts which seem promising. Furthermore, we must balance all medical research against other necessary social functions and goals. Within these bounds, Jewish theology and law certainly confirms and encourages all efforts to learn more about this genetic linkage and how genetic engineering may be helpful in preventing or curing the ailments which the mutation fosters or causes.

2. The Medical Care of Those Affected

Moral problems abound, though, when we turn from the question of whether further research should be done to the arena of medical practice, both now and in the future. Should

48. *See* Struewing et al., *supra* note 38, at 199.

we, for example, recommend testing for this mutation to all Ashkenazi Jews, or only to those for whom other factors identify them as being at-risk? If the tests show that a person has the mutation, what should be done with regard to the person, that person's children, to that person's future concepti? Does that person's fiancée have a right to know about the gene in his or her intended mate? Finally, in the future, if and when we develop the ability to affect this gene through genetic engineering, should we fix each fetus on a case-by-case basis, or should we attempt to affect the germ cells as well so as to protect future generations?

As difficult and as new as these questions are in the history of the Jewish tradition, we should minimally draw the outlines of a Jewish approach to these questions. As the researchers suggest, before testing every Ashkenazi Jew for the mutation, with the attendant financial and emotional costs involved, we should engage in further research to determine exactly who is at risk.

Once we have learned not only to identify those at risk but also to cure the disease through techniques of genetic engineering or other methods, there would be, in my view, a positive obligation for people in the group at risk to undergo the test. There would be a second positive obligation of those found to have the mutation to undergo the procedures necessary to correct it so that they do not suffer from the forms of cancer associated with it. When medicine has advanced to that stage, these duties would be exactly equivalent to the obligations of everyone to seek to avoid disease and, if stricken, to try to cure it. That is, the Jewish imperatives to prevent and cure illness are no different for genetically engendered diseases than they are for those which come from bacteria, viruses, or any other environmental factor. In all cases of illness, whatever its origin, Jews have the duty to try to prevent illness if at all possible and to cure it when they can.

The hard issues, of course, arise at the stage of research in which we find ourselves now, and undoubtedly will find ourselves for some years, namely, there is evidence of a genetic linkage to several forms of cancer, but we cannot change the gene to avert the disease.

Once again, the first order of business is to identify more

accurately the at-risk group. Once that has been done, it seems to me that those in that group would have the duty to be tested, even before we can effect a cure through genetic engineering. I base this duty on two premises: First, if the test proves positive, that will alert a woman to be more vigilant in performing self-examinations of her breasts and in having regular checkups by her doctor. It would also encourage her to engage in these diagnostic practices earlier in her life than she normally would. Second, the test will at least open the possibility to her of a radical mastectomy in an effort to prevent breast cancer. Often, not all the breast tissue is successfully removed in such procedures, but this course of action may nevertheless reduce the probability of contracting cancer. Even though we cannot currently guarantee a cure, the test for the BRCA1 gene is sufficiently therapeutic even now to make it mandatory as a Jewish religious obligation for the at-risk group to undergo the test.

It should be clear that, unlike the case of Tay-Sachs, the point of such testing would *not* be to provide the opportunity to abort a fetus carrying the BRCA1 mutation. After all, the current state of medical research on this gene indicates that there is a strong statistical correlation between at least one subset of people who have this mutation and the expression of that mutation in forms of cancer. However, even for that subset, the incidence of cancer is not one hundred percent. Likewise, even for those within this subset who do contract cancer, the age at which the disease begins to manifest itself varies widely.[49] Furthermore, environmental factors clearly play a role, along with genetic predispositions such as those caused by BRCA1 mutations, in determining whether cancer will occur at all in inheritors of BRCA1 mutations and, if so, at

49. *See id.* at 198. The researchers report that "[b]ased on studies in very high-risk families, the estimated lifetime penetrance for breast cancer among mutation carriers is about 90% .... The risk of ovarian cancer is lower, but may be as high as 84% in a subset of families." *Id.* Note that these numbers are for those families at the greatest risk for developing cancer in the first place, based on both a family history of the disease and the presence of BRCA1 mutations, and note also that these numbers are over a lifetime. As they report on the same page, "it can be estimated that the 185delAG mutation might account for 16% of breast cancers (range 7.9-23.1%) and 39% of ovarian cancers (range 22 -49%) diagnosed in Ashkenazi women before age 50." *Id.* As bad as that is, 16% and 39% are *much* lower than 90% and 84% and *much* further away from a 100% correlation.

what age.[50]

These factors would suggest that some medical and environmental therapies which are now available may be used by those who have the mutation to delay the onset of the cancer, perhaps for decades, or to cure it once it has begun to invade the body. Even without such therapies, affected women generally live at least several decades before developing cancer and may, in the meantime, produce children of their own. Furthermore, by that time means of preventing the mutation from expressing itself as cancer or a cure for such cancers may be found.

The possibility of using currently available methods to prevent, delay, or cure threatened cancers makes it a positive duty of Jews within the at-risk population for BRCA1 (as defined by future research) to be tested and, if one is an inheritor of the mutation, to follow the advice of physicians in employing whatever techniques or medications are available at the time to ward off or cure the disease Because some such therapies are now available, and because the affected person will generally live for several decades before the onset of any cancer caused by the gene, the presence of the mutation in a fetus definitely does not warrant aborting it. (In this respect the case of the BRCA1 mutation is closer to the case of carriers of Huntington's Chorea than to victims of Tay-Sachs.)

Our current information does not suggest that children should be tested. At present, nothing can be done in childhood to benefit the child that could not be done just as effectively later. It is, therefore, better to wait until the child is older and can make decisions for herself concerning the proper course of action.

Some of the women who suffer from breast cancer contract the disease as early as their twenties. Thus, it becomes a positive duty in Jewish law for teenagers in at-risk families to be tested. The objective of testing for the 185delAG mutation at that time is to alert teenagers as to whether they indeed carry this genetic mutation so that they are forewarned to do

50. *See Risk Assessment and Religion*, 11 NATURE GENETICS 105-06 (1995) (discussing the correlation between DDT and other pesticides and chemical pollution with the development of cancer).

two things: (1) to perform self-examinations to test for any incidence of cancer much earlier and much more frequently than the general population is advised to do; and (2) to consult their physician earlier and more frequently than is common so that they can be treated for any cancer which does occur at the earliest sign of onset.

The duty for at-risk teenagers to be tested at that time derives from the general Jewish obligation to preserve life and health. Of course, if the woman can achieve the goal of preventing or curing the disease without the test through some other regimen of medical care, that would satisfy the requirements of Jewish law: the duty is to take reasonable steps to prevent and cure disease, not to adopt a specific protocol to accomplish those ends.

Traditionally, Jews become adults in Jewish law at the age of twelve-and-a-half for girls and thirteen for boys; at those ages they become liable for all of the duties and prohibitions of Jewish law. That gives a legal framework in Jewish law to support the timing of the onset of this duty in one's teenage years.

3. Informing Prospective Spouses

Do affected women have the duty to inform their prospective mates of their condition? I think they do, but the answer to this is not as obvious as one might suppose. The Jewish tradition places a premium on truth and honesty in speech, business practices, and in personal relations.[51] It recognizes, though, that there are some times in life where tact should take precedence over truth. That is, truth is a critical value, but not an absolute one.

Specifically, there are two classical cases where truth is

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51. Some biblical verses emphasize the importance and imperative of truth: *see, e.g., Torah*, Exodus 18:21; *Prophets*, Zechariah 8:16, 19; *Writings*, Psalms 15:2, 24:3-4; *Writings*, Proverbs 12:19, 23:23. Conversely, the Torah says, "from falsehood you should stay far away" (*Exodus* 23:7) and "You shall not deal deceitfully or falsely with one another .... You shall not defraud your fellow ...." (*Leviticus* 19:11, 13). According to the rabbis, God's very seal is truth (*Midrash Rabbah*, Genesis 81:2) the world is preserved by truth, justice, and peace (*Mishnah*, Avot 1:18) and, in sum, "[o]ne's 'yes' should be yes, and one's 'no' should be no" (*Babylonian Talmud*, Bava Mezia 49a). *Cf. Mishnah*, Bava Mezia 4:2; *Jerusalem Talmud*, Berakhot 1:8 (3c); *Ruth Rabbah* 7:6 citing *Ruth* 3:18.

set aside in the name of some other good. According to the School of Shammai, one describes a bride on her wedding day as she is, whether she be beautiful or ugly, but the law follows the School of Hillel who maintain that on her wedding day one describes her as beautiful no matter what the case may actually be.[52] In addition, when a person may die of a disease but also may live, there is some support within the tradition to keep the worst possible prognosis from a dying patient in the name of supporting the person's efforts to be healed and his or her hope to get better.[53] In each case, the critical question is whether there is a pragmatic benefit for the person in being told the truth. When there is, it must be told. However, when there is not, it may be withheld if other values like good feeling, hope, and healing may be achieved by doing so.

In our case, the woman, by hypothesis, knows of the mutation and knows of its strong linkage to breast and ovarian cancer. A potential mate has a need to know that information for two reasons. First, the man has a right to know that his wife has a special propensity for cancer in making the decision of whether or not to marry the woman. When we marry, we always know that situations which we cannot predict will undoubtedly occur and that part of the marriage bond is the agreement to support one another if and when such occasions arise. When one partner knows ahead of time, though, that she is particularly prone to cancer, it is only fair that her potential husband be told so that he can make his commitment to marriage with informed consent. (This is not, incidentally, a male-female issue: the same would be true for a man who bears this mutation since his female children may be specially at risk and, for all we know, he or his male children may be particularly at risk for specific cancers too.)

Second, the man has the right to know of the woman's genetic mutation because the threat of his wife being afflicted with these cancers would undoubtedly require them to have children early in their marriage. That in turn, may well influ-

52. *Babylonian Talmud*, Ketubbot 16b-17a.

53. *See generally* BASIL F. HERRING, JEWISH ETHICS AND HALAKHAH FOR OUR TIME: SOURCES AND COMMENTARY 47-66 (1984) (summarizing and discussing halakhic requirements for informing terminally ill patients about their prognoses).

ence their professional and personal plans. In these respects the man has a right to know of her condition.

4. Retaining an Appropriate Perspective and Attitude

It clearly is anything but pleasant to find out that you or a member of your family is in the at-risk population for the cancers which the BRCA1 mutation causes — or, at least, seems to cause. Indeed, one might understandably feel frightened about the future and angry at God or simply at your terrible luck for being so afflicted. It all seems so unfair, so dreadful, and so utterly terrifying. On the other hand, if you discover that you yourself are not at-risk, the relief you feel is often immediately followed by a sense of guilt for being spared, akin to the "survivor guilt" experienced by some Holocaust survivors. This "survivor guilt" is compounded with anxiety about the futures of those relatives who were not so lucky.

Jews inherit a tradition which prizes medicine, and so they are prone to go overboard in tending to their care. Faced with a diagnosis of bearing the BRCA1 mutation, they may take the reasonable Jewish concern with preserving life and health to an extreme, obsessing over their fate.

Such a reaction would be unhealthy and, therefore, contrary to what Jewish norms would have Jews do. It is unhealthy because modes of therapy are currently available. Furthermore, the chances of their success are likely to be diminished if the individual becomes exhausted with worry. One certainly cannot be expected to be calm and collected; however, the best chances for cure require both the physical and mental cooperation of the patient in trying to prevent the disease or in curing it if it occurs. Because such a demeanor presents the best hope for prevention or recovery, Jewish law mandates that affected people do their best to engage in therapy conscientiously, but in as even-tempered a mood as possible. Toward that end, patients should avail themselves of the communal support which they can gain from their synagogues, and they should also use the many spiritual resources of the Jewish tradition.

E. Applying These Principles and Precedents to BRCA1 in the Future

In the future, if we are able to prevent cancer through some form of genetic repair of the mutation *in utero* or after birth, every rabbi who has written about such therapeutic possibilities, whether Reform, Conservative, or Orthodox, welcomes them.[54] The legal questions surrounding genetic engineering focus on using the technique for changing characteristics of the fetus which are not a disease. In addition, there is the overarching theological consideration, that is, when do we cross the line, if ever, between acting as God's legitimate partners in perfecting creation and, on the other hand, illegitimately preempting God's role such that we effectively play God?

While the material on these questions from a Jewish perspective is very sparse, it is interesting that an Orthodox rabbi finds grounds within the tradition to use genetic techniques even for enhancing the human being for non-medical purposes. Specifically, Rabbi Azriel Rosenfeld uses the Talmudic suggestions to prospective parents for having handsome and learned children as grounds for using genetic engineering techniques for accomplishing the same or similar ends, but not for diminishing the status of the fetus:

> Our sages recognize, and perhaps even encourage, the use of prenatal (or better, pre-conceptual) influences to improve one's offspring:
>
> > Rabbi Yohanan used to go and sit at the gates of the place of immersion [that is, the pool where women immersed themselves after their menstrual period so that they might resume sexual relations with their husbands], saying: 'When the daughters of Israel come out from their re-

54. *See, e.g.*, David Golinkin, *Response: Does Jewish Law Permit Genetic Engineering on Humans? 19* MOMENT, Aug. 1994, at 28, 29, 67 (explaining a Conservative position on genetic engineering). For Orthodox views, refer to Azriel Rosenfeld, *Judaism and Gene Design, in* JEWISH BIOETHICS 401, 401-08 (Fred Rosner & J. David Bleich eds., 1979); Fred Rosner, *Genetic Engineering and Judaism, in* JEWISH BIOETHICS 409, 409-20 (Fred Rosner & David Bleich eds., 1979) (explaining Orthodox perspectives on genetic manipulation or engineering recombinant DNA technology and research on gene splicing, nuclear transplants (cloning), and artificial insemination). For a Reform position, see WALTER JACOB, QUESTIONS AND REFORM JEWISH ANSWERS: NEW AMERICAN REFORM RESPONSA 252 (1992) (discussing the Reform position on genetic engineering); JACOB, CONTEMPORARY RESPONSA, *supra* note 33, at 32-34 (answering questions about *in vitro* revitalization and genetic engineering from a Reform perspective).

> quired immersion, they look at me and may have sons who are as handsome as I and as accomplished in Torah as I.'[55]

> This concept might well be extended to allow the use of gene-surgical techniques to produce physically and mentally superior children. On the other hand, turning a person into a monster by surgical means would very likely be forbidden, unless it were necessary to save his life; and creating monsters through gene surgery might thus also be forbidden.[56]

On the other hand, Conservative Rabbi David Golinkin specifically restricts the Jewishly legitimate use of gene therapy to the prevention or cure of diseases, reasoning that the sources which permit Jews to get involved in medicine in the first place only speak of using it for therapeutic purposes. I would imagine that Rabbi Golinkin would respond to the Talmudic source that Rabbi Rosenfeld adduces by maintaining that the source does not intend to announce law in the first place but rather only to give advice (or show how egotistical Rabbi Yohanan was). As an alternative, if it is to be construed as a legal precedent, it only permits people to look at images of, or imagine, the qualities they wish in their child, not to change nature to accomplish their end.

Certainly, the way Jews read such sources and the way Jews contemplate the eugenic possibilities of genetic engineering must be both colored in our day by the cruel Nazi experiments which were ostensibly for the same goal. Those experiments make it vividly clear that while some changes in human genetics are undoubtedly therapeutic, others raise troubling questions about the criteria for judging what constitutes a good change.[57] If it becomes possible to treat or reverse the BRCA1 mutation linked to cancer, every rabbi, I take it, would con-

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55. *Babylonian Talmud*, Berakhot 20a; *Babylonian Talmud*, Bava Mezia 84a. This is a Jewish version of Roman eugenics, for, according to the Talmud, the Roman notables used to hold beautiful figures while engaging in sexual relations. *See* Rosenfeld, *supra* note 54, at 407 n.3. *Cf. Babylonian Talmud*, Gittin 58a. *See also Numbers Rabbah* 9:34 (ascribing the fact that an Ethiopian couple produced a white child to their house having white figures in it). On analogous procedures involving animals, see *Torah*, Genesis 30:37-40 and *Babylonian Talmud*, Avodah Zarah 24a.

56. *See* Rosenfeld, *supra* note 54, at 403.

57. *See generally* GEORGE J. ANNAS & MICHAEL A. GRODIN, THE NAZI DOCTORS AND THE NUREMBERG CODE: HUMAN RIGHTS IN HUMAN EXPERIMENTATION (1992).

strue that as Jewishly legitimate. However, careful lines must be drawn and clear criteria formulated to define proper usages of this technique. Likewise, we must at all costs avoid improper or even monstrous usages.

The second legal question and the theological question posed above are related: if we change not only this mutation, but the germ line of all present inheritors of BRCA1, have we stepped over the line between our legitimate powers to cure and changed ourselves into virtual gods, or are we simply and legitimately preventing disease more effectively? I do not know of any rabbinic responses directly on point, but I would imagine that, given the principles described above, Jews would permit germ line changes only if they were clearly therapeutic according to a clear definition of what constitutes a disease and what does not. In other words, the more powerful our abilities to intervene in preventing genetic diseases, the more urgent it becomes that we accomplish the philosophical and moral tasks described in the last paragraph.

As we learn more ways to change human genetics, some ancient theological images come increasingly to mind. Are we Prometheus in trying to steal the fire from the gods, or the people of Babel trying to build a tower to heaven, or are we God's covenanted partners who were entrusted with the world "to work it and guard it," as the Bible says in the Garden of Eden story?[58] Drawing these lines and reinterpreting these ancient stories will become more and more the surprising, but critical, subject of medical ethics.

58. *Torah*, Genesis 2:16.