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I am submitting herewith a dissertation written by Toby Lee Fey entitled "Technology and Tradition: Jewish Bioethics in the Age of Genetics." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements of the degree of Doctor of Philosophy, with a major in Philosophy.

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TECHNOLOGY AND TRADITION:
JEWISH BIOETHICS IN THE AGE OF GENETICS

A Dissertation
Presented for the
Doctor of Philosophy
Degree
The University of Tennessee, Knoxville

Toby Lee Fey
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wish her, and all of my friends, happiness, love, and success in whatever arena they so choose.

ABSTRACT

The thesis that I defend in this project is that utilizing a care ethic is helpful in understanding the decisions reached by the observant Jewish community regarding medical care and the influence of genetics on those decisions. Previous analyses, as forms of "traditional" Jewish bioethics, have focused exclusively on the religious laws and principles that determine right action for this group. But it seems to me that identifying other patterns and core elements specific to this group will further illuminate and clarify the decision-making process. Specifically, the importance of relationships, especially family, is a pattern that must be addressed when analyzing the concerns of this community. Refocusing the discussion on relationships, on the "web of interconnectedness" that joins all the members of this community (and these members to other communities as well) will allow us to both make sense of some disparate decisions regarding genetic screening and information, and will allow us to make predictions about future responses this community might make. Hence, in order to understand or even predict the responses that this community will have to issues involved with genetic screening, we will need to understand the application of the relevant religious laws and principles in terms of the community's emphasis on family relationships. I discuss three particular diseases that have a genetic component, Tay-Sachs Disease, breast cancer, and colorectal cancer, in order to demonstrate the traditional approach and its shortcomings. I will show that augmenting traditional

Jewish bioethics with an ethic of care is actually not a new element, but instead describes the process that has been occurring all along.

PREFACE

Judaism is more than a religion; it is a culture, a tradition, a people. The rich history shared by the members of this community binds them together, as do the rituals that have evolved to remember and sanctify those events. Jews fast on the anniversary of the destruction of the Temples and rejoice on the day the Persian king spared the lives of his Jewish subjects. None of these celebrations or lamentations are conducted in private; rather, Jews gather with family and friends in times of joy as well as in times of grief. The celebration of Passover is commemorated by a glorious feast where, together with family and friends, Jews recount the story of God's wonders in Egypt. And at the loss of a loved one, a formal period of mourning for seven days is observed, during which time those whose lives the individual has touched come by to console and to grieve with the family. Even at the most personal holiday, Yom Kippur, where Jews must individually atone for their sins and ask for forgiveness from both God and those whom they have hurt, they assemble together with their community in the synagogue, in recognition that each individual is about the same task.

They pray together, laugh together, cry together, and live together.

It is this notion of togetherness, of community, which is so fundamental to understanding the Jewish people. It is a shared history, but it is so much more: shared work, shared worship, shared life. In this interconnected community, what happens to one happens to all. A death in one family means a meal preparation and a *shiva* call

for another. The birth of a son to a young couple means attendance at a *brit milah* for all.

Nothing in this notion of community and interconnectedness changes when we shift our focus to the medical sphere. Rather, any medical decisions made by members of this community are affected by this interconnectedness. Clearly principles and religious obligations will play a role in determining what the right action is for this group of people, but so will the emphasis on family and community. Only by understanding this background can we make sense of the choices made in a medical context.

For the purpose of this project, I am interested in analyzing a specific area in the medical realm, that of advances in genetic medicine. Concentrating on genetic medicine will allow us to see the influence of this phenomenon of interconnectedness even in the newest, most advanced medical fields. As we as a society move increasingly towards using genetic technologies, we are faced with a growing number of questions in relation to the use of those innovations. Questions about who to screen and when to screen, in addition to ascertaining what we should be screening for, are surpassed only by those questions that ask us to evaluate what indeed we plan to do with the information that these procedures produce. I will begin this project by looking at the moral questions regarding genetic testing and screening as generally understood. To that end, I will give a brief analysis of issues such as what knowledge is gained from genetic tests, who is and should be privy to that knowledge, what risks

are associated with such testing, who is affected by the decision to undergo or not undergo testing, etc. An important focus will be on the risks associated with the information-gathering aspects of genetic screening, since issues of privacy and confidentiality, as well as other corresponding duties of health-care workers, have become increasingly relevant. Another important point will be to recognize that issues will be framed differently in different contexts or from different perspectives.

In order to narrow down these issues, I will concentrate on a specific example of each of three different kinds of genetic traits. The overarching issues previously discussed will apply to all of these traits to varying degrees, and yet the differences among these traits will become important later in the project. I will begin by looking at Tay-Sachs disease, which is important for two major reasons. First of all, Tay-Sachs results in certain death of those affected. The cause of Tay-Sachs is relatively well understood by scientists, but a cure is not yet available. The disease is apparent from early on in life, and typically causes great anguish not only to the child suffering but to her family and support system as well. The second reason why Tay-Sachs disease is particularly important for this analysis is because this is an instance of a vastly successful screening program; hence it may give us some clues to help us duplicate the success for other traits.

The next trait I will discuss are the two prominent genes associated with breast cancer, known as BRCA1 and BRCA2. By no means does the presence of a mutation in one of these genes result in certain death, as is the case with Tay-Sachs disease.

Rather, the presence of one of these mutations indicates that the patient has an *increased susceptibility* to developing breast cancer. It is estimated that 1 in 8 women (12% of women in the population) will develop breast cancer in their lifetimes, but only 5-10% of those cases are inherited.[1] The major risk factor for breast cancer is simply age; 80% of breast cancers develop in women over the age of 50. However, of the 5-10% of cases that are of the inherited variety, researchers estimate that 30-70% of those cases develop because of mutations in either BRCA1 or BRCA2. These mutations do alter the woman's risk for developing cancer, as 50-85% of the women with these mutations will develop breast cancer. So although having a mutation in one of these genes increases a woman's susceptibility to developing breast cancer, it is still possible that one might have these mutations and never develop breast cancer at all. Hence, there is little certain knowledge that is gained from the information that one of these mutations is present or absent in the patient. The wrinkle that gets added to this story is the variable success of prophylaxis; some women with these mutations have substantially reduced, but not eliminated, their risk of developing breast cancer by having bilateral radical mastectomies. Hence, the overarching issues about screening (who to screen, when to screen, etc.) and about the use of information will be relevant here, as will the health professionals' obligations regarding privacy and confidentiality.

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[1] All of this subsequent data are from Fact Sheet 3.62 of the National Cancer Institute, June 30, 1999. <http://198.77.70.12/3_62.htm>.

A final interesting genetic trait will be one that falls between the above two cases -- something that does not lead to certain death in affected patients, but something that is more than a susceptibility trait. We may have found such a trait in recently discovered colon cancer genes, where the prevalent mutations may not be as penetrant or as lethal as in Tay-Sachs, but also may give affected patients a greater degree of risk than the susceptibility of BRCA1 and BRCA2.

There is, of course, another reason why these three traits have been selected. These traits all are particularly prevalent in the Ashkenazi Jewish community. For example, 2.5% of those of Ashkenazi Jewish descent will have a mutation in the BRCA1 or BRCA2 gene, as compared to 0.1% in the general population. There are both scientific and social reasons for this: this is a community that has predominantly married and procreated amongst itself, so any mutation that may have been introduced into one or a few members gets propagated throughout the masses. But in addition to the prevalence of these traits, this is also a community that has certain religious beliefs and traditions that will be interesting to analyze in terms of the genetic traits that affect them. For those within this community who are observant to the tenets of Judaism may face some challenges when making decisions about genetic screening. There seem to be conflicting duties to heal the sick and preserve human life, on the one hand, and perhaps to refrain from interfering in God's domain or to respect the sanctity of procreation on the other. Indeed, by exploring the values and priorities held by this community we will be able to understand just where the tension lies. In order to

facilitate that analysis, in chapter three I will discuss how the scholars in Judaism have approached information about new reproductive technologies. There is some agreement about the acceptability of procedures such as in-vitro fertilization (IVF) and artificial insemination (AI), and that seems to be relevant here. A discussion of the Jewish views on abortion also seems pertinent, as this will clearly relate to the relevance of the information gathered in such screening, for example, in the case of Tay-Sachs disease.

The overarching claim I wish to defend is that writers have misunderstood the rationale behind this group's acceptance or rejection of genetic screening. Only by looking at the decisions reached by this community in terms of a care ethic will we truly understand how and why certain conclusions are reached. This is because the care ethic allows us to adequately take into account the emphasis on family and community that is the backbone of this tradition. What I want to emphasize in the discussion of this community is the realization that there are *real people* who are being tested for these genetic traits: real people with families, with values, with lives and livelihoods. Weighty decisions such as these are not made in isolation. It is true that often authority figures in Judaism are consulted for guidance on these matters. But it is just as important to remember that this is a community that is really interconnected; decisions made are discussed with family and friends, and these decisions then have an impact for the whole community. The role of nurturing in this community is quite large; parents are responsible for ensuring that children grow up with a certain respect

for themselves, each other, and the sacred traditions of which they are a part. A decision about whether or not to be tested for Tay-Sachs, or whether or not to have a prophylactic mastectomy, is not and cannot be made in isolation between the patient and her physician. Rather, just as she relies on the community for support in raising her children and nurturing their spiritual lives, so does she rely on them for advice and support in making these sorts of decisions.

Hence, refocusing the discussion on relationships, on the "web of interconnectedness" that joins all the members of this community (and these members to other communities as well) will allow us to make sense of some disparate decisions regarding genetic screening and information. Previous analyses have focused exclusively on the religious laws and principles that determine right action for Jews. But it seems to me that to focus exclusively on the application of rules to a given situation is to miss a core element of this community: the importance of relationships, especially family. Hence, in order to understand or evaluate the responses that this community will have to issues involved with genetic screening, we will need to understand the application of the relevant religious laws and principles in terms of the community's emphasis on family relationships.

By analyzing the various priorities and values of the observant Jewish community and those of the medical establishment and science, we may be able to achieve some reconciliation of goals or to explain the levels of agreement or disagreement among those goals in terms of a differing focus: that of the care ethic.

Of course this will require an exposition of the care ethic itself, as well as a defense of why this is the appropriate framework to use for this discussion, both of which will be forthcoming.

One final note relates to my intended audience with this work. Part of what I hope to do here is to facilitate communication between three distinct groups: (1) the medical professionals who care for patients from within the Jewish community and who engage in the research that furthers the science; (2) the rabbis and authority figures from within Judaism who explicate traditional responses to these dilemmas and whose task it is to determine the (im)permissibility of engaging in new procedures; and (3) the observant Jewish community itself, whose members are to some degree committed to the tenets of Judaism and at the same time are confronted with the reality of the possibilities of genetic medicine. I hope that this work illuminates the decision-making process in a way that is useful to all of these groups. Families will find this to be a way to understand how their multiple allegiances – to Judaism and to each other – can be an asset in decision-making, rather than a hindrance. This work will benefit rabbis and authority figures in Judaism as it provides a way to describe their guidance process as one that is both richly informed and responsive to current medical trends. Finally, this project will be useful to clinicians and general practitioners who are often confronted with Jewish patients who are struggling with these kinds of dilemmas, or for individuals who are curious about how to reconcile apparently disparate goals and values. While the arguments offered here are likely too detailed to serve as a quick

guide for clinicians who need an immediate answer about how to approach an issue or a patient, this work will be helpful to providers who have some time to devote to the study of the issues discussed here.

Because I envision this work to have relatively broad appeal, I have written it in such a way that members of all of these groups should be able to understand the material provided. I do not assume in-depth familiarity with genetic medicine or Judaism, but instead assume the reader has a general familiarity with both of the concepts. Since the care ethic, unlike genetics or Judaism in general, is rarely discussed in popular culture, I do not assume that the reader has any familiarity with that whatsoever. I present enough detail of the ethic of care and of the other important claims to make this work able to stand alone, while suggesting other means of investigation if the reader has those correlative interests.

The purpose of this project is to offer a new way to think about issues linking Judaism to genetic medicine. Previously, scholars of Judaism have applied rules and principles or the notion of duties exclusively to determine the ethically correct or consistent choice, given a particular medical context and the values and priorities of observant Jews. What I hope to show is that these values and priorities themselves more naturally lead us to a care ethic, and in fact many decisions have, perhaps unwittingly, been made according to this theory in the past.

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CHAPTER ONE

INTRODUCTION

The recent announcement of the completion of the "rough draft" of the human genetic code has engendered much excitement in the medical field. Mapping the human genome promises to lend scientists and physicians new information useful for the treatment of illness and disease, as well as to give individuals a greater opportunity to understand some of the causal mechanisms that account for some of their constitution. As the role of our genes in determining our characteristics becomes clearer, the interaction between genetics and environment will be elucidated. Once we learn about the limitations of one, we will have more information about the influence of the other. This may lead to better interventionist strategies on the part of medicine, as researchers and physicians utilize this newfound knowledge of patient care.

While these developments in genetics are exciting and promising in terms of patient care, they are not unproblematic. Many aspects of the new genetic age raise ethical challenges. For example, the increased information that will become available to individuals about their genetic makeup will create related ethical issues in medicine. Genetic information about me, for example, has direct implications for my immediate family: knowledge that I carry the mutation responsible for Huntington's Disease indicates that my sister and brother are also at risk. Issues related to privacy and confidentiality are certainly not new with genetics, but now may assume a different form. Patients may be interested in keeping such information private for a variety of

reasons, and yet there may be an obligation to disclose this knowledge to those whom it affects so that they can seek treatment, make plans, etc; family members may, in fact, have a right to this information. Hence, the arguments regarding disclosure of information may in some way parallel the discussions regarding transmission or risk of communicable diseases like tuberculosis or even HIV infection, where the safety of potentially affected individuals may override the individual patient's right to privacy. Granted, the parallels will not be exact, but "social risk," I would argue, may be interpreted in a number of ways. Depriving individuals of their liberty because of considerations of others is a social issue, and has features that may parallel the deprivation of liberty that is justified in other areas of health care.

There are other interested parties regarding such information, specifically third-party payers, for whom genetic information may mean something entirely different. Insurance companies may exclude coverage for certain disorders for which genetic screening is available on the basis of it being a "preexisting condition," regardless of the fact that the individual may be asymptomatic.[2] Alternatively, such organizations may raise the premiums of those who are found to carry a genetic mutation on the grounds that they may elevate the cost of the plan.

Genetic discrimination is not limited, of course, simply to the realm of paying for medical care. Employers, despite legislation to the contrary, may find some way to discourage hiring individuals who carry genetic predispositions to certain traits for

fear that this may, at some point, impact the individual's job performance or – again, the financial consideration – it may cost the employer more to provide health care for her employees on account of this information. Perhaps public schools will begin using genetic information to group students according to ability very early in their educational career, rather than waiting to sort them according to demonstrated ability later in life. We already see some movement in this direction, as we test children before they enter kindergarten to see if they "qualify" for special programs. Imagine how much easier – and less subjective – this would be if it could be accomplished by simply analyzing a blood sample.

Apart from these considerations is the question of how the information itself benefits certain individuals. Certainly the information may assist researchers in developing cures and interventions for certain diseases, for example, by identifying candidates for a clinical trial. That is, individuals who may not have known they were genetically predisposed to a particular disease, or who would be victims of a late-onset disorder, might be identified through such a process. If experimental (preventative) therapy was in trials, then, these individuals would seem to be good candidates for it.

The use of the information for particular individuals seems less clear. Knowledge that an individual carries a certain lethal allele may encourage her to make different reproductive decisions than she otherwise would. And knowledge that one

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[2] See Mary Briody Mahowald, *Genes, Women, Equality* (New York: Oxford University Press, 2000), 196-197.

has a genetic predisposition or susceptibility to a particular affliction may increase her vigilance for signs of the development of the disorder. But since at present there are few genetic diseases for which cures are available, and limited treatment interventions for many others, the benefit of receiving such information is debatable. There has been some limited success with gene therapy – in cases of ADA deficiency, for example – but the best "therapeutic" option available for most genetic disorders is the prevention of their transmission by altering reproductive choices. Even when there are such choices, often the side effects are sufficiently bad to warrant an individual to make a real assessment of her risk prior to proceeding with therapy. Hence, the intervention that is possible is problematic.

On the other hand, many would argue that simply having this information is important: knowing that my reproductive options ought to be limited is significant. Yet with this information may also come psychological stressors: knowing that one has a higher susceptibility to breast cancer may be more of a burden than a benefit, given the limited therapeutic options available. The opposite is possible as well: some individuals find relief in "simply knowing" their specific genetic risk. Similar problems arise with screening for other sorts of genetic traits: suppose the man I want to marry is a carrier for trait X, like me. Since I am opposed to abortion and desperately want children, does that mean we should refrain from marriage? Should we adopt? Should we chance it?

It is at times such as these, in instances of indecision regarding real moral dilemmas, that individuals may turn to their spiritual guides to assist them in making tough choices. Deciding whether or not to undergo genetic screening and what to do with the information garnered from such procedures are issues that must be addressed. It is at times of such uncertainty when religious affiliations enter the discussion. Many religions have weighed in on issues in medical ethics (the abortion debate is particularly noteworthy for such participation), and in light of the new challenges raised by genetic medicine, it seems likely that sources of authority will weigh in on the debates at hand.

Studying the interplay between medical decision-making and Judaism specifically will be particularly interesting for a number of reasons. Since Judaism is one of the world's oldest religions, it is illuminating to study the ways in which ancient Jewish texts and sources are utilized by contemporary thinkers to directly address the ethical challenges that arise out of advances in medicine. In the field of genetics, however, Judaism becomes particularly interesting. A specific group of Jews known as Ashkenazim, who trace their ancestors back to eastern Europe, have been found to be carriers of the mutation responsible for Tay-Sachs disease, an affliction that results in early death of children born with two copies of this gene. Recently researchers also identified three specific mutations responsible for a genetic susceptibility to breast cancer that has a high incidence in this particular population. As many genetic traits are concentrated in specific populations (for reasons to be

explained later), understanding certain aspects of the decision-making process for specific groups of people will be quite useful. And since this particular religious tradition has specifically addressed the issue of genetic screening regarding one of these traits, this is an excellent place to begin our discussion of genetics. Hence, this community is a particularly rich one for study.

Underlying the discussion in the subsequent chapters is an understanding of the actual practice of individuals. That is, just as I am concerned about the new challenges that advanced medical technology has presented for Jewish medical ethics, I am also concerned about how contemporary Jews work an understanding of Jewish legal prescriptions into their daily lives. Hence, I will not focus on theoretical applications of principles and rules, but rather on actual practice. An analysis of the practices of members of this community has led me to conclude that the traditional schema cannot stand alone. Instead, for this group, the most consistent ethic in the age of genetics is one that combines the traditional approach with an ethic of care. This is the thesis that I will defend in this project.

The remainder of this chapter serves as an introduction to the issues and themes that I will discuss at greater length in the subsequent chapters. In chapter two I focus on three specific genetic diseases – Tay-Sachs disease, breast cancer, and colorectal cancer – and I identify some general ethical issues involved with each one. This helps to set up the problem for Jewish bioethics by indicating the issues that a framework for decision-making must address. In chapter three, I detail the rules and

principles in Jewish bioethics that relate to the issues I suggested in chapter two in order to accomplish two things: (1) to demonstrate how issues in medical ethics have been addressed in Judaism, and (2) to extrapolate about how scholars could consistently apply this reasoning to the genetic issues that were introduced in chapter two. At the end of that chapter, I discuss why the traditional approach is unsatisfactory. Chapter four contains the heart of my argument, where I describe and defend two claims: (1) the care ethic is an appropriate orientation for this group, and (2) the care ethic is a better decision-guide than traditional Jewish bioethics. I then make some suggestions about how to incorporate a care ethic with the traditional principled approach. Hence, I defend a care ethic as an important element for moral decision-making for members of the committed Jewish community, and also suggest that neither it nor traditional Jewish bioethics ought to stand alone as a decision guide. Finally, in chapter five I analyze the values and priorities of those who would be affected by my suggestions, and compare those to the values and priorities that come out of genetic medicine.

Jewish Medical Ethics: Past and Present

It will be illuminating to ascertain how discussions of Jewish medical ethics occurred prior to the advent of genetic information in order to understand how individuals involved in moral quandaries were aided by consultation with Jewish sources. Prior to the middle of the twentieth century, discussions in Jewish medical ethics proceeded along the same lines as other matters that required textual

interpretation; medical ethics was not a discipline of its own, but was rather another facet of the complex intellectual culture. Judaism is a tradition with a certain reliance on authority, both for scriptural interpretation and spiritual guidance. Jews rely on three major texts for guidance. First there is the Torah, which comprises the first five books of The Hebrew Bible, and contains the Decalogue and other important laws and regulations by which Jews are to orient their lives (e.g. dietary restrictions). Then there is the Mishna, which "is both a law code and textbook, collecting together the orally transmitted teachings and legal traditions…." An important source in Judaism is what as known as the Talmud, which is a "commentary on, and supplement to, the Mishna."[3] There are also collections of codes of law – the most complete and famous of which is the *Shulkhan Arukh* – which specify the legal requirements for proper Jewish living.

In addition to these texts, Jews rely on rabbis, learned in both law and tradition, to interpret the works, as well as to guide passage through these difficult texts to the relevant *midrashim* (stories or parables) or *halakha* (law). These stories are found in the texts previously mentioned, and have been interpreted by various authorities. Hence, the rabbis do take into account the ways in which their predecessors understood the passages and stories, and how subsequent rulings were made. It is from this process that precedent is formed, much like in a secular court of law. The

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[3] David J. Goldberg and John D. Rayner, *The Jewish People* (New York: Penguin Books, 1989), 84.

rulings that the legal experts hand down become part of the source material the next time a similar case arises. That is not to say that the rabbis always follow the guidance given by other rabbis, however. In fact, some famous debates emerged from instances where two different rabbis interpreted the same passage differently,[4] and such dissent is how new precedent emerges. However, the interpretations offered and the rulings set by the rabbis previously are considered by contemporary sources, whether or not they are accepted.

These ancient religious laws and customs deal not only with medical ethics, of course, but with all facets of Jewish life: "…kosher food laws, business dealings, marriage, divorce…"[5] etc. And so the questions with which the rabbis were entrusted were answered in the same way: according to religious law, precedent, and ritual or custom. Problems or questions were addressed on an individual basis, where the learned individual would consult the sources for the relevant laws and precedent about a specific question, and make decisions from there. This system operated for thousands of years – well before bioethics emerged as a unique academic discipline.

The change to a separate – but perhaps not entirely separable – discipline apart from other issues in Judaism occurred when Immanuel Jakobovits wrote his doctoral

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[4] See the discussion of abortion in chapter 3 for an example of this.
[5] Velvl Greene, "Ethical Issues in Community Health," in *Science in the Light of Torah*, ed. Herman Branover and Ilana Coven Attia (Northvale: Jason Aronson Inc., 1994), 149.

dissertation on the subject of Jewish medical ethics. Its publication in 1959[6] signaled an important milestone in the field: for the first time, an authoritative work, including relevant history as well as law and doctrinal interpretation, presented the traditional Jewish perspective on ethical issues in medicine.[7] In this work, not only does Jakobovits offer an overview on the Jewish perspectives on health and medicine, but he also catalogued positions on specific topics such as abortion, euthanasia, and palliative care.[8] Subsequent to the publication of this treatise were a number of other forays into Jewish medical ethics, in both monograph and article forms, which attempted to augment and modify Rabbi Jakobovits' work.

As the field of bioethics emerged in the secular sphere in the 1970s, the study of Jewish medical ethics was also coming of age; Jakobovits' book had its second printing in 1975. The new edition included a section on "recent developments in Jewish medical ethics," in which he discussed issues of contraception, organ donation, and human experimentation, among others. 1978 saw the publication of *Contemporary Jewish Ethics* edited by Menachem Marc Kellner, and in the next few years many other books were published in this new field.[9] In addition, books devoted to specific areas of interest within this larger discipline became common. Jakobovits

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[6] Immanuel Jakobovits, *Jewish Medical Ethics* (Bloch Publishing Company: New York, 1959).
[7] Yoel Jakobovits, "Lord Immanuel Jakobovits," in *Pioneers in Jewish Medical Ethics*, ed. Fred Rosner. (Northvale: Jason Aronson Inc., 1997), 131-133.
[8] Immanuel Jakobovits. *Jewish Medical Ethics*. Bloch Publishing Company: New York, 1975.

himself refers to David M. Feldman's *Birth Control in Jewish Law* (1968).[10] In 1983, the *Journal of Medicine and Philosophy* devoted the entire August issue to "medical ethics from the Jewish perspective," and the 1980s saw a huge proliferation of texts in this area (especially noteworthy are David M. Feldman's *Health and Medicine in the Jewish Tradition*, 1986, and, in the same year, Fred Rosner's *Modern Medicine and Jewish Ethics*, 1986). The trend towards specialization also flourished in the 1980s, where Fred Rosner, for example, authored a number of articles in the specific areas of genetics and new reproductive technologies.[11] There were also many articles that appeared in religious (as opposed to strictly academic) journals on these subjects, as well as the material published in Hebrew rather than English. Suffice it to say, then, that the field that Rabbi Jakobovits pioneered has developed into a rich and complex area of study.

In the recent *Pioneers in Jewish Medical Ethics*, Fred Rosner identified four specific individuals who helped shape the field of Jewish medical ethics. It is useful to spend some time describing the work of these individuals to demonstrate how scholars in the field of traditional Jewish bioethics have focused their time and energy.

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[9] See the preface (specifically p. xi) of Fred Rosner, ed. *Pioneers in Jewish Medical Ethics* (Northvale: Jason Aronson, Inc. 1997).

[10] Immanuel Jakobovits, *Jewish Medical Ethics*, enl. ed. (New York: Bloch Publishing Company, 1975), 252.

[11] See Fred Rosner, "Test Tube Babies, Host Mothers and Genetic Engineering in Judaism," Tradition 19, no. 2 (Summer 1981): 141-148; Fred Rosner, "Medical Genetics: The Jewish View," The New York State Journal of Medicine (August 1982): 1367-1375 for examples.

These individuals have all been influential in the field, and hence even a brief description of the history of Jewish medical ethics would be incomplete without an account of them. A more detailed account of some of their specific rulings will be discussed in chapter three.

First among these pioneers is Rabbi Moshe Feinstein, the predominant scholar in America in this field. He spent most of his life in the United States as the head of Yeshiva Mesifta Tiferet Jerusalem in New York.[12] Some of Feinstein's more noteworthy contributions were the definition of death as the cessation of brain stem function and the (correlative) argument for the permissibility of organ donation.[13] Also, Feinstein was one of the few authorities who argued for the permissibility of artificial insemination with donor sperm (AID) from a gentile sperm donor, and he received much criticism for this opinion.[14]

Next among Rosner's pioneers was Rabbi Shlomo Zalman Auerbach, a life-long Israeli who sought little attention for himself but was nonetheless very influential to thousands of his followers.[15] He disagreed with Feinstein's definition of death, and instead proposed that a person was officially dead only when there was a complete and irreversible cessation of all brain cell activity. And since (at least at the time of this writing) we have no test to allow us to determine this accurately, organ donation is

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[12] Rosner (1997), p. 56.
[13] Ibid., 61-67.
[14] Ibid., 95.
[15] Ibid., 99-100, 125-126.

prohibited until such time as we are able to "…ascertain with absolute certainty the complete and irreversible cellular death of the brain."[16]

Immanuel Jakobovits (whom we already mentioned) was Rosner's third pioneer. Jakobovits was the Chief Rabbi of Ireland when he undertook his doctoral studies in Jewish medical ethics at the University of London.[17] Perhaps the noteworthiness of his work results from its historical approach and comprehensive nature. But just as interesting was his inclusive language and form. As Jakobovits' son, Yoel, wrote in Rosner's book, "My father's chief focus…[was] to proclaim Torah values in contemporary language and current frames of reference that are convincing and attractive to modern men and women, whether committed to Jewish practice or not."[18] Dr. Jakobovits stressed that his father intended his application of Torah values to medicine to be relevant "in their universal context, as well as in their more confined Jewish sphere."[19] So in addition to its comprehensiveness and its publication in English, one might argue that Jakobovits' inclusiveness also contributed to the large impact his work enjoys.[20]

Rosner's last pioneer was Rabbi Eliezer Yehuda Waldenberg, an Israeli who continues to write on the subject of Jewish medical ethics. He is the most prolific of

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[16] Ibid., 109.
[17] Ibid., 132.
[18] Ibid., 136.
[19] Ibid., 137.
[20] Ibid.

any *halakhic* authority, and his references are extensive.[21] Waldenberg deals with issues that have arisen in contemporary medicine in no less detail than the classical issues, and might be considered progressive by some regarding his arguments for the permissibility of abortion, for example, in certain situational contexts.[22]

The final chapter in Rosner concerns "contemporary specialists in Jewish medical ethics," where Dr. Nisson M. Shulman, who was the head of the department of Medical Ethics for Britain's Office of Chief Rabbi, gave a short biography of seven current pioneers who specialize in medical ethics. They are, in alphabetical order: Abraham S. Abraham, David J. Bleich, David M. Feldman, Mordechai Halperin, Fred Rosner, Avraham Steinberg, and Moshe David Tendler.[23] Each of these authors has multiple books and articles in the area of Jewish medical ethics, and each of them extensively refers to their contemporaries and predecessors for additional foundation in their work. With the exceptions of Abraham and Rosner, all of the contemporary pioneers are Orthodox rabbis, whose understanding of Jewish law and tradition extend far beyond the scope of medical ethics. Abraham and Rosner are both physicians, whose area of interest is the connection and tension between medicine and *halakha*.

Despite the proliferation of texts and the increased number of participants in the discussion, an interesting point to note is the similar approaches with which the authors discussed the topics in question. All seem to (in no particular order): (1) Get

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[21] Ibid., 165.
[22] Ibid., 179.
[23] Ibid., 203.

the relevant facts about the medical situation in as much detail as possible. (2) Determine what principle(s) and corresponding duty, obligation, or responsibility from *halakha* is (are) relevant to the situation. (3) Apply this principle to the situation at hand. But as previously mentioned, the tradition dates back long before Jakobovits' work. Rather, when a question about medical ethics arises, a rabbi will consult ancient sources and an expert in Talmud in order to make a practical decision. That is:

> …the Jew depends on a responsum from a qualified rabbi, one expert in Talmud, the legal codes, and the responsa that have been handed down over the generations. The Talmud provides the philosophical and theological foundations, the codes provide the legal systematics, and the responsa are the precedents. Based on these sources, a God-fearing *posek* (adjudicator) will derive a practical answer acceptable in Jewish law as a continuation of the *halakha* (law) that originated with the Almighty's instructions to Moses.[24]

From this process, we clearly see the individual nature of the discussion: first, a particular question will result in the rabbi searching out specifically relevant responsa and textual passages. Only with this background in hand will a rabbi advise the patient or physician about the ethically permissible course(s) of action. Furthermore, one should not underestimate the influence of this process. Greene states: "Halakhic decisions rendered by the unqualified are the equivalent of brain surgery performed by the untrained. In Jewish tradition, the responsa become a part of Torah and represent

[24] Greene, 149.

divine instruction."[25] Greene later suggests that it is precisely because of this import that most texts on Jewish medical ethics will include some disclaimer to the effect that the information covered should not be used in lieu of a discussion with a "qualified rabbi."[26]

Clearly, this process did not begin with our contemporary field of bioethics, and Greene acknowledges this history. He further argues, however, that "[a]fter centuries of responsa, certain principles can be derived."[27] Similarly, in the entry on "Judaism" he authored in the 1978 *Encyclopedia of Bioethics*, Rabbi Jakobovits argued that there are five fundamental moral or religious principles with which we are to assess dilemmas of a medical character: (1) the duty to preserve life and health; (2) the sanctity of human life; and principles concerning (3) the limits of life; (4) the generation of life; and (5) the conclusion of life.[28] These principles have developed from a combination of interpretation of ancient law and the precedent that previous interpreters have set. So, for example, by appealing to the principle of the sanctity of human life, we are to conclude that from a Jewish perspective, "…a physically or mentally handicapped life, in whatever state of debility, is worth no less than a full and healthy life."[29] This precept is presumably addressing the quality of life issues that so often come to the forefront when we discuss patients who have medical limitations of

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[25] Ibid.
[26] Ibid., 150.
[27] Ibid., 149.
[28] Immanuel Jakobovits, "Judaism," in *Encyclopedia of Bioethics*, Vol. 2, ed. Warren T. Reich. (New York: Macmillan and Free Press, 1978), 791-802.

some kind. Jakobovits argues that applying these principles and their accompanying duties and obligations will give us the ethically permissible action (or range of actions) according to Jewish law.

Other authors argue similarly. For example, when discussing the permissibility of using contraception, Rabbi Feinstein allows the temporary use of oral contraceptive pills when a woman has both a boy and a girl and "…would have a difficult time raising more children until the first two were somewhat older."[30] There are two *halakhic* principles applied in this case: the first is that since the couple already has a boy and a girl, they are considered to have fulfilled the commandment to procreate.[31] Secondly, since there will be no physical barrier to the husband's semen with the use of this method of contraception, it does not "…violate the prohibition of emitting semen for naught."[32] In this example, then, one requirement was fulfilled and another was not violated, so the action was deemed ethically permissible.

In his article on euthanasia in volume one of Rosner's *Medicine and Jewish Law*, Abraham S. Abraham begins by stating the three principles fundamental to understanding the impermissibility of the action: (1) We are only permitted to kill another human being when an innocent person is in mortal danger from a *rodef*, or pursuer. (2) Our body was given to us by God and it is His alone to take away. (3)

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[29] Ibid., 794.
[30] Rosner (1997), 91.
[31] David M. Feldman, *Health and Medicine in the Jewish Tradition* (Crossroad: New York, 1986), 70.
[32] Rosner (1997), 91.

Life is of infinite value.[33] After coming to an understanding of these principles, he applies them to the issue of active euthanasia and concludes that any such action is unequivocally forbidden according to Jewish law.[34] Again, the approach here is the application of *halakhic* rules or principles to a particular situation.

The Tragic Flaw: Individuals and Communities

It is precisely this approach that has been applied to issues of genetic screening, as is evidenced by the response from the observant Jewish community regarding Tay-Sachs disease.[35] The determinations of the requirements of the patient and the physician, as well as other relevant principles (such as the sanctity of human life) were applied to determine a morally correct course of action. It is the contention of this work, however, that despite its longevity, this method of moral reasoning is fundamentally flawed. One problem with this form of reasoning may be evidenced from the following case:

> Deborah Schwartz has been actively involved in her synagogue since early childhood. This involvement has taken many forms, with one major area of emphasis involving programs of health promotion. As a laboratory professional she has encouraged and assisted in the organization of blood pressure screening, diabetes detection, cholesterol checks, and general fitness evaluations. As a result of her efforts, a significant level of health consciousness has developed among members of the congregation.
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> Following the unfortunate death of a young child with Tay Sachs disease, the community health committee of the synagogue voted to

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[33] Abraham S. Abraham, "Euthanasia," in *Medicine and Jewish Law*, Vol. 1, Fred Rosner, ed. (Northvale: Jason Aronson Inc., 1990), 124.
[34] Ibid., 125-128.
[35] The history of decisions regarding Tay-Sachs disease in the Jewish community will be discussed in detail in chapter three.

> initiate a Tay Sachs screening program. This program was designed to offer testing to all pregnant women and all couples planning marriage. The discussions and vote on this program occurred while Ms. Schwartz was on vacation.
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> Upon learning of the plans for the screening program, Ms. Schwartz immediately began to raise questions. She learned that pregnant women with positive tests would be counseled to have abortions and engaged couples would be advised to avoid having children. Ms. Schwartz was philosophically against this component of the screening program.
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> With a personal family history of victims of the Holocaust, Deborah Schwartz was raised to believe in the sanctity of life and the need to preserve the Jewish faith through continual creation of new lives. This program was being developed in a manner that was the antithesis of her beliefs.
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> As a health professional, Ms. Schwartz supported the concept of all people knowing as much as is feasible about their own bodies and health. She could not, however, participate in a program that violated her religious beliefs. Her dilemma was whether to actively oppose the implementation of the program because of her uncertainty about which belief was of a higher order.[36]

The dilemma Ms. Schwartz faces is a common one: she is having difficulty understanding her role at the conjunction of multiple communities. She is simultaneously a member of the scientific community, the specific synagogue community, and the larger Jewish community. And as the values and priorities of one community conflict with those of the other(s), Ms. Schwartz finds herself not knowing what the morally right thing is to do. As a member of an observant Jewish community, she is concerned with how the Jewish legal rules apply to her situation. Yet her multiple community affiliations cause some conflict for her.

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[36] Case taken from Robert M. Veatch and Harley E. Flack, *Case Studies in Allied Health Ethics* (Upper Saddle River: Prentice Hall, 1997), 166-167.

I contend that the dilemma in this case arises from the network of relationships in which she is involved. As we are all multiply committed, her problem is representative of moral agents in general. The question seems to be one of balance; an assessment of the morally justifiable action must include an acknowledgement of the often contradictory tenets that we hold. A satisfactory moral theory will include a method by which consistency in our moral action can be obtained.

It is not clear that applying the traditional methodology of Jewish bioethics will adequately accomplish this goal. Ms. Schwartz is already familiar with many of the relevant principles and duties that relate to this case: in fact, it is those principles and duties that serve as the foundation of the problem, when combined with her fidelity to the tenets of the other communities. Any decision that Ms. Schwartz arrives at will inevitably affect others around her, and her deliberation must take this into account. The morally appropriate role of the individual in the community cannot be taken for granted here or in any other dilemma, and yet this is what the traditional approach seems to assume. Relevant duties and principles that have some bearing on the particular situation can certainly be identified and usefully applied,[37] but it is unclear that this application alone will suffice to form an action guide for moral agents.

Suppose that we change the case a little and now assume that Ms. Schwarz is not in doubt about the religious proscriptions. Even if it *were* clear to her that Jewish law prohibited abortion counseling, for example, there would still be limited courses of

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[37] The specific sorts of rules and principles will be specified in chapter three.

action available to her. She is deciding whether or not to "actively oppose" the implementation of the screening program. Even if she were successful doing so, this would likely not prohibit couples from getting screened; they would simply need to choose an alternative location or source. While I do not intend to underestimate the possible hardship involved in such a consequence, it is important to recognize that Ms. Schwartz's values will *influence* the community, but will be unlikely to *bind* the community to her priorities in any meaningful way. Fully informed individuals may choose to agree with her and hence curtail their options, but others may not. Part of determining her moral responsibility to the community might involve Ms. Schwartz engaging in such opposition in order to inform her fellow community members of the relevant Jewish law. The community members are then free to do as they choose: to abide by the legal principles, to seek more information, or to act in opposition to the law.

This problem of multiple commitments – social commitments as well as ideological ones – is not unique to the field of genetics, but it is brought into specific relief in this area. Consider somatic cell gene therapy, for instance.[38] Relevant duties of the Jew may include the duty to seek treatment, a physician's duty to heal, the

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[38] For review articles on the goals, procedures, and products of gene therapy, see W.G. Kerr and J.J. Mule, "Gene Therapy: Current Status and Future Prospects," *Journal of Leukocyte Biology* 56, no. 2 (August 1994): 210-4; J.H. Wolfe, "Recent Progress in Gene Therapy for Inherited Diseases," *Current Opinions in Pediatrics* 6, no. 2 (April 1994): 213-8; I.M. Verma and R.K. Naviaux, "Human Gene Therapy," *Current Opinions in Genetic Development* 1, no. 1 (June 1991): 54-9.

sanctity of human life, etc. But the (im)permissibility of gene therapy must be considered on a more fundamental level: on the level of what it is to be a person. It is clear that Jews reject the notion of genetic determinism, but it does not follow that changing our genes has no effect on our identity whatsoever. Perhaps the larger concern is with the issue of personal identity, as gene therapy may alter something essential to us. If the discussion moves then to germ-line gene therapy, as is often the case, the issues become even more complicated since changes in the germ cells will be passed on to future generations. Jews are commanded to continue the work of creation with their Creator in the making of children, and this principle has led many sources to discuss the permissibility of some forms of assisted reproduction. When coupled with our duty to heal, a case could be made for supporting such a practice.[39] Yet the implications from such action are far from clear: we are participating in creation in a way we have never been able to before.

Few would question the assertion that the community is the fundamental unit in Judaism.[40] Because of this, an individual's actions must be considered in light of the effects such an action may have on others around her, as well as regarding the

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[39] …that is, once the techniques are sufficiently perfected. For a sampling of the literature on the Jew's participation in medical experimentation, see : Laura Jane Bishop and Mary Carrington Coutts, "Religious Perspectives on Bioethics, Part I," *Kennedy Institute of Ethics Journal* 4, no. 2 (1994): 155-183; Immanuel Jakobovits, "Jewish Medical Ethics--A Brief Overview," *Journal of Medical Ethics* 9, no. 2 (June 1983): 109-12; Fred Rosner, "Human experimentation and Clinical Trials," *Israel Journal of Medical Science* 31, no. 9 (September 1995): 580-2.

[40] …unless, of course, it is by those who claim that the family has primacy. But since the family is, after all, a special kind of community, the point still stands.

implications that those decisions may have for others. It is not clear that the applications of principles and duties alone will serve as sufficient action guide in the face of genetic medicine. The requirements that we have to others, as well as the acknowledgement that we are all fundamentally related to others, is a complexity of life that an ethic composed exclusively of principles and rules fails to appreciate. This claim will be further explored in chapters three and four.

The paradigmatic cases that serve as the cornerstone of casuistry and find similar company in Jewish bioethics are also of little help, since there are no precedents based on contexts alike enough in kind to the debates about genetics. The cornerstone of casuistry is the creation of a "moral taxonomy" of similarities and differences among cases.[41] With the advent of genetic medicine, the morally relevant features of the situation create a preponderance of differences without accompanying similarities. Hence, there are no relevant precedents to serve as a guide to moral decision-making.

Of course, an objector might argue, there has to be a starting point; new precedent is created by making decisions in uncharted territory. It is unclear, however, that Jewish bioethics contains within it enough of a framework to make such assessments. The moral question in these particular cases is not, as Jonsen and Toulmin remark,[42] a debate about the universal principles; everyone might agree that

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[41] Albert R. Jonsen and Stephen Toulmin, *The Abuse of Casuistry* (Berkeley: University of California Press, 1988).
[42] Jonsen and Toulmin, 6-7.

the Jewish physician has a duty to save a life. The moral question comes in applying those principles to the particular situation. The woman faced with a decision on whether or not to undergo genetic screening for the genes responsible for certain types of breast cancer does indeed have a responsibility to the community to consult the relevant sources for guidance to be sure that she understands the traditions and customs of the group. Yet she has other responsibilities as well, it seem. Her responsibilities to her first-degree relatives, who may also gain information about their own health from the information that she receives, may conflict with her right to keep information about her health private. Her responsibilities to those she cares for and to those who care for her who may also be impacted by this information, as she may choose actions based on this information that otherwise would not appeal to her, etc.

It seems to me that it is here that we must assess the responsibilities that the community has to the individual: to respect her autonomous decision making, to support her in the decision she makes, and to serve as a resource for the process. The biggest challenge that faces the traditional approach to Jewish bioethics is that it does not capture the web of relationships that is so central to Judaism: it takes the community and the family as primary, but fails to appropriately consider the moral agent's role in such a capacity. What I am alluding to here is an internal contradiction within Jewish medical ethics: Judaism views the family and community as a priority, and yet fails to carry this priority through in its decision guides. A further analysis of the values and priorities of the community will help to make this clear, and this is the

task I undertake in chapter five. Regardless, it seems that what Jewish bioethics needs, is a way to capture this focal element of the Jewish tradition.

Reconciliation: Caring and families

Throughout this work, I will argue that by incorporating an ethic of care and responsibility, where families and relationships (communities) are considered as part of the process of moral reasoning, a Jewish bioethic can indeed be sustainable in the genetic age. Much of the debate surrounding issues of genetics occurs precisely because of the connectedness of the information (information about my health may give me unwanted information about my sister's health as well), and recognizing this in the course of deliberation will augment the precedent and principles and serve as a more useful action guide for the contemporary patient. I will argue that the two approaches should be combined, and in chapter four I suggest both the grounds for such a combination as well as a model for their incorporation.

Briefly put,[43] an ethic of care has both a different starting point and a different methodology from that of traditional Jewish bioethics. As previously mentioned, the role of the rabbi in decisions of medical ethics is to apply the appropriate principle(s) from the myriad of sources to facilitate decision making for the problem at hand. Selecting the appropriate principle or duty and/or adjudicating among conflicting duties are the modus operandi. These principles, of course, originate from the sacred texts, traditions, and precedents that have been established over time by the sages.

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[43] A detailed discussion of care ethics can be found in chapter four.

An ethic of care and responsibility, on the contrary, derives its origin from a realization that "…morality arises from the experience of the relationship."[44] The relationship referred to here may be any one of a number of relationships in which we find ourselves: that of a family member, a neighbor, a teacher, a friend. In fact, in her well-known discussion of care ethics, Carol Gilligan claims that "…morality lies in recognizing connection" among individuals, and that "…morality…[is] contingent on sustaining connection."[45] It is this focus on "…keeping the web of relationships intact" that serves as the foundation for morality.[46]

What is present in relationships and yet lacking in principle-based ethics, often referred to as ethics of justice, is the "relation of natural caring" that is the hallmark of relationships.[47] One cares for others and is likewise cared for by the recipient, so that the exchange is mutual. This is not to say, of course, that the exchange must always be equal, as can be seen in the paradigmatic relationship of friendship. Sometimes our friends need more from us and sometimes we need more from them. Regardless, being a friend involves both caring and being cared for. The same is true for the parent-child relationship: inherently unequal relationships also include both caring and being cared-for. "Our motivation in caring is directed toward the welfare, protection,

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[44] Carol Gilligan, *In A Different Voice* (Cambridge: Harvard University Press, 1982), 57.
[45] Ibid., 59.
[46] Ibid.
[47] Nel Noddings, *Caring: A Feminine Approach to Ethics and Moral Education* (Berkeley: University of California Press, 1984), 4.

or enhancement of the cared for….To act as one-caring, then, is to act with special regard for the particular person in a concrete situation."[48]

In order to do this, of course, the one-caring will need a precise and detailed accounting of the actual situation at hand. Only by understanding what is truly at stake in the dilemma will the one-caring be able to make a decision that preserves the crucial relationships. Hence, the importance of a "sensitivity to contextual detail" cannot be underestimated.[49] Such attentiveness to detail is in some senses lacking in a principle-based ethic such as traditional Jewish bioethics. Context may be important in the initial recounting of the moral problem, but soon afterwards the moral question is "boiled down" to a (series of) rule(s) or principle(s) as interpreted from the ancient sources. In the traditional schema, it is the task of the rabbis to identify the rules and principles that apply to the situation that will serve as guidance for the patient. Ascertaining according to which principles the individual is required to act or refrain from acting is the extent of the guidance offered.

I contend, however, that in the observant Jewish community, whose primary unit and focus is the family, that such context is crucial for decision making. Given the focus on the family, from which many claim we first experience caring, it seems to me that in order to provide an appropriate action guide for individuals, Jewish bioethics must take account both of this relationship and this affective response, as it is

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[48] Ibid., 23-4.

from here that ethical behavior is derived.[50] Being in a family where we not only experience caring ourselves, but also witness caring for others, we learn about appropriate modes of behavior. This is why society blames the family when troubled children do not seem to have learned "right from wrong" or "know how to act" in public: because an important function of the family has not been fulfilled. Recognizing the feelings we have for one another, and gaining the ability to decide on appropriate outlets for those sentiments, is the beginning of moral education.

It is important to be clear here: I do not contend that the family or larger community is completely missing from current patterns of Jewish bioethics. On the contrary, one striking feature of this perspective is its inclusive nature: neighbors are considered more than friends, but as brothers. Yet by focusing exclusively on the duties of individuals (physicians, patients, and others) in order to determine the appropriate course of action in a medical context, important moral insights are ignored. Furthermore, while a woman may have duties to God, to herself, and to her family, there does not seem to be a clear way to adjudicate between these conflicting duties from the traditional perspective. This problem with adjudication is characteristic of principled approaches generally.[51] In fact, often the priority that the authority figures place on these duties may conflict with the priorities that the woman

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[49] Marilyn Friedman, "Care and Context in Moral Reasoning," in *Women and Moral Theory,* ed. Eva Feder Kittay and Diana T. Meyers (Savage, MD: Rowman and Littlefield, Inc., 1987), 200.
[50] Noddings (1984), 3.
[51] Jonsen and Toulmin, 7.

herself gives to the varying roles in which she participates, and hence may lead to heightened moral conflict rather than resolution.

An ethic of care, on the other hand, treats these important relationships – the relationships with family, with friends, with those for whom we care – as primary. It recognizes that the dealings we have with one another profoundly influence the choices that we make and, in some sense, serve as the justification for such decisions.[52] "What we do depends not upon rules, or at least not wholly on rules – not upon a prior determination of what is fair or equitable – but upon a constellation of conditions that is viewed through both the eyes of the one-caring and the eyes of the cared-for."[53] The decision about whether or not to be screened for a breast cancer mutation has implications for my family as well as for me, and this must be part of the decision-making process. A care ethic will avoid the need for higher-level adjudication that is a problem for principles because of the differences in priority: the right action to perform is the one that, on balance, seems to preserve or maintain relationships. There are no rules that might conflict. There is, however, a possibility for conflict in the schema that I suggest: one might envision a course of action that is justified by care ethics might be prohibited according to Jewish law. In chapter five, I argue that such conflicts can be resolved by both appealing to the level of commitment of an individual and by understanding the fundamental notions that the principles of Jewish bioethics preserve.

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[52] This claim will be justified in chapter four.

The emergence of new genetic technologies is truly a double-edged sword: it gives us new tools by which to plan our lives and our futures, and yet brings with it new dilemmas for which there are no easy answers. Only by employing a form of moral reasoning that similarly encompasses the complexity of actual life will these dilemmas be able to be addressed adequately, and augmenting traditional Jewish bioethics in this way does just that.

Limitations and Definitions: A Particular Community

Not every Jew-as-patient or Jewish family, however, will be discussed in this work. As was previously mentioned, when a question of medical ethics arose, rabbis dealt with it in a very individualistic manner. But as the tradition continued, certain principles were derived that served to guide the authorities regarding new questions. And as these more general ideas developed, it stands to reason that more people would be affected by these decisions. That is, originally an individual person or family approached a rabbi when she/they were faced with an ethical dilemma. Using various sources and precedents, the rabbi was able to discern the ethically permissible course of action for the participants. Of course, this decision then becomes part of the precedent to which the rabbis will appeal for future decisions by being recorded in writing or by being passed down from one authority figure to another. And insofar as others are affected by this particular decision in this way, the answer no longer simply

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[53] Noddings (1984), 13.

applies to a particular family in a particular situation; it applies to all who seek counsel about this issue.

This may become clearer with an example. Suppose that Sue, an otherwise healthy woman in her mid-thirties, is in a serious car accident and suffers major head injuries. The physicians tell her family that there is no hope that Sue will ever regain consciousness, and her physical functions are being entirely sustained by artificial means. The staff recommends to the family that they say their good-byes to Sue and allow the staff to withdraw or remove the life-sustaining equipment. The family then seeks out the assistance of a rabbi to discuss the permissibility of such an action from the perspective of Jewish law. In his section on "The End of Life" in *Modern Medicine and Jewish Ethics*, Fred Rosner discusses how questions of this type have typically been handled: first, certain Biblical passages are considered relevant.[54] Then Talmudic sources are consulted.[55] Then one investigates the various passages in the codes of Jewish law.[56] But the most interesting process to note is what happens when the rabbis reach the "precedent" stage. While questions regarding the removal of life-sustaining treatment are relatively new from the perspective of Jewish law, rabbinic authorities have been quick to respond to these challenges. Regarding this issue, for example, the sources make three critical distinctions: (1) between initiating such treatment and removing it, (2) between the presence and absence of "independent

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[54] Fred Rosner, *Modern Medicine and Jewish Ethics*, 2nd rev. and aug. ed. (New York: Yeshiva University Press, 1991), 203-205.
[55] Ibid., 205-206.

brain function or spontaneous cardio-respiratory activity," and (3) between "hastening death" and "prolonging dying."[57] The point here is that as these specific cases developed in medicine, the authorities used the ancient texts and principles to decide the (im)permissibility of particular actions. And while initially these decisions only applied to particular individuals in specific cases, as the issues became more common the appeals to these decisions became much more frequent. So an initially narrowly-applied decision ends up affecting many, many people.

Of course, the group that is affected by these decisions will be limited to those who consult rabbis or various other Jewish authorities when such questions arise, or those who hear about them in some other way. Yet not all of these individuals will consider such rulings in their decision-making process. The group of those who do could be as wide as the entire Jewish community, and could be as narrow as a select handful of ultra-Orthodox groups within the larger community. Rabbi Jakobovits, whose appeal is at least partly derived from the inclusiveness of his focus, states that the principles of Jewish medical ethics apply to *all* Jews. As his son writes: "…he [Rabbi Jakobovits] does not distinguish between Orthodox and non-Orthodox. All Jews have the obligation to accept, and become familiar with, our heritage."[58] All of the "pioneers" that Rosner mentions are Orthodox Jews, and one could argue that their responses are also intended for all Jews. However, insofar as it is (most?) often

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[56] Ibid., 206-208.
[57] Ibid., 209.
[58] Yoel Jakobovits, 136-137.

Orthodox Jews who consult rabbinic authorities about such issues, one might argue that these rulings apply specifically to them. By "Orthodox" here we refer to those both self and externally identified as strict adherents to the body of Jewish law. In some senses, restricting the applicability of these responses to Orthodox Jews makes sense: only if one considers obeying Jewish law as morally required will one be motivated to act according to the decisions of religious authority.

But limiting the scope of applicability in this way is problematic on a number of fronts. First, there is the problem of theological justification. The entire procedure previously described assumes that these particular individuals have an authority that others do not; that somehow these individuals are closer to the Truth than their less observant counterparts. For when rabbis who are not Orthodox investigate these questions, there may be an entire additional body of precedent to which they will appeal on account of a different interpretation of textual sources, for example. To privilege one set of responses over another is clearly a value judgment that presupposes other moral principles not overtly discussed.

Second among the problems with the limitation of scope is the very confusion of the terms, particularly if we focus on American Jewry. There are synagogues that belong to organizations of "Orthodox Congregations" and whose members are then labeled "Orthodox" Jews. Then there are those who are members of what are often called "ultra-Orthodox" communities: the Lubavitcher Hasidim are an example of this. Add to this mix "Modern" Orthodoxy, which couples an awareness of secular progress

with adherence to this historic tradition. Jack Wertheimer discusses this phenomenon in his book *A People Divided*.[59] "…Orthodox Jews do not share a clearly articulated theology, let alone movement ideology."[60] Wertheimer quotes Charles Liebman, who categorizes Orthodox Jews a bit differently. Liebman divides the group into the "uncommitted Orthodox," the "modern Orthodox," and the "sectarian Orthodox."[61] As Wertheimer interprets this distinction:

> The first [uncommitted Orthodox] were East European immigrants who, out of inertia rather than religious choice, identified as Orthodox, or they were individuals who had no particular commitment to Jewish law but preferred to pray in an Orthodox synagogue. The modern Orthodox 'seek to demonstrate the viability of the *halakha* for contemporary life…[and also] emphasize what they have in common with all other Jews rather than what separates them.' The sectarians are disciples of either *roshei yeshiva* (heads of yeshivas) or Hasidic rebbes, whose strategy it is to isolate their followers from non-Orthodox influences.[62]

So exactly what we mean when we use the terms "Orthodox Jew" is contentious, to say the least.

Yet it is not clear that even if we could adequately define the terms that we would want to limit the application of responsa in this way. In a footnote in his article on his father, Yoel Jakobovits discusses this very issue: "My father stresses his dislike of the term 'Orthodox.' There is only one body of Jewish law. The different

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[59] Jack Wertheimer, *A People Divided* (New York: Basic Books, 1993), 114-136.
[60] Ibid., 115.
[61] Ibid., 116.

'branches' within Judaism more properly classify Jews in accordance with their varying shades of belief in the enduring, binding character of the law and their differing degrees of fastidiousness in the application of its principles to the modern era."[63] In addition to recognizing the problem of the application of particular terms, Rabbi Jakobovits also seems to indicate another related issue: the implication of contemporary society. As we see from Liebman's classification, Orthodox Jews themselves differ on the role Judaism must play given the changing nature of modern life. In fact, Wertheimer claims that within Orthodoxy itself, " [t]he critical fissure…is between Orthodox Jews who accommodate to modernity and those who resist it."[64] If the Orthodox community, however we construe it, is internally divided to this degree, then the question of theological justification once again becomes relevant. Certainly varying interpretations of sources will be affected by these various commitments to "modernity" as will the application of principles and precedent. But it is not just in relation to modernity where we see the rabbis disagree. As we will see when we get to the section on abortion in chapter three, there is a famous disagreement between two ancient sources, Rashi and Maimonides, regarding the status of the fetus in relation to the mother's mental health. Hence, there is evidence of internal dissent regarding the (im)permissibility of certain actions from Orthodox sources. It seems reasonable, then, to take the process one step further and state that

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[62] Ibid., 116-117.
[63] Yoel Jakobovits, 136-137, fn. 27.
[64] Wertheimer, p. 117.

different, *but equally ethically permissible*, decisions will be reached by those who have a different set of commitments outside of the Orthodox community – by Reform Jewish authorities, for example. That is, decisions may be reached that coincide with the general rules and principles that are specified in Jewish law, and yet are applied differently to individual cases on account of additional commitments (or the absence of commitments): for example, out of commitment to personal autonomy, or a commitment to the "living nature" of the law.

Certainly this obscurity of terminology is not exclusive to the Orthodox Jewish community; all established "branches" of American Jewry will have similar identification problems. Are Conservative Jews only those who currently belong to a synagogue which is affiliated with a Conservative Jewish organization and whose rabbi was ordained at the Jewish Theological Seminary? What about those individuals who do not currently belong to any organized congregation but were raised according to traditionally Conservative precepts? What about those who faithfully attended (Conservative) Camp Ramah every summer?

And while these questions clearly identify the problem of classification, they also indicate another interesting phenomenon. We might call all of the aforementioned groups "religious" or "observant" in a particular way. Certainly, parents to whom Judaism is important enough to dictate the summer camp choice for their children are "religious" in a sense of the word, just as are members of a Conservative synagogue. After all, they *chose* to so affiliate and channel certain

resources in that way from among various other options. Sending one's children to Boy Scout camp, for example, indicates certain commitments on the part of the parents: they are committed to having their sons learn how to survive in the wilderness, for example, or to obey authority, or to get along with other children. Sending one's children to a religiously-affiliated camp suggests that the parents are committed to exposing their children to particular religious activities or a way of life. Our choices do demonstrate commitments. Granted, there are (perhaps many) members of synagogues who send their sons or daughters for Bar or Bat Mitzvah lessons and never step foot into the building again after the ceremony, but the fact that this rite of passage was a priority for them at all is significant.

When we change our focus to a medical context, this point becomes much clearer. Often people "find" their religion during times of crisis, when their world has somehow been thrown off kilter and they need assistance in helping it to once again make sense.[65] We see this in a medical context as much as in any other: families often consult clergy members when faced with a traumatic, end-of-life sort of issue like the one described with Sue's family earlier in this chapter. But the crisis need not involve death.

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[65] For an extended discussion of this theme, see Bradford R. Smith (1998) Reestablishing Connections Between Bioethics and Christianity: Narratives and Virtues in Caring for a Christian Patient. Ph.D. diss., Department of Philosophy, University of Tennessee, Knoxville.

After all, clergy members regularly make rounds in hospitals to visit the sick, not just the dying. This must be at least partly justified by the fact that people want them to be there. After all, if everyone consistently reacted negatively to visits from these folks, the practice would have evolved differently. (Perhaps they would only come when called by the patient or family, rather than visit people as a matter of routine.) And it is not just the so-called "religious" individuals who welcome such visits. Rather, given that the context of medicine and hospitals is so foreign to many people, finding reassurance from the familiar sources (whether it be familiar from my childhood or by virtue of being part of my parents' narrative, for example) often serves an important role. It is clear that some people – many of those who are very active in their synagogue's religious life, for example – will likely welcome the advice of their rabbi on many matters, those medical included. What is not clear is who else might welcome such advice. Maybe a woman facing an end-of-life treatment decision for her husband who has not stepped foot in a Jewish building in 40 years would decide that she needs information from Jewish law to help her make her decision. Even if this woman would not be particularly inclined to "follow orders" when she learns of what the tradition dictates, she still may include this information as a part of her mostly-independent decision-making. Maybe a couple who is very active in the Jewish community will decide that in-vitro fertilization is the correct reproductive option for them, regardless of the tenets of Judaism.

The overall point here is that limiting the scope of the applicability of responsa in Jewish medial ethics to Orthodox Jews is not only difficult, but is also ill-advised. Rather, by evaluating these decisions from a variety of perspectives we will be able to assess the impact of these decisions. It is for this reason that in this project I will not limit my discussion to the Orthodox Jewish community, or in fact to any one "community" at all. Rather, when discussing questions of Jewish medical ethics, I will include any individuals who would seek out the advice of Jewish sources (rabbis, texts, other authorities) when trying to make decisions in medical contexts. This will most likely include individuals from all four recognized "branches" of Judaism – Orthodox, Conservative, Reform, Reconstructionist -- as well as many individuals who do not affiliate in this way at all (or who have multiple and sometimes conflicting affiliations). For the sake of simplicity, I will call this collection of diverse individuals "committed Jews," which signifies that all of these individuals have some sort of commitment to Judaism or Jewish law that will result in them searching out these sources for assistance in medical decision-making. However, it is important to keep in mind that this group is heterogeneous, unified only by a commitment to some aspect of Judaism.

One might wonder, if this group is already so heterogeneous, why I do not include *all* Jews in my analysis, but instead limit the group under discussion. In principle, I construe this group very broadly indeed. And in principle, I suppose I could include all Jews in my analysis. But it seems to me that the most interesting

cases will arise when we discover conflicts between *halakha* and medicine, and this is the focus of chapter five. These conflicts may involve fundamental differences in goals or values or priorities among the medical/scientific community and what I am calling the "committed" Jewish community. Or perhaps *halakha* dictates a course of action simply not recommended by medicine. Regardless of the specifics, instances of conflict – both real and apparent – will be most interesting to analyze from this perspective. My suspicion is that if we imposed no limitations on our group but instead included "all Jews," we would not as readily identify these instances of conflict. This is because the Jews who fall outside of the "committed" group *by definition* will not consult Jewish texts or authorities for guidance in instances of medical decision-making. So they will either appeal to strictly secular considerations (admittedly, no small task) or will consult some other tradition or framework. And since the focus of this project is to develop a framework for medical decision-making from a Jewish perspective, consideration of those who fall outside of the group will yield little of interest.

One final word is necessary regarding the large community on which we are limiting our focus. The group of "committed" Jews is admittedly heterogeneous, and really quite diverse. Because of its varied nature, one would naturally expect to uncover some (or maybe quite a lot of) disagreement within this group, in addition to outside of it. That is, it is not just the medical establishment and Jewish law that may be at odds, but rather different Jewish frameworks may be at odds themselves. (E.g.

The Conservative Rabbinic Assembly may argue for the virtually blanket permission for abortion of a fetus carrying Tay-Sachs disease, while we may uncover the rejection of such permission by some Orthodox authorities.) Hence, the impact of internal dissent of this group must be assessed.

While I grant that this point is significant, I will argue that there are two unifying factors that will help us to reconcile this disparity. First is the point we have previously discussed in the form of this group's definition: these diverse people are unified by their commitment, in whatever fashion that commitment manifests itself, to seeking guidance from Judaism and Jewish law when making decisions of a medical nature. Granted, the answers may differ given the particular source or authority appealed to, but all will appeal nonetheless.

The second, and more fundamental, unifying feature of this group is the very process of decision making itself. I will argue in this project that when we look at the way people actually make decisions in this community, we will see that it involves much more than an appeal to authority and an application of principles. It also involves an actual consideration of context, of the real people who will be affected by these decisions, and of the relationships and lives that will be altered as a consequence of these actions. Only by augmenting the traditional perspective with an ethic of care and responsibility will we take account of the richness of moral life and hence reach satisfactory conclusions regarding the ethical permissibility of genetic screening, testing, and therapy.

CHAPTER TWO

GENETICS

In order to begin the discussion of augmenting the framework of Jewish bioethics with an ethic of care, it will be useful to discuss three specific diseases that have a genetic component and that are of particular interest for the Jewish community. All of these diseases have a prevalence that is higher in this group of people than it is in the general population, and for that reason these diseases will be relevant for an analysis of moral decision-making in this community. All three of the diseases to be discussed, Tay-Sachs disease, breast cancer, and colorectal cancer, have the hallmarks of what are commonly referred to as "genetic" diseases, and yet the genetics behind each affliction are importantly different. This difference in biology may lead the observant Jewish community to make different decisions regarding intervention and therapy. And as the difference in biology also leads to different ethical concerns, ethical issues will be explored as well.

Tay-Sachs Disease

Descriptions of the Disease

Tay-Sachs disease (TSD) was first identified in 1881 by Warren Tay, an ophthalmologist who reported a "cherry-red spot" in the macula of the eye in a child who suffered from degeneration of the nervous system. Six years later Bernard Sachs, a neurologist, described the clinical nature of the disease and its pathology. Sachs noted that the disease tended to run in families, and was characterized by rapid

neurological degeneration. He initially called this disorder "amaurotic familial idiocy."[66] It was later renamed "Tay-Sachs Disease" in honor of its discoverers.

TSD is an autosomal[67] recessive disorder. This means that in order to be affected, an individual must possess two copies of the affected gene. The only way that this can happen is if both of an individual's parents donate his or her copy of the affected gene to the offspring. This means that the parents of a child with TSD are carriers of the disease, since they each "carry" one copy of the mutation. Such carriers, who have one mutated gene and one normal copy of the gene, are known as heterozygous for the allele in question. Individuals who are homozygous for the allele, by contrast, carry two copies of the affected gene. Hence, all children born with the trait are homozygous for the gene. Every individual has 46 chromosomes, and on each chromosome are thousands and thousands of genes. Half of these chromosomes, 23, come from our mother, and the other half come from our father. Our parents also have 46 chromosomes, or two copies of each. Hence, there is a 50/50 chance that a carrier will pass the affected chromosome to her offspring (and a 50/50 chance that she will not). If both parents are carriers, then, there is a 1/4 chance that the child will receive both affected copies of the gene. Because the disease requires two copies of the affected gene, carriers are not clinically affected. In fact, prior to the large-scale

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[66] Fred Rosner, "Tay-Sachs Disease: To Screen or Not to Screen?" *Journal of Religion and Health* 15, no. 4 (1976): 271.

[67] Autosomal disorders are to be contrasted with sex-linked disorders, where the affected gene is on one of the sex chromosomes. Autosomes are the 22 pairs of chromosomes that do not determine one's sex.

screening programs instituted in the 1970s, many couples discovered their carrier status in reverse: they gave birth to a child afflicted with TSD, which meant that both parents must be carriers of the alleles.

Children with TSD appear normal for the first 4-6 months of their lives, after which time the neurologic degeneration becomes apparent. The specific cause of this disorder is an absence of the enzyme Hexosaminidase A (Hex A). The function of this enzyme is to break down G_{M2} gangliosides, a specific lipid, and in the enzyme's absence this fatty material accumulates in the neurons to such a degree that life's functions are impaired. Specifically, children develop "…progressive mental and motor deterioration, blindness, paralysis, dementia, seizures and death" usually by 3-5 years of age.[68] There are many clinical variations of the disease, some of which will be discussed later in the chapter. Typically, "[t]he severity of the disease…correlates with the level of residual Hex A,"[69] and since Hex A is completely absent from individuals with the infantile form of TSD, the clinical manifestation is regularly severe. There is no known therapy for this disease.

What makes this disorder particularly interesting for the Jewish community is the frequency of its occurrence. "Approximately 1 in 3,600 Jewish children born is

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[68] Thomas D. Gelehrter, Francis S. Collins, and David Ginsburg, *Principles of Medical Genetics*, 2d ed. (Baltimore: Williams and Wilkins, 1998), 295; also Rosner, (1976), 271.

[69] Roy A. Gravel, Barbara L. Triggs-Raine and Don J. Mahuran, "Biochemistry and Genetics of Tay-Sachs Disease," *The Canadian Journal of Neurological Sciences* 18 (1991): 419.

afflicted with this condition as compared with 1 in 360,000 non-Jewish births."[70] While less than 0.3% of the general population are carriers for TSD, 3% of the Ashkenazi[71] Jewish population are carriers. Hence, the disorder is 100 times more common in this population than in the international society-at-large.

There are two rival (but not mutually exclusive) hypotheses as to how the frequency became so concentrated in this relatively small community. The first hypothesis, advocated by Gary Chase and others, accounts for the frequency according to the founder effect and genetic drift.[72] Because of certain religious prescriptions that require Jews to marry other Jews, and because of the geographical and social isolation (both from coerced and voluntary sources) of many subsets of this community, mating tended to occur within this population, making them a genetic isolate. If the founder members of such a community had a genetic mutation, the frequency of these mutations would be higher than in the general population, where mating with non-carriers allows for a decrease in the chance of passing along the mutant alleles. This is

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[70] Michael M. Kaback, Ted J. Nathan, and Susan Greenwald, "Tay-Sachs Disease: Heterozygote Screening and Prenatal Diagnosis – U.S. Experience and World Perspective" in *Progress in Clinical and Biological Research*, eds. George J. Brewer, Vincent P. Eijsvoogel, Robert Grover, Kurt Hirschhorn, Seymour S. Kety, Sidney Udenfriend, and Jonathan W. Uhr, vol. 18, *Tay-Sachs Disease: Screening and Prevention*, ed. Michael M. Kaback (New York: Alan R. Liss, 1977), 13.

[71] Ashkenazi Jews trace their ancestry back to central and Eastern Europe; the vast majority of American Jews today (approximately 6 million) are of Ashkenazi descent.

[72] Gary A. Chase, "The TSD Gene Among Ashkenazic Jews: Founder Effect and Genetic Drift," in *Progress in Clinical and Biological Research*, eds. George J. Brewer, Vincent P. Eijsvoogel, Robert Grover, Kurt Hirschhorn, Seymour S. Kety, Sidney Udenfriend, and Jonathan W. Uhr, vol. 18, *Tay-Sachs Disease: Screening and Prevention*, ed. Michael M. Kaback (New York: Alan R. Liss, 1977), 107-110.

the founder effect; initial members of a community passing along a mutation to further generations by means of mating within a small, isolated population. It is common for members of the observant Jewish community to have many children, and hence this also increases the likelihood that the founder mutation will be passed on to future generations. Genetic drift refers to the actual frequency of the mutation in a population such as this small community, where the number of individuals who are carriers of this mutation will vary greatly from one generation to another.[73]

Chase and others[74] postulate that both the founder effect and genetic drift account for how the frequency of TSD became 100 times greater than that of the general population. Founder members of the community had the mutant alleles for TSD, and their mating produced both homozygotes and heterozygotes for the disease. Interestingly, Chase claims that history may have been an unwitting accomplice to this increase in frequency: he believes that "…the parents of Tay-Sachs infants are in reality distant cousins whose ancestors have been separated by decades of unsystematic migration resulting from the many persecutions to which the Jewish people have unjustly fallen heir."[75]

Others claim that the high frequency of the mutant gene within this small population occurs because of a selective advantage for carriers of this trait.

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[73] Gelehrter, Collins, and Ginsburg, 47.
[74] See also GA Chase and VA McKusick, "Founder Effect in Tay-Sachs Disease," *American Journal of Human Genetics* 24 (1972): 339-347.
[75] Chase, 108.

Myrianthopoulos and Melnick and others[76] argue that heterozygotes for the mutation have an evolutionary advantage in a particular environment that non-carriers lack. Specifically, the authors argue that an increased resistance to tuberculosis is the benefit that carriers receive for their status. As a result of this advantage, natural selection has selected "for" heterozygotes for TSD as those who are most fit to survive in that particular environment. The authors utilize both scientific and historical evidence, where they elucidate the history of the Diaspora in order to account for this selective advantage.[77,78]

While they are all associated with the same gene, a number of different mutations are responsible for the lack of effective Hex A; in effect, there are a variety of factors that lead to a similar outcome. In the Ashkenazic Jewish population, three mutations account for 98% of all of the cases of TSD.[79] Two of these are responsible for the disorder described above, which is also referred to as "infantile" TSD since infants are first affected with the disease. The third mutation is responsible for an

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[76] See also Gloria M. Peterson et al, "The Tay-Sachs disease gene in North American Jewish Populations: Geographic Variations and Origin," *American Journal of Human Genetics* 35 (1983): 1258-1269.

[77] Ntinos C. Myrianthopoulous and Michael Melnick, "Tay-Sachs Disease: A Genetic-Historical View of Selective Advantage," in *Progress in Clinical and Biological Research*, eds. George J. Brewer, Vincent P. Eijsvoogel, Robert Grover, Kurt Hirschhorn, Seymour S. Kety, Sidney Udenfriend, and Jonathan W. Uhr, vol. 18, *Tay-Sachs Disease: Screening and Prevention*, ed. Michael M. Kaback (New York: Alan R. Liss, 1977), 95-106.

[78] Some dispute the claims of resistance to tuberculosis as the advantage, however. See Petersen et al., 1267.

[79] Gelehrter, Collins, and Ginsburg, 295.

adult-onset form of TSD, which is often simply referred to as G_{M2} gangliosidosis.[80] With adult-onset gangliosidosis (AOG), patients have the Hex A enzyme that is missing in the infantile form of TSD, but the Hex A they possess is defective. Hence, the lipids gradually accumulate in the neurons over the course of the patient's life and impair function much later than in the infantile form. Often this disorder masks itself as clinical psychiatric disorders, as "…the clinical picture is diverse, with symptoms mimicking dementia, depression, mania, schizophrenia, paranoid, and anxiety states."[81]

What is interesting about this adult-onset form is that in all of the cases identified, the allele bearing the point mutation is found in the patient along with "…one of the two Ashkenazi infantile Tay-Sachs alleles."[82] Later studies that identified individuals not of Jewish origin with the adult-onset form of TSD also had some form of a mutation in the gene that codes for the enzyme.[83] Hence, the adult-onset alleles must work in combination with the others, and has led some study authors to conclude that "…the appearance of the adult disorder in Ashkenazi Jews is,

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[80] Barbara L. Triggs-Raine et al, "Screening for Carriers of Tay-Sachs Disease Among Ashkenazi Jews," *New England Journal of Medicine* 323, no. 1 (July 5, 1990): 6.
[81] Diane Hamilton, "A Nursing Challenge: Adult-Onset Tay-Sachs Disease," *Archives of Psychiatric Nursing* 5, no. 6 (December 1991): 383.
[82] Ruth Navon and Richard L. Proia, "The Mutations in Ashkenazi Jews with Adult G_{M2} Gangliosidosis, the Adult Form of Tay-Sachs Disease," *Science* 243 (March 17, 1989): 1473.
[83] Ruth Navon, Edwin H. Kolodny et al., "Ashkenazi-Jewish and Non-Jewish Adult GM2 Gangliosidosis Patients Share a Common Genetic Defect," *American Journal of Human Genetics* 46 (1990): 817.

in large part, due to the high carrier frequency (1/30) of the infantile Tay-Sachs alleles."[84]

Screening Programs

Once scientists isolated the missing or defective Hex A as the cause of the various forms of Tay-Sachs disease[85] physicians were able to offer screening for the disease to their patients.[86] Two methods of testing are employed today.

> Serum testing is used for carrier screening in men and nonpregnant women. Leukocyte HEX A testing must be used in pregnant women or in apparent serum-defined carriers who are taking oral contraceptives, are on unusual medications, or are suffering with a tissue destructive-disease [cancer, etc.] (as determined by a personalized questionnaire that is completed by each individual at the time of testing).[87]

Leukocyte testing is more specific and hence is necessary for individuals who present with the aforementioned confounding factors. Serum analysis is automated, while leukocyte testing must be done manually, making it more costly in terms of time and personnel. Hence, leukocyte testing is performed only in the circumstances previously

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[84] Navon and Proia, 1473.

[85] There is also a juvenile form of TSD that is characterized by a reduced amount of Hex A. This form of the disease is not particularly prevalent in the observant Jewish community and accounts for fewer cases of the disease than the infantile form; hence it will not be discussed here.

[86] Carrier screening is almost exclusively limited to the infantile, or classic, form of TSD.

[87] Michael Kaback, Joyce Lim-Steele, Deepti Dabholkar, David Brown, Nancy Levy, and Karen Zeiger, "Tay-Sachs Disease – Carrier Screening, Prenatal Diagnosis, and the Molecular Era," *Journal of the American Medical Association* 270, no. 19 (November 17, 1993): 2307.

mentioned. Screening is relatively inexpensive for patients ($20 - $75 according to 1993 statistics)[88], and hence financial hardship is rarely an impediment to testing.

As previously mentioned, prior to the 1970s, individuals learned of their carrier status through the birth of an affected child. Once these screening procedures had been developed, however, researchers were able to institute large-scale screening programs. This is important in order to accurately predict those who will be affected by TSD. "Overall fewer than 20% of pregnancies at risk of important single gene disorders can be predicted on the basis of a positive family history….Hence selective testing of pregnancies on the basis of a positive family history, while of benefit to the families concerned, can never have a major impact on the birth frequency of these genetic conditions."[89] If the goal is to reduce the number of children born with this lethal condition, then mass screening must be implemented.

The first such program occurred in the Baltimore/Washington D.C. area in 1971, and with its success (defined in terms of the number of individuals screened and also by the number of Tay-Sachs affected children prevented from being born) came multiple copies of the program in other metropolitan areas. The rationale for the screening programs included three major components. First, the disease predominately affects individuals in a defined population. This allows physicians and researchers to target the screening programs to those most at risk. Second, there is a

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[88] Ibid.

[89] Darren Shickle and Ian Harvey, "'Inside-Out,' Back-To-Front: A Model for Clinical Population Genetic Screening," *Journal of Medical Genetics* 30 (1993): 580.

reliable, effective, and relatively inexpensive screening test available for the mutations. Third, an alternative is available for those pregnant women whose fetus is found to be affected by TSD, namely, selective abortion.[90] As long as these three factors are in place, genetic screening for TSD seems appropriate. After all, "[a]t issue is not the saving of lives for the affected children, but the prevention of suffering for them and their families….This prevention of suffering must be considered, alongside the avoidance of uncertainty, as the cardinal benefit of Tay-Sachs screening."[91]

While those three components may be necessary prior to the implementation of a screening program, the list is certainly not complete. Other important elements are required in order for the program to be a success, and those elements are education and counseling. Education is necessary in order to inform patients exactly what it is that they are being tested for and what the results of the test might show. This is especially important when screening for a recessive trait, since the information gained from screening will have implications regarding future relationships. Mating with another carrier brings with it the risk of affected offspring. There is some evidence that misunderstandings prevail regarding carrier testing, such that some who have undergone genetic screening (and ostensibly were told that they were not carriers for

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[90] Peter Hechtman and Feige Kaplan, "Tay-Sachs Disease Screening and Diagnosis: Evolving Technologies," *DNA and Cell Biology* 12, no. 8 (1993): 653.
[91] Madeline J. Goodman and Lenn E. Goodman, "The Overselling of Genetic Anxiety," *The Hastings Center Report* (October 1992): 22.

gene X) were falsely reassured about their health.[92] Screening for a particular genetic trait does NOT give information about one's overall health; finding out that one is not a carrier for TSD does not imply that an individual is healthy or even is free from risk for other genetic diseases.[93] In a related study, it was discovered that individuals tend to be overly optimistic regarding their risk of developing disease; "that is, they tend to think their own chances of experiencing health and safety problems are less than the chances of their peers."[94]

Misunderstandings work the other way, however, as well. In a volume edited by Daniel Kahneman, Paul Slovic and Amos Tversky, a plethora of examples enumerate how judgments made under uncertain conditions vary greatly according to a wide variety of factors. The ways in which material is presented to an individual, the similarities and differences between the representative and the category, and the environment in which one is making the decision are all factors that influence an

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[92] T. Tymstra and B. Bielman, "The psychosocial impact of mass screening for cardiovascular risk factors," *Family Practice* 4 (1987): 287-90.

[93] Since there may be additional genes associated with this disease that were not tested for – presumably because we are currently unaware of them or because tests have not yet been developed – this also does not guarantee that the individual is free from this genetic disease. I am grateful to Glenn Graber for pointing out this complication to me.

[94] Neil D. Weinstein, "Why It Won't Happen to Me: Perceptions of Risk Factors and Susceptibility," *Health Psychology* 3, no. 5 (1984): 432-3.

individual's perception of risk, in addition to many, many other factors.[95] Proper education can help to alleviate these types of misunderstandings.

Because the information gathered from such testing may be psychologically burdensome, appropriate counseling measures must also be in place to ensure a quality program. There is some evidence to suggest that health screening can actually damage one's health in terms of psychological distress and subsequent behavior.[96] Consider how much greater the distress must be to discover that one is carrying a child afflicted with TSD. Even if selective abortion is an option for the couple (and it is not for everyone, a point to be discussed at length in the next chapter), the psychological strain of such a decision can be immense. As Goodman and Goodman point out, once a couple discovers it has conceived an affected child, what the parents have to confront "…is not the choice between life and death for that fetus, but a choice between prenatal death and a lingering and painful death in early childhood after the rudiments of personality have begun to emerge."[97] When that knowledge is coupled with the fact that any future pregnancy the couple has is also at 25% risk for TSD, the need for counseling becomes apparent.

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[95] Daniel Kahneman, Paul Slovic and Amos Tversky, *Judgment Under Uncertainty: Heuristics and Biases* (New York: Cambridge University Press, 1982); see also Debra G. Froberg and Robert L. Kane, "Methodology for Measuring Health-State Preferences – I: Measurement Strategies," *Journal of Clinical Epidemiology* 42, no. 4 (1989): 345-354.

[96] Howard G. Stoate, "Can Health Screening Damage Your Health?" *Journal of the Royal College of General Practitioners* 39 (1989): 193.

[97] Goodman and Goodman, 21-22.

For those who are not currently pregnant, information that one is a carrier for TSD can become burdensome as well. This information may restrict one's marriage and/or mating choice. It may also put someone in the position of urging a significant other to undergo testing in an already tense situation. Authors of one early study of a screening program noted that screening may have another unanticipated effect.[98] When interviewed prior to screening, only 2 out of 21 couples[99] interviewed stated that they already had all of the children they wanted. Yet after discovering their carrier status, only 2 out of the remaining 19 couples have attempted subsequent pregnancies. Many possible explanations may be offered for this phenomenon,[100] but the authors themselves are "disconcerted" by these results and acknowledge that "[p]erhaps the anxieties created by carrier screening are greater than we realize."[101] Hence, the knowledge that one is a carrier is not psychologically neutral and thus requires the availability of counseling services.

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[98] J. Alexander Lowden and John Davidson, "Tay-Sachs Screening and Prevention: The Canadian Experience," *Progress in Clinical and Biological Research*, eds. George J. Brewer, Vincent P. Eijsvoogel, Robert Grover, Kurt Hirschhorn, Seymour S. Kety, Sidney Udenfriend, and Jonathan W. Uhr, vol. 18, *Tay-Sachs Disease: Screening and Prevention*, ed. Michael M. Kaback (New York: Alan R. Liss, 1977).

[99] The twenty-one couples here refer to those that were identified as carriers from 10, 567 individuals initially tested. (Lowden and Davidson, 43.) Hence, this is a retrospective analysis.

[100] The authors of this article, in fact, offered few explanations; they did not present the data regarding whether or not the non-carriers had initially stated that they wanted more children, nor did they present the data regarding how many more children the non-carriers did, in fact, have. However, my point in mentioning this study was to demonstrate that screening may have adverse affects on people's subsequent behavior, and the point stands regardless of lack of the aforementioned data.

[101] Lowden and Davidson, 45.

Misunderstandings can occur here as well. The heterozygous state of TSD apparently has no ill-affects on an individual's health. Yet there is some evidence that patients who discover that they are carriers for a particular trait suffer negative effects as a result of screening. One study demonstrated that individuals who discovered their carrier status through screening were more worried about their future health than the non-carrier and control groups.[102] Perhaps this increased concern is justified, since this knowledge may have an impact on intimate choices that these patients will make. On the other hand, this worry may result because "…these carriers (erroneously) consider that their future health will be jeopardised by the presence of an abnormal gene."[103] Regardless, recognizing the psychological or social aspects of screening is imperative for a successful program.

The delivery of such information must be carefully orchestrated as well. There is some indication that compliance with screening is much higher if an advocate takes an active role, specifically a physician.[104] Perhaps this increased compliance reflects a certain level of confidence in the medical establishment, so that if one's personal physician recommends screening, it takes on a different importance than if one simply reads about the program in the newspaper or is contacted by a social worker from a local organization. Furthermore, it seems that the better that individuals understand the issues of heredity and genetics as they relate to their health and risk for TSD, the

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[102] Theresa M. Marteau, Monica van Duijn, and Ian Ellis, "Effects of genetic screening on perceptions of health: a pilot study," *Journal of Medical Genetics* 29 (1992): 24-26.
[103] Ibid., 25.

more likely it is that the patients will comply with screening. Hence, having an individual capable of delivering this sometimes complicated information to the patient is crucial for increasing the likelihood that she will be tested.

This is not to suggest, of course, that physicians are the only individuals capable of delivering such information: genetic counselors do so on a regular basis. And in this particular case, one might make the argument that involving specific members of the community would greatly increase participation in screening. Since this disease primarily affects Ashkenazic Jews, involving the Jewish community would seem to reaffirm the importance of screening for this population. One study suggests that premarital counseling by rabbis is the ideal setting for discussing Tay-Sachs screening, as that is a point in a couple's relationship when knowledge of carrier status could indeed determine procreation plans.[105] Furthermore, both parties are presumably of an age and/or maturity level when considering marriage to allow for greater understanding of the results of screening. Screening programs that directly targeted a younger clientele – specifically high school students – have been criticized for a failure to recognize this problem of an inability to understand the test results and put their risk in perspective. Increasing the involvement and education of the community will help to ensure a successful program.

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[104] Lowden and Davidson, 39-40.
[105] Dianne N. Abuelo, Judith Rosenstein, and Michael Sheff, "Tay-Sachs Disease: Knowledge and Attitudes of the Rabbinical Community," *Rhode Island Medical Journal* 68 (May 1985): 225-226.

It is also noteworthy that this screening program is taking place within the Jewish community, a community often marked by persecution and suspicion. Too often in the history of the Jewish people had edicts been imposed from without for the "benefit" of the members of this group, and instances of medical "interventions" generated externally from the community are particularly sinister. Nazi experimentations come to mind here, as do the overall attitudes of the Third Reich, where the goal of creating a genetically superior race required the elimination of the genetically "inferior."[106] These attempts singled out the Jews as a distinct group, and often it was their difference alone that "justified" the special treatment. It makes sense, then, that this particular group of people would be suspicious of any attempt to classify them that is explicitly directed at their difference; and in the case of TSD, they are the targets of screening precisely because they are Ashkenazi Jews.

In order for this screening program to be successful, then, the impetus had to come from within the community. In order to do this, the program coordinators made contacts with the rabbinate in the particular communities, as well as enlisting the aid of lay volunteers from within the community. Since "…the entire success of screening programs is predicated on, and directly proportionate to, the in-depth

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[106] See Daniel J. Kevles, *In the Name of Eugenics* (New York: Knopf, 1985), 74-75, 117-118.

education of the medical profession, the rabbinate, and the lay community,"[107] ensuring that such education occurred with these various groups was essential. From the very first pilot screening program in the Baltimore/Washington D.C. area, where 1800 people were voluntarily tested, to the greater-than 700,000 people that have since been tested, involvement of the community was key for recruitment, education, and counseling services. These features account for the judgment of many that the mass screening programs that occur(ed) within the Jewish community constitute a "model" screening program.

This can be contrasted with a much less successful program that was instituted in the African-American community in America in the early 1970s. Sickle-cell anemia, another recessive disease, affects predominantly those of African and European-Mediterranean descent. Unlike the controversy surrounding the reason for the preponderance of carriers of TSD in the Jewish community, there is agreement as to the cause of the high frequency of the mutation here: having one copy of the sickle-cell gene, or being a carrier for sickle-cell anemia, confers a specific advantage: resistance to malaria. Given the geographical history of carriers of this disease, one can easily see how being a heterozygote for this mutation would be an evolutionary advantage and hence selected "for." Of course, with advances in medical technology

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[107] Judith Saperstein, "The National Tay-Sachs and Allied Diseases Association, Inc.," in *Progress in Clinical and Biological Research*, eds. George J. Brewer, Vincent P. Eijsvoogel, Robert Grover, Kurt Hirschhorn, Seymour S. Kety, Sidney Udenfriend, and Jonathan W. Uhr, vol. 18, *Tay-Sachs Disease: Screening and Prevention*, ed. Michael M. Kaback (New York: Alan R. Liss, 1977), 10.

for the prevention and treatment of malaria, it can be argued that this advantage is now evolutionarily and practically unnecessary. But with the expensive nature of medical care and the lack of attention that much of the developing world receives in terms of health care, even in the 21st century such an evolutionary advantage may prove useful.

Around the same time that Tay-Sachs screening programs were being instituted in the United States, the government began to take action against sickle-cell disease. In 1972 the Legislature passed the Sickle-Cell Anemia Control Act which allocated funds to ensure the "'establishment and operation of voluntary sickle cell anemia screening and counseling programs' and to 'develop information and educational materials relating to sickle cell anemia and to disseminate such information and materials to persons providing health care and to the public generally.'"[108] The problem came with the implementation of such programs. States enacted their own sickle-cell screening programs, but without the community involvement, educational, or counseling services promised. As one writer put it, "[t]his wasn't something a community was doing to help itself; this was a congressional program to control a disease in an already burdened community."[109] Two points are significant here regarding the comparison of the two screening programs. One is the difference between sickle-cell anemia and TSD. Possessing two copies of the Tay-Sachs mutation means certain death at a very young age for the

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[108] Philip Reilly, *Genetics, Law and Social Policy* (Cambridge: Harvard University Press, 1977), 80.

unfortunate bearer. The same cannot be said for sickle-cell anemia. The mutation in this case causes red blood cells to be shaped like a sickle, which are then more likely to clog capillaries and cause oxygen deprivation to the affected area. This effect happens sporadically in what are known as "sickle-cell crises," which occur with little warning and in different degrees for different individuals. Hence, the fate of one afflicted with sickle-cell anemia is by no means assured. Individuals with the sickle-cell trait can lead full, productive lives, unlike with TSD. So the goal of the government is in some ways quite curious here: "controlling" a disease that is less virulent and less deadly than many other afflictions.

This relates to the second significant point, which is that in the United States, sickle-cell anemia predominantly affects the black population. Hence, "control" of a disease takes on a sinister connotation, as a group already discriminated against becomes the target of a governmental program. It is worth remembering that the now notorious Tuskeegee syphilis study had only recently been stopped at the time of the start of these programs, so the African-American community had good reason to be suspicious of the American medical institution.[110] Because of poor educational strategies, there was a widespread misunderstanding that being a carrier of sickle-cell anemia, known as having sickle-cell trait, was also detrimental to one's health, which is not at all clear. And as the psychological effects of screening are as important as the

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[109] Barbara Katz Rothman, *Genetic Maps and Human Imaginations* (New York: W.W. Norton and Company, 1998), 117-118.
[110] Ibid., 118.

physical effects (what we are to do with the knowledge that we have gained, what sort of burden we have by virtue of being carriers, etc.) a lack of available counseling services is problematic, to say the least. Whereas Tay-Sachs screening involved the community, sickle-cell screening was imposed on the community. Given the poor way in which this program was handled, it is not surprising that the public reacted so negatively. It was not long before insurance companies began canceling policies or raising premiums for those who were sickle-cell carriers, and the U.S. Air Force excluded carriers from consideration as airlines fired or grounded carriers across the board.[111]

Given all of this, it is understandable why some argue that concern over the degree to which particular groups are targeted for genetic screening is justifiable. In "The Overselling of Genetic Anxiety," Madeline Goodman and Lenn Goodman are critical of the educational interventions offered to the Jewish population, charging that even those messages that originate within the community have an element of manipulation or coercion.[112] Some of the educational innovations in question played on the fears and anxieties of the population in order to "guilt them" into screening, emphasizing the genetic nature of the disease and that there is no hope for success in treatment; only prevention of this dreadful disease is possible by avoiding births of homozygotes. Goodman and Goodman are also critical of the appeal to community members in the educational process. While it is true that such intervention may be

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[111] Ibid.

more effective coming from those sources on whom individuals have relied, it is precisely this relationship that calls the ethics into question. Who am I to disagree with screening if my rabbi thinks it's a good idea? Hence, the utilization of community resources themselves may be implicitly coercive. Finally, Goodman and Goodman address the issue of stigmatization, where even though the scientific data attest to the fact that carriers of TSD are not in ill health and present little "danger" to others, the reputation that this is a "Jewish" disease or is limited to this often-derided community can serve as a psychological stigma. This stigma can apply both within the community and outside: within the community in terms of finding marriage partners once carrier status is known, and from outside of the community lies the "…problem of apparent scientific confirmation to age-old prejudices about racial debility, clannishness, and the like."[113]

One subset of this community, however, has solved the problem of the internal stigma by initiating a screening program that keeps the identity of the carriers a secret.[114] Rabbi Josef Eckstein began a Tay-Sachs screening program in his ultra-Orthodox Jewish community in Williamsburg, New York. The program is called Dor Yeshorim, from a phrase in the Talmud meaning "generation of the upright." Eckstein himself watched four of his eleven children die from Tay-Sachs disease, and both as a way to deal with his own grief as well as to prevent other parents from suffering a

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[112] Goodman and Goodman, 22.
[113] Ibid., 24.

similar fate, Eckstein rose to the challenge of prevention. It is important not to underestimate the power of the stigma within this community. Having a child with TSD would "taint a family like a curse" such that it would be almost impossible to find matches for siblings of TSD children. It was so bad that "some families hid Tay-Sachs kids in Catholic hospitals before they died so that none of the Jews would learn about it."[115] So Eckstein's chief dilemma was "How do we prevent children with Tay-Sachs without causing the stigma?"[116] It took many years to develop, but the result of Eckstein's efforts was that every senior in high school in Orthodox Jewish schools gets a blood test to screen for the Tay-Sachs mutation. Each sample is identified by a six-digit number. In this community, a matchmaker still arranges the marriages of eligible individuals, so when a match is proposed, the matchmaker submits the names to those who safeguard Eckstein's databank. If the proposed match is between two carriers, the matchmaker is told that the match is unacceptable. To further preserve confidentiality, the matchmaker is likely to offer another reason why the match is

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[114] See Lois Wingerson, *Unnatural Selection: The Promise and the Power of Human Gene Research* (New York: Bantam Books, 1998), 1-20.
[115] Wingerson, 7.
[116] Ibid., 10.

unacceptable. Hence, the individuals will likely never know that they are carriers.[117] Dor Yeshorim now processes tests not just from New York high schoolers, but from people all over the world; they have offices in New York and Jerusalem, and work with laboratories and volunteers in England, Belgium, Switzerland, Canada, and all across the U.S. and Israel. Over 50,000 people have been tested to date, and Eckstein has reduced the incidence of Tay-Sachs disease in his community to zero.[118]

It is clearly the availability of the matchmaking framework that permits the achievement of such a dramatic decline in the incidence of TSD. Yet the world-wide mass screening programs that have occurred in other Jewish communities have also been successful in terms of a substantial decrease in incidence of the disease. Recall that the frequency of the Tay-Sachs mutation in the Ashkenazi Jewish population is 1/30, as compared to 1/300 in the general population. Prior to 1970 (and hence prior to mass screening programs) approximately 60 new cases a year of TSD were diagnosed. In the United States and Canada "[s]ince 1983, when only two new cases

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[117] According to an earlier source, if the matchmaker proposed a match between two carriers, she was told to have both families contact the testing center to verify their numbers. This would obviously alert the families to their carrier status, and then counseling referrals would also be offered. "Thus, carriers would learn their status only if they were to be matched with other carriers. Then both families could report that the match had failed to come about for other reasons and could look for new matches." (Beverly Merz, "Matchmaking Scheme Solves Tay-Sachs Problem," *Journal of the American Medical Association* 258, no. 19 (November 20, 1987): 2639.) The end result of this method would be practically the same: the stigma could be avoided by respecting the confidentiality of the two parties involved. Of course, the psychological burdens that often accompany test results would not be avoided here, as knowledge of carrier status would be provided, unlike in the aforementioned procedure.

were diagnosed, the annual number of newly diagnosed infants in the Jewish population has remained at around three to five cases per year. This represents a greater than 90% reduction…" in the number of Tay-Sachs-affected babies born.[119] Since prenatal diagnosis has been available, statistics show that between 1969 and 1992, prenatal detection prevented nearly 500 births of Tay-Sachs afflicted children. Organizers want to emphasize, however, that "the TSD carrier screening experience is mostly about the birth of nearly 2000 healthy infants"[120] that might otherwise never have been born had their parents feared the birth of a(nother) Tay-Sachs afflicted infant.

Ethical Issues

Typically, preventing the birth of Tay-Sachs affected babies means one of two things: preventing the carriers from mating in the first place, as is attempted by Dor Yeshorim's program, or prenatal detection and subsequent abortion of affected fetuses. Hence, the (im)permissibility of abortion is a crucial part of the debate surrounding Tay-Sachs disease. Aside from religious prohibitions on abortion (which will be discussed in the next chapter), individual assessments regarding the permissibility of abortion of affected fetuses plays a large role in determining the morally right course of action. If abortion is not an option for a woman, for personal or religious reasons, then one may question the wisdom of prenatal screening in the

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[118] Wingerson, 11.
[119] Kaback, Lim-Steele et al, 2309.
[120] Ibid.

first place. This problem is not unique to screening for TSD, however. When questioned about the "routine" triple screen that is performed on pregnant women for the purpose of detecting three particular genetic diseases (Down's Syndrome, Open Neural Tube Defect, Trisomy 18), many obstetricians say that they require their patients to have the procedure performed even if the patients refuse to be informed of their results. This is because the outcome of the screening changes the way that the physician in question cares for her patient, either during the course of the pregnancy or in terms of having the appropriate specialists at the delivery of the child. The same argument does not apply here, as the outcome of the results of Tay-Sachs screening have few clinical implications for obstetricians. There is currently no way to replace the deficient enzyme in these children or to compensate for the degenerative effects, so the knowledge of having a Tay-Sachs affected patient requires little intervention from obstetricians.

That is not to say, however, that such knowledge is useless. As with many other conditions for which no cure exists, information that helps parents to plan for a special needs child is valuable. There may be physical, financial, emotional, and psychological considerations that parents need to prepare for prior to the birth of such a child.

With TSD, however, such information often stands as more of a burden than a benefit. With the knowledge that one's child will have an inevitably fatal disease and with a lack of any means by which to prevent such an end, such information can be

psychologically and emotionally devastating for patients. Knowledge that the child for whom there were so many hopes and dreams would be permanently impaired not only affects the future of this family but also, in the words of Barbara Katz Rothman, "spoils the pregnancy." By informing the woman of the disaster waiting to befall her yet-unborn child, physicians have robbed her of an important part of the motherhood experience: enjoyment of the pregnancy itself. For something for which there is no cure nor hope, then, Rothman argues that women (and, by analogy, couples) are better off not having this information so that at least this part of the parenting experience can be preserved.[121]

It must also be remembered that even if both members of a couple are carriers of TSD, there is only a ¼ chance that each pregnancy will result in a child who has TSD. So while this number may be alarmingly high to some, for others the risk is low enough to allow them to feel comfortable "playing the odds" and concentrating on the 75% likelihood that a resultant child will be free from this dreadful affliction. It is noteworthy that in this particular community, having a family is religiously important in addition to being socially and traditionally valuable, and hence these obligations may override any personal feelings about the risk to individual couples.

Alternative forms of reproduction are now available for those couples who discover that they are both Tay-Sachs carriers and do not want to risk the chance of conceiving a child with TSD. The husband's sperm can be replaced with the sperm of

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[121] Rothman, 180-192.

a donor (screened for TSD and many other genetic diseases prior to acceptance) and inseminated into the woman. That way, the resultant child will not be a victim of TSD, and yet will be biologically related to at least one of the parents raising her. If biological parentage is crucial for both members of the couple, then in-vitro fertilization (IVF) may be a better option. This technology allows technicians to combine the eggs and sperm in a petri dish in a laboratory. Once the fertilized egg has divided several times, the zygote is then implanted in the woman. Before implantation, it is possible to test the embryos for TSD and subsequently only implant those embryos that are not homozygous for the disease. There is usually a greater likelihood of multiple pregnancies with this technique, as multiple embryos are often implanted at once in order to increase the chances that at least one of them will properly implant in the uterus and develop. But many view this as a reasonable risk in exchange for the huge psychological burden that is lifted from those who felt they were doomed to have a very sick child.

It is important to note, however, that while the new reproductive technologies do offer hope for many individuals, this hope does not come without its price. IVF is particularly expensive and usually not covered by medical insurance, running at approximately $10,000-$15,000 per attempt. This alone puts this technology out of the reach of many who might otherwise utilize this service. So what may be an option for some is made impossible by financial considerations for others.

This psychological burden would also hold true for those who discovered they would fall victim to the fate of adult-onset TSD, with its accompanying mental and physical degeneration. In this respect, many of the ethical issues are similar to those faced by victims of Huntington's Disease (HD), also a genetic disorder which does not affect its victims until later in life. Many who have HD lead productive and meaningful lives until the onset of the disease's effects. There is now a genetic test to detect HD, but interestingly, many who are at risk (as determined largely by family history) have opted not to be tested on account of the psychological burden that may result from doing so. True, it might work the other way as well: individuals who presumed they were at risk may learn from genetic screening that they are not in fact carriers of the trait.[122] Yet the certainty of knowing that one will develop a disease for which there is no treatment or cure may be devastating enough to significantly outweigh any benefit received were the data to come back with the opposite findings. What is important for the decision-making process is the likelihood of each outcome and the individual's assessment of its value or disvalue.[123] One can make the same case for adult-onset TSD: finding out that you are going to develop an irreversible and degenerative disorder may outweigh any considerations to the contrary. The benefit of

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[122] Being a carrier of the trait is sufficient for developing the disease, as HD is a dominant disorder: one copy of the mutated gene is all that is necessary to develop the disease.

[123] For a more detailed discussion of decision analysis in relation to medical decisions and genetic testing using a related genetic disease, see Samuel Holtzman, et al., "Decision Analysis and Alzheimer's Disease: Three Case Studies," *Genetic Testing* 3, no. 1 (1999): 71-83.

testing lies in either prevention or preparation. Preventing carriers of HD from reproducing (where offspring have a ½ chance of having HD) or from doing so in the conventional way is one goal of testing. Another important goal is simply gaining information from the test so that individuals, for example, do not postpone important projects in their lives.

Furthermore, there is some question as to the wisdom in pursuing measures whose purpose is to completely eradicate a genetic trait from the population. With the example of sickle-cell disease, where there is a clear advantage to being a heterozygote, and where the majority of the population affected by this trait may still benefit from it, preventing the continuation of this trait has a disadvantageous effect as well. So if the government's plan to "control" sickle-cell anemia had worked ideally, the trait – and its accompanying advantage – would have disappeared completely from the population. While the heterozygotic advantage is not quite as clear in the case of TSD, it is still significant that some advantage may be conferred on carriers such that eradication of the trait is not desirable. It is still a fact that even as quickly as the human genome project is progressing, there are still many things that are left to be discovered. Eradicating one trait, such as a mutation responsible for TSD, by germ-line gene therapy, for instance, may in turn have some disastrous effect on some other part of an individual's physiology. We do not currently have the scientific knowledge to assure us that this would not happen. Until our technical knowledge progresses to

the point where we more fully understand the risks involved to both physical and emotional health, we ought to be cautious in our adoption of various interventions.

Part of that caution should be suggested from history. One author wonders "…why, after the 'eugenic' programs of the Nazi state, post-war Jewish communities would be interested in even considering participation in a program which would identify what some would have called a 'race-based' genetic 'defect' present among Eastern European Jews."[124] While Edelson here makes a similar point to that of Goodman and Goodman discussed earlier, his mention of eugenics is worth pointing out. While some make a distinction between "positive" eugenics as the project of increasing the number of favorable genes and "negative" eugenics as the attempt to decrease the number of harmful genes[125], others conflate the two programs and condemn all such attempts as unethical. While it is not clear that charges that with screening procedures we are attempting to "play God" or "interfere with nature" hold for this community, it is worthwhile to take a few steps back to analyze proposed policies and procedures prior to implementation to ensure that they are more beneficial than harmful for all those in question.

Part of doing just that involves the development of a cost/benefit analysis of screening. Factored into such an analysis must be the financial burden of instituting

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[124] Paul J. Edelson, "The Tay-Sachs Disease Screening Program in the U.S. as a Model for the Control of Genetic Disease: An Historical Overview," *Health Matrix* 7, no. 125 (1997): 130.

mass screening programs as compared to the cost of caring for Tay-Sachs affected children that would otherwise have been born. Previous analyses have indicated that the cost of caring for children with TSD far outweighs the financial considerations imposed by mass screening programs.[126] The problem with these analyses is that the authors fail to consider professional salaries and volunteer efforts in their figures.[127] While these services were donated at the time of initial screening, it is unreasonable to assume that they (or others) would continue to do so in perpetuity. Furthermore, many critics point out that the particular community in question is unique in its education level and its fortune, so that many individuals (mostly women) had the luxury of being able to volunteer their time. When viewing the TSD screening program as a "model," one must be aware that this is not a feature easily exportable to other communities. Hence, when assessing the financial considerations of a screening program, volunteer efforts and professional salaries must be included.

More alarming than this omission, however, is Kaback et al.'s failure to include the costs for counseling and/or psychological facilities in their analysis.[128] As previously discussed, such services are essential to a screening program and must be

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[125] Daniel J. Kevles, "Out of Eugenics: The Historical Politics of the Human Genome," in *The Code of Codes*, eds. Daniel J. Kevles and LeRoy Hood (Cambridge: Harvard University Press, 1992), 9-10.
[126] Michael Ruse, "Genetics and the Quality of Life," *Social Indicators Research* 7 (1980): 424-5.
[127] Ibid., 433.
[128] Ibid., 430.

included. As these services in particular typically carry with them high fees, their omission in a cost/benefit analysis is suspect to say the least.

That is not to say, however, that Kaback et al. are completely misguided in their investigations. In fact, they are likely correct that it is economically more sound to engage in screening programs than to pay for the care of babies with TSD. My point is only that one needs to be cautious when evaluating such economic analyses.

Another potential cost of screening relates to insurance. While the federal government has instituted certain regulations to prevent insurance companies from discriminating against those with disabilities of various kinds, it is not at all clear how far such regulation extends. If the sickle-cell screening program is any indication for how the public reacts to discovering carriers – by denying employment in certain fields and canceling insurance plans – then this must also be factored in as another cost of screening. (This point will be discussed in greater detail in the next section.)

Hence, while engineers of the TSD screening programs were pioneers in detecting genetic disease of a particular community, the programs were not unproblematic. Careful consideration must be given to the ethical dimensions of the program so that mistakes are not repeated.

Breast Cancer

There are many forms of breast cancer, just as there are multiple forms of TSD. However, all of the forms of TSD are associated with the same gene, albeit with mutation in different regions of that gene; the result is that a necessary enzyme is

either not produced, is produced in a diminished form, or is defective. The same is not true of breast cancer. The majority of cases of breast cancer are associated with sporadic mutations, rather than due to a mutation or series of mutations being passed down through families. In fact, only 5%-10% of breast cancers are "considered due to an inherited predisposition."[129] Of that 5%-10%, "[g]ermline[130] mutations in the BRCA1 and BRCA2 genes are thought to account for most of familial breast-ovarian and breast cancer."[131]

So why the fuss over the genes associated with breast cancer? According to some estimates, "[t]he lifetime risk of breast cancer may approach 80%-90% in women who have germline mutations of either…BRCA1 or BRCA2."[132] Hence, for those unfortunate women who have this genetic predisposition, their chances of getting breast cancer are high indeed. To make matters worse, the frequency in mutations of these two genes in the Ashkenazi Jewish population – the same population with a high frequency of mutations responsible for TSD – is also high here: around 2%-2.5%. There are over 100 different BRCA1 mutations that have been identified, but three specific mutations have are the most prevalent in the Ashkenazi

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[129] Ephrat Levy-Lahad et al, "Founder BRCA1 and BRCA2 Mutations in Ashkenazi Jews in Israel: Frequency and Differential Penetrance in Ovarian Cancer and in Breast-Ovarian Cancer Families," *American Journal of Human Genetics* 60 (1997): 1059.

[130] Germline mutations affect all of one's cells and may be transmitted to offspring through reproduction.

[131] Levy-Lahad, 1059.

[132] Susan Neuhausen et al, "Recurrent BRCA2 617delT Mutations in Ashkenazi Jewish Women Affected by Breast Cancer," *Nature Genetics* 13 (May 1996): 126.

community community, with mutations in BRCA1 accounting for 45% of familial breast cancer and 90% of familial breast-ovarian cancer.[133] "[T]he risk of breast cancer among carriers of one of the three mutations is 33 percent by the age of 50 and 56 percent by the age of 70."[134] Thus, the "breast cancer genes," as they are called, are of specific concern to this community.

Scientists account for the prevalence of the mutations in this community again according to the founder effect: a small group of "founder" individuals in the community passed down the mutations through marriages and reproduction within this tight-knit community to future generations. Specifically, some trace this founder population back to the "Jewish Pale of Settlement" in the western part of Lithuania and Poland.[135] This founder population is combined with three additional elements that contribute to the founder effect: (1) drastic changes in population over the history of the Diaspora, (2) a complex and rapidly changing demographic history, and (3) a commitment to marriage within the group.[136]

Interestingly, the most common mutation in the breast cancer gene, 185delAG, is also prevalent among Iraqi Jews. What is interesting about this is that Iraqi Jews are

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[133] Benjamin B. Roa et al, "Ashkenazi Jewish Population Frequencies for Common Mutations in BRCA1 and BRCA2," *Nature Genetics* 14 (October 1996): 185.
[134] Jeffery P. Struewing et al, "The Risk of Cancer Associated with Specific Mutations of BRCA1 and BRCA2 among Ashkenazi Jews," *New England Journal of Medicine* 336 (May 15, 1997): 1404-5.
[135] David B. Berman et al, "Two Distinct Origins of a Common BRCA1 Mutation in Breast-Ovarian Cancer Families: A Genetic Study of 15 185delAG-Mutation Kindreds," *American Journal of Human Genetics* 58 (1996): 1166.
[136] Ibid.

not of Ashkenazi descent, but are rather Sephardic in origin. Since the "Iraqi Jewish community is thought to be the oldest Jewish community living outside Israel (since the Babylon exile in 586 B.C.)" some have suggested that "the presence of an Ashkenazi mutation among Iraqi Jews indicates that the age of the mutation is > 2,500 years."[137] The supposition is that since the Babylonian Jewish community was the "main cultural Jewish center until the 11th century," close contact with other Jewish communities transferred the mutation from individuals of Ashkenazi descent to members of the Babylonian community, or vice versa.[138] Thus, the founder effect is still a reasonable explanation for these empirical findings.

What is particularly interesting about this prevalence data is what it really means for individuals in this community. The breast cancer mutations are importantly different from the mutations that cause TSD. Mutations in BRCA1 and BRCA2 confer on its bearers a *susceptibility* to developing breast cancer. There is no way to determine whether or not individuals will in fact develop breast cancer. And given the importance of environmental factors and gene-gene interactions (both of which will be discussed later), the predictive value of having the mutation is even more uncertain. The knowledge that one has mutations in one of the genes associated with breast

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[137] Dvorah Abeliovich et al, "The Founder Mutations 185delAG and 5382insC in BRCA1 and 6174delT in BRCA2 Appear in 60% of Ovarian Cancer and 30% of Early-Onset Breast Cancer Patients Among Ashkenazi Women," *American Journal of Human Genetics* 60 (1997): 513.
[138] Ibid.

cancer offers probabilistic information at best: it is likely that one will develop breast cancer, but not certain.

Similarly, as only 5%-10% of breast cancers are considered to be on account of inherited predispositions, knowledge that one does not have mutations in the breast cancer genes does not guarantee freedom from developing breast cancer. In fact, since one in nine (perhaps one in eight, according to some estimates) women can expect to develop breast cancer over the course of their lifetimes, vigilance in screening for signs of this disease is recommended, genetics notwithstanding.

Screening

Given this information, then, there is reason to be cautious when recommending genetic screening for such a predisposition. There are three categories of concern with regard to BRCA1 and BRCA2: scientific questions, economic and efficiency questions, and general ethical questions.

1. Science

Scientifically, the genetic contribution to breast cancer is complex. As over 100 mutations have been identified in BRCA1 alone, screening for all of these mutations would be unreasonable given current technology. But given that three prominent mutations are responsible for the majority of cases of familial breast cancer in Ashkenazi Jews, and that "[u]p to 40% of all Ashkenazi Jewish breast cancer patients aged < 50 years could…be carriers of either of the…mutations," broad

screening seems justified.[139] However, it isn't that simple. It is not enough to determine that someone has a particular genetic mutation, as not all mutations become expressed as disease in the same way or with the same frequency. Some of the mutations responsible for breast cancer, like 185delAT, frequently get expressed as breast cancer; that is, having this in one's genome often results in the phenotypic expression of breast cancer. Yet, through mechanisms that are not yet fully clear, other mutations, like 6174delT, get expressed as breast cancer much more infrequently than other mutations. In fact, 6174delT gets expressed as breast cancer approximately only 25%-30% as often as does 185delAG. This phenomenon, referred to as penetrance, is an important factor when considering large-scale screening programs. Since the mutation 6174delT is only expressed as disease 25%-30% as often as 185delAG,[140] possessing this trait presents less of a risk to carriers than a trait of higher penetrance.

Furthermore, the likelihood that a woman's cancer has a genetic component depends on an additional element: the patient's age. In general, "1.7% of all breast cancer cases diagnosed below age 70 years are due to BRCA1," but the percentage

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[139] P. Devilee, "BRCA1 and BRCA2 Testing: Weighing the Demand against the Benefits," *American Journal of Human Genetics* 64 (1999): 943.
[140] Levy-Lahad et al, 1060. Earlier estimates suggested that the penetrance of 185delAG is actually four times greater than that of 6174delT. (Benjamin B. Roa et al, 186.)

rises to 5.3% for those diagnosed below age 40 and 7.5% below age 30.[141] The numbers climb when applied to specific mutations: the 185delAG mutation in BRCA1 accounts for "16% of breast cancer and 39% of ovarian cancer diagnosed before age 50 in Ashkenazi Jewish women."[142] In fact, "[o]ne in five Jewish women with breast cancer at <40 years of age has been found to carry a germ-line 185delAG mutation."[143] Hence, while it does seem clear that women who are carriers of the 185delAG mutation are more likely to develop breast cancer than those who carry the other mutations, the actual risk of an individual depends on the patient's age.

Furthermore, at least one study demonstrated that presymptomatic testing for individuals without a strong family history for breast or ovarian cancer had poor predictive value.[144] This is illustrative of an important point in genetics: few diseases or conditions are actually the result of a single gene or mutation acting alone in an individual's body. Much more common are what are known as multifactorial traits, where a combination of genes and environmental factors are responsible for the resultant condition. The mechanisms of such interactions are complex and the vast majority have yet to be fully understood. Hence, it is not clear that testing for one

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[141] D. Ford, D. F. Easton, and J. Peto, "Estimates of the Gene Frequency of BRCA1 and its Contribution to Breast and Ovarian Cancer Incidence," *American Journal of Human Genetics* 57 (1995): 1459.
[142] David E. Goldgar and Philip R. Reilly, "A Common BRCA1 Mutation in the Ashkenazim," *Nature Genetics* 11 (October 1995): 113.
[143] C. Sue Richards et al, "Screening for 185delAG in the Ashkenazim," *American Journal of Human Genetics* 60 (1997): 1086.

mutation alone would give sufficient information to patients or clinicians to implement a care plan.

Finally, it is important to remember that with many conditions that have a genetic component, understanding the ways in which the genome interacts with the environment in which it is located is essential to predicting the expression of the condition for the particular individual in question. Sometimes the environmental interaction is readily apparent, but often it is not. Hence, any prediction of the likelihood of developing a disease like breast cancer must be done with caution, as environmental factors may confound any such prediction – in either direction.

2. Economics & Efficiency

This relates closely to the issues of economics and efficiency. It is both extremely costly to screen for the hundreds of mutations and inefficient: in a specific population where the prevalence of three particular mutations has become apparent, it is cheaper and more efficient to screen for those. But given the data about the decreased penetrance of the BRCA2 mutation, as well as the fact that 185delAG is much more prevalent than 6174delT, perhaps screening can be limited yet further. Hence, it may be more cost effective to only screen for the 185delAG mutation in this ethnic population. The problem with this, of course, is that the full mechanistic explanation behind this difference in expression is yet to be offered, as was indicated

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[144] Flora H. Fodor et al, "Frequency and Carrier Risk Associated with Common BRCA1 and BRCA2 Mutations in Ashkenazi Jewish Breast Cancer Patients," *American Journal of Human Genetics* 63 (1998): 49.

in the previous section. And if it turns out that one mutation is influenced by another, then limiting screening in this way is too restrictive and will be detrimental to overall benefit. There is some indication that the third mutation, 5382insC, may confer a higher lifetime risk than the other mutations, but this must be investigated further.[145] Hence it is not at all clear that limiting the screening to one, or a few, particular mutation(s) is the best way to go, either: screening that doesn't take into account other facets of an individual's history may lead to test results that are inconclusive at best and misleading at worst. And if this leads individuals to pursue further testing or even to engage in litigation on account of misleading test results, then limiting the screening in this way may not be the most cost effective. The most efficient strategy would be to restrict screening to high risk women only, defined as those with a strong family history and/or early onset breast cancer themselves. But again, this methodology would be less than ideal, since many who have the mutations would be missed by this scheme.

Ideally, of course, as the science of genetics progresses, scientists will gain a greater understanding of the mechanisms involved with various diseases, including the effects that various environments have on genetic expression. Screening for the various traits will then become more specific and results of such tests will be better predictors for an individual's actual risk of disease.

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[145] Fodor et al, 149.

The problem with this, however, is that often a large expenditure of money is required to engage in such research, which initially appears economically unjustified. After all, while these mutations are prevalent within the Ashkenazi Jewish community, that community itself is still a minority within the population. Spending large sums of money to improve a test for such a small segment of the population, while praiseworthy in itself, may not be economically efficient when compared with other research needs of the population.

What is interesting about this predicament is that in order to fully assess the predictive value of a screening test for 185delAG in Ashkenazim, for example, testing must be done on other groups, as well as increasing research on the Ashkenazim specifically. While this will benefit a minority group, it may also benefit the other large groups that are being tested in order to gain more information. It is also worth noting that the kind of research I am suggesting here is "basic biological research" and hence of value more generally, both to medicine and biology more generally.[146]

Another economic consideration is relevant to a positive finding of one of the breast cancer mutations in an individual. Just as with carrier status for both sickle-cell anemia and TSD, genetic discrimination is an unfortunate reality. The federal regulations offer some protection for individuals, but gaps remain. Regarding discrimination in health insurance, federal legislation has passed that offer some

[146] I am grateful to Jonathan Kaplan for pointing this out to me.

safeguards for individuals. The Health Insurance Portability and Accountability Act (HIPAA) of 1996:

- Prohibits excluding an individual from group coverage because of past or present medical problems, including genetic information.
- Prohibits charging a higher premium to an individual than to others in the group.
- Limits exclusions in group health plans for preexisting conditions to 12 months, and prohibits such exclusions if the individual has been previously covered for that condition for 12 months or more.
- States explicitly that genetic information in the absence of a current diagnosis of illness shall not be considered a preexisting condition.

HIPAA does not:

- Prohibit an insurer from denying coverage based upon genetic information to individuals seeking health insurance in the individual market.
- Prohibit the use of genetic information as a basis for charging more for health insurance.
- Limit the collection of genetic information by insurers and prohibit insurers from requiring an individual to take a genetic test.
- Limit the disclosure of genetic information by insurers.[147]

Hence, the fear of information of this type "getting into the wrong hands" is palpable for many people, and may prevent them from seeking genetic testing. Most states have issued legislation confirming their support of this federal regulation, and thirty-seven states (including Tennessee) have issued their own legislation regarding insurance discrimination. Yet the fear regarding the possibility of losing one's health insurance or being faced with unaffordable premiums on account of information

gained in a genetic test remains. In one study, "[of] the participants who declined testing, 80% cited concern about losing or obtaining health insurance as the reason for their decision…and 50% ranked this reason as the most important factor in their decision."[148] The National Human Genome Research Institute argues that it is not sufficient to limit the definition of "predictive genetic information" to "information derived from a genetic test, as many states have done. Failing to protect information about family medical history would allow insurers in the individual market to use predictive genetic information, such as cause of death and/or a history of disease in parents or siblings, to deny coverage or charge exorbitant premiums."[149]

Similar arguments can be made regarding discrimination in employment based on results of genetic screening. In fact, the concerns may take on greater importance since no federal regulation has passed on this issue.[150] Fewer than half the states have enacted their own legislation on this matter,[151] so patients may be right to be worried about this possible consequence. Since results regarding a predisposition towards cancer are inconclusive at best, some may fear that the harms that are an outcome of testing may outweigh any incentives for testing. Losing one's insurance coverage

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[147] "Health Insurance Discrimination," (August 2000), Issue Update, *National Human Genome Research Institute* September 26, 2000 <http://nhgri.nih.gov/Policy_and_public_affairs/Legislation/00upins1.htm>.
[148] Richards et al, 1092.
[149] "Health Insurance Discrimination."
[150] Of course, other governmental pressures could be brought to bear, but the point still stands.

(because of an inability to pay increased premiums, for example) or being denied employment may be significant enough harms to outweigh any desire to learn of one's likelihood of developing breast cancer. After all, there are few therapeutic options available to carriers, aside from the increased vigilance that may be recommended for all women. Hence, economic considerations alone may encourage some women to forgo screening for breast cancer mutations.

3. Ethics

More importantly, however, are the ethical considerations related to screening for breast cancer. The primary benefit of screening for any of the breast cancer mutations is in the information gained. Specifically, an Ashkenazi Jewish woman who discovers that she carries the 185delAG mutation has learned that she has a much higher risk of developing breast cancer than if she did not have that mutation. The value of such information must be weighed according to a relative scale: what harms are generated by such knowledge as compared to the benefits. Many view knowledge about one's health and risk of disease as valuable in and of itself. To those for whom this is true, screening for mutations in BRCA1 or BRCA2 may indeed be beneficial. Others, however, measure the benefits of a screening test by the predictive power of the information gained. For individuals like that, the value of breast cancer screening is unclear. The results from a screening test are importantly inconclusive no matter

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[151] "Employment Discrimination." *National Human Genome Research Institute.* March 2000. Issue Update. September 26, 2000. <http://www.nhgri.nih.gov/Policy_and_public_affairs/Legislation/99upemp.htm>.

what the outcome: a positive result indicates that an individual has an "increased" (the amount of the increase depends on a number of other factors, as previously mentioned) risk of developing breast cancer, and a negative result simply indicates that an individual will not develop breast cancer *on account of one of the mutations screened for which the individual was screened*. This by no means indicates that the individual is free from the risk of developing cancer, as only 5%-10% of the cases of breast cancer are due to one of the mutations in these genes. In fact, receiving a negative screening result may result in more harm than good: women may misinterpret the results of the test and assume that since they "don't have the gene" for breast cancer then they are not at risk. This in turn may lead to a decreased vigilance on their part, so that they grow lax with self or clinical breast exams and/or mammography. Individuals who discover that they do not have one of the identified breast cancer mutations simply share the same risk as the rest of the population: about one in nine women will develop breast cancer. Clearly this decreased attention to the warning signs of a problem may have a negative impact on the health of the women receiving negative test results and hence must be considered when offering screening.

Receiving information from screening that indicates that a woman is carrying one of the mutations for which she was screened, may lead to negative psychological effects. Of course a woman who discovers that there is an 80% probability that she will develop breast cancer over the course of her lifetime has reason to be dismayed. But some women may be so devastated by the information as to allow it to impair

other aspects of their life. This may be coupled with the fact that it is unclear what therapeutic options are available as prophylaxis for these women. There is some indication that double radical mastectomy decreases the risk of those women who undergo such disfiguring surgery,[152] but it is by no means certain that this will prevent an individual from developing breast cancer. So for those for whom these negative effects would outweigh the benefit of the information, screening for these mutations may not be a recommended course of action. There are some studies about women's attitudes towards breast cancer screening, and more must be attempted before we will know the best approach to take in counseling these women.[153]

Another interesting point is related to the fact that the disorder in question is genetic in nature. Since the screening process detects mutations in the germline, that is, mutations that appear in every cell in the body, any mutations that are detected in me have the possibility of being passed down to my offspring. Similarly, mutations that are in me may have resulted from mutations in my parents, and hence may be detectable in them or in my siblings. So any information that I receive about the presence or absence of mutations may have implications for my family members. As

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[152] L.C. Hartmann, D. J. Schaid, J. E. Woods, T. P. Crotty, J. L. Myers, P. G. Arnold, P. M. Petty, T. A. Sellers, J. L. Johnson, S. K. McDonnell, M. H. Frost, and R. B. Jenkins, "Efficacy of bilateral prophylactic mastectomy in women with a family history of breast cancer" *New England Journal of Medicine* 340, no. 2 (January 14, 1999): 77-84.

[153] See Richards et al; Sharon J. Durfy et al, "Attitudes and Interest in Genetic Testing for Breast and Ovarian Cancer Susceptibility in Diverse Groups of Women in Western Washington," *Cancer Epidemiology, Biomarkers and Prevention* 8, no. 4, part 2 (April 1999): 369-375.

Barbara Katz Rothman points out sardonically, as a result of inheritance, "a three-year-old girl can have a diagnosis of breast cancer before she even has breasts."[154] Certainly it would not be recommended to share such information with a child who is far from being able to understand or deal with this knowledge, and, strictly speaking, this is false, since all that we would know at that point would be her genetic predisposition, not whether or not she would actually develop the disease. Regardless, this does paint a powerful image about the importance of (not) sharing information. Just because I have made the decision to engage in screening so that I know if I am at increased risk for breast cancer does not mean that my sister has a similar desire to know this information. Hence, the fact that the knowledge gained from screening has implication for other family members must be considered in the testing process.

There is yet a more fundamental concern with screening for mutations in the breast cancer genes. Breast cancer was once a very private diagnosis, one that was shared only with family members and intimate friends, and one that often spelled a death sentence for the unfortunate bearer. That is not the case any longer. For a number of reasons, breast cancer has moved from the very private sphere into that of the very public. This might be on account of public figures sharing with the rest of the world the battles of themselves and/or their family (notably Happy Rockefeller, Betty Ford, Ann Jillian, and Rosie O'Donnell). Alternatively, it may be the result of scientific and statistical research that demonstrated the large number of women who

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[154] Rothman, 149.

can expect to develop breast cancer over the course of their lifetime. It is largely on account of this that the medical establishment began the very public campaign to ensure that women were vigilant regarding the signs and symptoms of breast cancer, because survival rates with breast cancer are dramatically higher when the cancer is detected at early stages and then treated rather than at later stages. As a result, the public has been bombarded by the statistics of breast cancer risk and implored to engage in whatever preventative measures are appropriate for an individual of that age and situation. Women are scared.

What is interesting about this campaign is the emphasis the medical establishment places on this particular condition. Not only is breast cancer not the leading cause of death among women (heart disease is), but it is also not the leading cause of cancer deaths (lung cancer is).[155] Furthermore, skin cancer is even more common than breast cancer.[156] One wonders, then, why breast cancer in particular has gained so much attention. Certainly lung cancer and skin cancer may be more readily preventable (don't smoke; stay out of the sun), and there are some proven ways to combat heart disease (eat a low fat diet, get regular exercise, etc.). Yet it is breast cancer about which women are to be especially vigilant. Why?

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[155] See "Women and Cardiovascular Disease," Biostatistical Fact Sheet – Populations, *American Heart Association*. May 16, 2000 <http://americanheart.org/statistics/biostats/biowo.htm>; "Facts About Lung Cancer," *American Lung Association*. May 16, 2000 <http://www.lungusa.org/diseases/lungcanc.html>.

Some might argue that the "early detection, early cure" mantra with which 21st century individuals are so familiar speaks to the real reason behind the public campaign: women who are careful about watching for the early signs of breast cancer are more likely to seek treatment regularly and hence the cancer may be caught in the early stages. After all, survival rates are higher when the cancer is caught early, before it has spread to other organs. The problem is that it is not clear that breast cancer is unique in this way: one can say the same thing for skin cancer, certainly, and watching for evidence of heart disease (regular cholesterol checks, or stress tests, for example) may accomplish the same goal. There is little data on the benefit of intervention in early stage lung cancer simply because it is rarely caught in the early stages; once an individual is showing symptoms, the cancer may already be too far progressed. Regardless, the point remains that early detection of lots of disorders may indeed lead to increased survival rates.

It is significant that the cancer in question affects *breasts*, often a defining characteristic of women. The traditional focus on women's physique reflects an attitude in society of shallowness and subjugation, where what is important about a person can be viewed at a glance and she can then be grouped accordingly. I contend that this perspective is operant in the attempt to so forcefully encourage women to be aware of their breasts and problems with them. In some way, a diagnosis of breast

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[156] "Colon and Rectum Cancer," Cancer Resource Center, *American Cancer Society.* May 22, 2001 <http://www3.cancer.org/cancerinfo/load_cont.asp?st=ds&ct=10&language=english>.

cancer is "worse" than that of the more genderless lung cancer or heart disease, and hence is to be avoided at all costs.

My present concern regarding genetic screening, then, is that such procedures may play into the masculine-centered emphasis on a woman's different-ness rather than on health concerns that are more prevalent and more preventable. I am not arguing that women should relax all vigilance regarding the signs of breast cancer; on the contrary, I would like to see them step up their vigilance regarding these other disorders. My concern is that if we focus our attention (energy, money, research) on a program that can at best tell us if there is an increased probability of developing something that there is very little we can do to prevent, then we may miss many opportunities to take a proactive role in the prevention of other disorders. Genetic screening is not at fault here, but may be one element contributing to a larger problem.

Colorectal Cancer

Colorectal cancer (CRC) is another disorder for which genetic testing may be useful in some instances. Approximately 25% of colon cancers are thought to be inherited, as suggested by the fact that they occur in younger individuals and/or that there is a personal or family history of cancer.[157] Furthermore, "[a]bout 3% of colorectal cancers are accounted for by two well-defined, highly penetrant, dominant

[157] Jonathan P. Terdiman, Peggy G. Conrad and Marvin H. Sleisenger, "Genetic Testing in Hereditary Colorectal Cancer: Indications and Procedures," *The American Journal of Gastroenterology* 94, no. 9 (1999): 2344.

hereditary syndromes for which genetic testing is now available."[158] These two syndromes are familial adenomatous polyposis (FAP) and hereditary nonpolyposis colorectal cancer (HNPCC). As with Tay-Sachs disease and breast cancer susceptibility, there is a specific mutation that is particularly dominant in the Ashkenazi Jewish community. One variant of APC, the gene responsible for FAP, was "first identified as a founder mutation in ~6% of the Ashkenazi Jewish population."[159] Hence, genetic testing for the APC mutation is of particular interest here. Since it is the gene responsible for FAP that is of interest to the community, the following discussion will be limited to FAP and will not address HNPCC.

FAP is an autosomal dominant disorder, which means that one defective copy of the APC gene is enough to cause the individual to be affected by the disease. FAP is characterized by "the presence of hundreds to thousands of colonic polyps occurring in the second or third decade of life. In most cases, one or more polyps will progress to CRC."[160] A particular allele, or form, of the APC gene, I1307K, has been identified in Ashkenazi Jews with CRC. One study indicated that carriers of this mutation have a "twofold increased risk of CRC" and that this allele is responsible for a "significant percentage of family CRC in Ashkenazi Jews."[161] Since "the lifetime incidence of

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[158] Ibid.
[159] Diane L. Maresco et al, "The APC I1307K Allele and *BRCA*-Associated Ovarian Cancer Risk," *American Journal of Human Genetics* 64 (1999): 1228.
[160] John Abrahamson et al, "No Association of the *I1307K APC* Allele with Ovarian Cancer Risk in Ashkenazi Jews," *Cancer Research* 58 (July 15, 1998): 2919.
[161] Steven J. Laken et al, "Familial Colorectal Cancer in Ashkenazim Due to a Hypermutable Tract in *APC*," *Nature Genetics* 17 (September 1997): 82.

CRC in the general Ashkenazi population has been estimated to be 9-15%,…the lifetime risk for CRC in patients with I1307K is likely to be in the range of 18-30%. Moreover, our data suggest that 28% of familial CRC in Ashkenazim is associated with the I1307K mutation."[162] Other studies have not been able to confirm these findings,[163] but have instead confirmed a "modestly elevated risk for developing cancer" for those who carry the I1307K allele.[164] Nevertheless, the authors of one review article contend that "even a small increase in CRC risk conferred by a gene that is common in a particular population will have important implications for that population."[165]

There is some indication that the I1307K allele, while predisposing certain individuals to colorectal cancer, may also confer a susceptibility to breast or ovarian cancer.[166] We previously mentioned the various degrees of penetrance associated with the breast cancer mutations, and suggested that, while the mechanisms of such varied expression are largely unknown, one possibility is that an interaction with other genes may account for the high penetrance of some mutations rather than others. The I1307K allele may be just such a gene which, when combined with one of the BRCA1 or BRCA2 mutations, modifies the penetrance of the mutation. The result, then, is that

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[162] Ibid.
[163] Abrahamson et al, 2920.
[164] Trevor Woodage et al, "The *APC* I1307K Allele and Cancer Risk in a Community-Based Study of Ashkenazi Jews," *Nature Genetics* 20 (September 1998): 64.
[165] Ibid.

individuals with both of these mutations may have an increased likelihood of expressing this disease than they would if they simply had one of these mutations. "Thus, even though APC I1307K alone does not appear to confer a substantial risk of ovarian cancer in the Ashkenazi Jewish population generally…, it remains possible that ovarian cancer risk may be increased in carriers of both APC I1307K and a BRCA mutation."[167,168] This, then, provides another indication for genetic screening for this mutation.

Ethical Issues

There are both similarities and differences in the ethical issues that surround breast and colon cancer. One difference is that colon cancer is not as prevalent as breast cancer in the population, and as many men are at risk as women. One similarity may be regarding an aspect of screening for the two diseases. Just as mammograms are not recommended for women as routine heath care until the age of 50 or so, colonoscopies (for those who have no reason to expect a particular susceptibility to the disease) typically are not considered until that age as well.

Another similarity to breast cancer is the fact that a particular genetic mutation

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[166] …or not. See Luba Petrukhin et al, "The I1307K APC Mutation Does Not Predispose to Colorectal Cancer in Jewish Ashkenazi Breast and Breast-Ovarian Cancer Kindreds," *Cancer Research* 57 (December 15, 1997): 5480-5484.

[167] Maresco et al, 1229.

[168] As it turns out, the authors of this study concluded that the APC I1307K mutation "…is a significant modifier of BRCA penetrance for breast, but not ovarian, cancer." (Maresco et al, 1229-30.) However, the point still remains that testing for the APC I1307K allele may reveal information about the patient's risk for other diseases.

seems to confer an increased likelihood of developing colon cancer on its unfortunate bearers. This mutation is unlike the Tay-Sachs mutation that means certain lethality for individuals who carry two copies of the gene. But it is also unlike the breast cancer mutations in the chances it confers of developing the disease. The numbers are nowhere near as high as the 80-90% prevalence rate of disease development as it is with carriers of one of the BRCA mutations, and this difference in prevalence is significant for decision-making (a point to be discussed in greater detail in chapters three and four).

One important empirical difference we see with colon cancer is that the rate of genetic screening is quite low, even among those who have reason to think that they are at high risk.[169] In light of some of the issues discussed relating to breast cancer screening that also seem to apply to colon cancer, this is curious. That is, if the same kinds of presuppositions hold here, screening rates ought to be much higher. Recall that we said that many people state that simply having the knowledge about their actual risk is valuable to them. For some this is reflective of an increased ability to make plans in their lives based on this information. These plans could consist of things that had been put off until the individual was more certain about his or her likelihood of developing the disease. Some suggest that "[d]ispelling the uncertainty of cancer risk may reduce anxiety, improve coping, aide [sic] in planning for the future, and

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[169] See Lois C. Friedman et al, "Psychological and Behavioral Factors Associated with Colorectal Cancer Screening among Ashkenazim," *Preventive Medicine* 29, no. 2 (1999): 119.

improve compliance with medical recommendations."[170] Alternatively, perhaps the possibility of developing cancer was so psychologically and emotionally distressing that until one received good news (that he or she was free from the mutation) or more definitive bad news (that one had the mutation), plans could not be made. If these things are true, then screening rates ought to be higher.

Another possible reason for a lack of enthusiasm about genetic screening represents another difference between breast cancer and colon cancer. The "early detection, early cure" mantra of breast cancer indicates the benefit of clinical screening: the earlier the cancer is caught, the more effective intervention can be offered. Identifying individuals who are carriers of the mutations for breast cancer provides an opportunity to monitor those who are most likely to develop the disease, and hence therapeutic intervention can be most effective.

It is not clear that similar measures can be taken for colon cancer. A major difference lies in the invasiveness of clinical examination. Individuals who are at increased risk for breast cancer can be more vigilant about watching for the signs of breast cancer by performing monthly self-breast exams in addition to annual clinical exams. The same cannot be said for colon cancer, where the most effective monitoring procedures are clinically intensive. Some "options for cancer surveillance and prevention for FAP…in known or suspected gene mutation carriers" include:

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[170] Terdiman, Conrad and Sleisenger, 2349.

- Annual flexible sigmoidoscopy beginning by age 10-12.
- Annual colonoscopy, beginning at age 20, when attenuated FAP suspected.
- Prophylactic colectomy in teen years or when polyps are detected at endoscopy.
- Endoscopic surveillance every 4-6 mo after ileorectal anastomosis and annually after ileoanal anastomosis.
- Upper endoscopy, including duodenoscopy, every 6 mo to 3 yr starting by age 20.[171]

Hence, while a negative result from genetic screening might levy the important consequence of reducing the frequency with which individuals need to be so screened (from every year to every two years, for example), a positive result confers no such benefit.

Of course, genetic information about one member of a family has implications for other members here as well. One clear benefit of a positive genetic screening would be to inform families of the risk children face of developing colon cancer long before any routine screening would be instituted. Hence, it is in this way that the benefits of screening most resemble that of breast cancer: where information from test results will prompt individuals to be more vigilant about the signs of disease development. This has a downside as well, however. Individuals who receive negative test results may experience some psychological feelings of guilt or shame from knowing that other members of their family may not be as fortunate as he or she is.[172] This must also be weighed as a factor when considering screening.

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[171] Ibid., 2346.
[172] Ibid., 2350.

The dangers of receiving negative test results from genetic screening for colon cancer may be even worse than they are for breast cancer in some ways. We previously mentioned that individuals who find that they are not BRCA mutation carriers may misinterpret that information and assume that they are then free from risk of developing the disease. A possible consequence from this is a reduction in the vigilance by individuals in either self or clinical breast exams or in mammography. The situation could be even worse for the case of colon cancer, where the only way to detect masses is through an invasive procedure; one can imagine that for individuals who learn they are not carriers of the mutation becoming lax in making or attending appointments for the abovementioned clinical procedures would be almost welcome.

An interesting side note relates to the frequency with which people usually get routine screening for colon cancer. With breast cancer becoming popularized in the media and with the baby boomer population aging, clinical screening for breast cancer, including mammography, has become increasingly popular. Most women see their health care providers for an annual exam, even if this initially is to enable them to obtain birth control or pregnancy counseling. The same cannot be said for clinical colon cancer screening. Fewer individuals go for colonoscopies than go for mammograms. This may be partly on account of the invasive nature of clinical screening for colon cancer than mammography; colonoscopies, sigmoidoscopies, etc. are uncomfortable and disruptive. And given that the most reliable method of

detecting early colorectal cancer is through a colonoscopy, comparisons can be made to the use of mammography for breast cancer.

This reduced use of screening in comparison to breast cancer may also be because of the differing degrees of public attention associated with the two diseases. Breast cancer used to be a very private diagnosis, one that women rarely discussed, until some very public figures brought the disease to the limelight.[173] Colon cancer has yet to achieve such notoriety, and short of a physician's recommendation to engage in regular screening procedures, few voluntarily choose such a path. In contrast, the genetic screening for this disease is much less invasive, requiring a blood sample from participants. Hence, it is possible that increased genetic screening might lead to the identification of more cases of colon cancer. At the very least, it will identify individuals who are at increased risk. So indeed genetic screening for this disease may provide benefits for those who otherwise would not engage in a screening process.

Part of the difficulty with such procedures, though, are the risks of genetic discrimination that may plague individuals who opt for screening. Given that prophylaxis for this disease is questionable and often radical (coloectomy, for example), one must weigh the costs of screening with the benefits. A conversation with a health care provider may reveal information that indicates that yearly colonoscopies, preferable in many ways, would be a better option for someone who is

[173] Happy Rockefeller, Betty Ford, and Ann Jillian, just to name a few.

concerned about his or her colon cancer risk. Assuming that such yearly preventative measures are included under one's health insurance plan (not a neutral assumption, to be sure), then it seems as though the clinical exam may be more beneficial than the genetic screening which runs the risk of increasing premiums, canceling policies, or influencing employment decisions.

These tests are also rather expensive to perform, and many individuals may be hesitant to claim such procedures against their insurance for the reasons mentioned previously. This is further complicated by the issue of reimbursement for those who would be willing to submit a claim; most insurance plans cover colonoscopies only when they are indicated by an abnormal finding in a previous – and less expensive – test: the fecal occult blood test or a sigmoidoscopy. Medicare typically reimburses physicians anywhere from $125 to $200 for a sigmoidoscopy and from $400 to $600 for a colonoscopy; the average price charged to private patients for a colonoscopy is $700, while a sigmoidoscopy is only $200.[174] Hence, the cost of the tests may be an impediment to having the screening done.[175]

Conclusion

What we see from the examples of "genetic" disease listed in this chapter is that for each disorder, there are unique features that are important to consider when

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[174] Melissa Schorr, "Scopes Trial." Abcnews.com, July 19, 2000. April 22, 2001 <http://abcnews.go.com/sections/living/DailyNews/coloncancer000719.html>; Of course, this figure is just for the procedure itself, and may as much as double when sedation, recovery services, etc. are included in the calculation.

[175] Terdiman, Conrad and Sleisenger, 2351.

making medical decisions. Some of the issues surrounding these disorders may be shared with other diseases. For example, the decision whether or not to abort a fetus that a family has discovered has Tay-Sachs disease may involve much of the same thought process as a family who is considering abortion for any reason: what abortion means to the family personally and religiously, how this act will compare with alternative acts (such as raising the child), when a life becomes a "person," etc. But I contend that with the age of genetic medicine and genetic information, new issues emerge that raise important problems for ethical decision-making. Knowing that the information received from a genetic test for one of the breast cancer mutations has implications for my siblings and my children will, and should, affect my decision to engage in such a procedure. Understanding that by submitting a claim for reimbursement for a genetic test for colon cancer, I might be endangering my family's, and my own, ability to find affordable health insurance should factor into my decision as well. These are just a few samples of the unique features of the genetic age of medicine that make these issues so compelling.

As a community that typically seeks religious guidance for ethical questions, the observant Jewish community will look to its leadership and tradition for assistance in making these difficult decisions. The traditional approach to answering such questions has been to apply certain rules or principles to the case or problem at hand in order to aid in decision-making. What I contend is that such an application of rules or principles, which necessarily requires some analysis and "simplifying" of the case in

order to pick the appropriate (set of) principle(s), will miss an important part of the decision-making process. In a tradition that focuses on the family as the central unit, the nurturing, caring, and sustaining roles of the family must be considered as equally important to the application of the traditional principles and rules. Hence, augmenting the traditional perspective with an ethic of care will lead to a more complete ethical framework.

In the next chapter I will discuss the traditional Jewish bioethical approach to medical decision-making, focusing primarily on the issues that relate to the three examples mentioned in this chapter. I will also point out where it apparently fails to adequately capture all of the important moral components of the problem. In chapter four, then, I will give the argument for why augmenting the perspective with an ethic of care is actually not a new aspect of this system, but is in fact part of the process that the rabbis have used all along. A recognition of this will lead to a more satisfying guide to moral decision-making in a medical context.

CHAPTER THREE

TRADITIONAL JEWISH BIOETHICS

With those three cases in mind, we are now in a position to turn to the question of traditional Jewish medical ethics. As mentioned in chapter one, Jewish scholars were dealing with questions of medical ethics long before it evolved into its own discipline. Obviously, then, many of the issues predate the development of genetic screening, testing, and intervention. Even before we knew there were such things as genes that were at least partially responsible for a variety of disease states, however, physicians and scientists did recognize the "heritability" of certain disorders: that some families were prone to particular ailments and others were not. This may have served as the basis for some of the ancient guidelines regarding the permissibility of treatment and risk-taking in these and similar situations.[176]

Early on in the discussion of Jewish medical ethics proper, though, scholars began dealing with the issue of Tay-Sachs Disease (TSD). Since this ailment was so common in the Ashkenazi Jewish population as compared to the population overall, this was a natural place to focus attention for the Jewish sources: on a disease that primarily affects Jews. Contemporary Jewish ethicists spent a fair amount of time early on discussing TSD and the possible options, so there is a good deal of literature on the subject.

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[176] See, for instance, Immanuel Jakobovits' discussion of hemophilia and its relation to the requirement for circumcision (1975, 198-199).

The tests for BRCA1 and BRCA2 are still relatively new in comparison with the test for TSD, as is genetic screening for colorectal cancer. Hence, while there is some literature on this issue from a Jewish perspective, much work is yet to be done. My task in this chapter is to review the Jewish bioethics literature of these ethical discussions. What will emerge is an exemplification of the process mentioned in the first chapter: particular principles will be isolated from each of the cases, and then the authority figures will use these principles to guide the patient to action. The primary principles, I argue, in cases of TSD are the sanctity of human life, the duty to preserve life and health, the obligation to procreate, and the principle of mental anguish. Issues related to abortion will also be relevant. For the genes associated with breast cancer, three main principles are important: the sanctity of human life, the notion that the body belongs to God, and, once again, the principle of mental anguish. In the section on colorectal cancer, I will discuss Jewish attitudes towards risk-taking.

In each of the cases (TSD, breast cancer, and colon cancer) I will further suggest why the analysis offered or suggested by traditional Jewish medical ethics is inadequate, and make some suggestions as to what is lacking. The inadequacy arises from a failure to fully take the context into account for each of the cases discussed, and this leaves an important part of moral decision-making out of the process. Incorporating an ethic of care into the traditional schema will help to alleviate this problem. In chapter four, I will further argue that this addition is really not new at all,

but instead is already a part of how the rabbis counsel individuals in their decision-making, and focusing on this aspect of the process will lead to a richer moral theory.

Tay-Sachs Disease

Both because of the early date at which the causal mechanism was discovered for TSD and because of the effect it has on this particular community, Jewish scholars have been thinking and writing about the issues involved for over thirty years. In this abundance of literature, one is able to discern the crucial issues for discussion from the perspective of a traditional Jewish bioethic. The first issue concerns the permissibility of genetic testing for TSD, or, for that matter, for other similar genetic problems. There are three time periods in an observant couple's life when this testing could occur: prior to marriage, after marriage but prior to conception, and after marriage and conception but prior to the birth of the child. These are the morally significant stages from the traditional Jewish perspective, as each stage carries with it different obligations and permissions, as will be described below.[177] A second issue becomes relevant after the discussion of the third time period, and that is the permissibility of abortion in Judaism. Each of these issues will be discussed in turn.

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[177] It is certainly possible, of course, that a couple might seek testing post-conception but prior to marriage. It is not clear to me that such a time period has different moral significance attached to it, apart from issues about premarital sex. There might be issues about the pregnancy that stem from this particular relationship of the couple, but these are not issues that arise from genetic medicine (or from medicine at all, for that matter). A discussion of how this complexity factors into this schema would be interesting but tangential to the line of argument presented here. The issues that related to this group, then, will be captured in the discussion of post-conception (post-marriage) testing, and will relate to the discussion of abortion.

Genetic Testing Prior to Marriage

The first time period at which a couple may be concerned with their risk for TSD is prior to marriage. Since there is a ban on premarital sex in Judaism, and since the disease in its most common form only affects children, couples who are considering marriage may be concerned about TSD for the first time. As we saw in chapter two, one particularly noteworthy example of a group that engages in genetic testing at this stage is the Orthodox group Dor Y'shorim. The founder of the group, Rabbi Eckstein, believed that this was the best opportunity to make a difference in the alarmingly high affliction rate within the Jewish community. As a result of his efforts, the rate of TSD within this community has dropped radically.

To understand why Rabbi Eckstein and others argue that prior to marriage is the most appropriate time to screen for TSD, one must understand the significance of marriage in the Jewish tradition. Marriage is commanded to all Jewish individuals, independent of procreation.[178] Yet it is within the context of procreation that the importance of marriage relates to issues of genetic screening. With a recessive trait such as TSD, where two copies of the mutant gene are necessary for the expression of the disease, it is only the coming together of the two sets of genes that is significant with respect to the risk of a child acquiring the disease. Hence, if it is the case that procreation is important in this culture, then there is added concern for genetic testing.

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[178] For an extended discussion of marriage independent of procreation, see chapter 2 of David M. Feldman, *Birth Control in Jewish Law* (New York: New York University Press, 1968).

In fact, procreation is of primary importance in this culture. David Feldman argues that, contrary to common opinion, the primacy of procreation does not derive from the fact that "Be Fruitful and Multiply" is often listed as the first in a long list of mitzvoth, or good deeds. Rather, "[t]he first-rank importance of the duty of procreation is set forth by the Talmud itself: 'He who does not engage in procreation is as if he committed murder; alternatively, 'is as if he diminished the Divine Image.'"[179]

Feldman further divides the mitzvah into three distinct parts: one biblical and two rabbinic. All of the "parts" of the deed attempt to ascertain what is required for the fulfillment of the "be fruitful and multiply" commandment. The biblical interpretation refers to Genesis 1:27, "male and female he created them," to argue that the commandment has been satisfied when a couple has produced both a son and a daughter, thereby replacing themselves.[180] The rabbinic interpretations are derived from two additional concepts: *la-shevet* (habitation) and *la-erev* (evening). The mitzvah known as *la-shevet* refers to a passage in Isaiah where the author speaks of the world being created for the purpose of habitation. The mitzvah known as *la-erev* speaks of the commandment to engage in intercourse both in the morning and in the evening, since the participants can never be sure as to when conception will occur. From these two additional interpretations, scholars conclude that simply having one son and one daughter is insufficient to fulfill the commandment. After all, the son or daughter might be infertile, which would result in the decrease of population,

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[179] Ibid., 47.

something that is at odds with "habitation" of the world. Furthermore, as Feldman points out, it is easy to add social and practical reasons to bolster the rationale of the law. Given infant mortality and morbidity rates, it is relatively easy to see why having two children may not be sufficient. Finally, in a culture that has been systematically persecuted throughout its history, it is understandable why there would be an injunction on couples to have more than the minimally required two children, to replace those who can no longer engage in procreation themselves. Hence, what seems clear is that Jewish couples are required to have a minimum of two children, but are strongly encouraged to have more.[181]

Given the importance of having children, then, it makes sense why Eckstein and others view prior to marriage as the best time to evaluate one's Tay-Sachs probabilities. If it is discovered prior to marriage that both individuals are carriers of the mutant gene, the marriage and hence potentially affected children can be avoided. This is the most straightforward way of ensuring that TSD rates decrease in that population.

Remember what is at issue here: whether or not genetic screening for TSD – or for any other disease, for that matter – is permissible under Jewish law. The permissibility of screening during this particular time period – prior to marriage – will depend upon the permissibility of genetic screening in general. That is, if genetic

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[180] Ibid., 48.

screening is prohibited in this community, then the time period during which it would be done would be irrelevant. It is to this issue that we now turn.

The permissibility of genetic screening derives from the overall perspective towards medicine in Judaism. First among important principles is the mandate to heal in Judaism. This mandate derives from a number of different sources. Exodus 21:19 speaks of healing another in case of an injury resulting from a confrontation. The wording used in this passage is a bit vague; when translated literally, the word "heal" is repeated: "…and heal he shall heal."[182] The rabbis of the Talmud interpret "this duplicate mention of healing as intended to teach us that authorization was granted by God to the physician to heal."[183] This is important, of course, to counter the supposition by some that any intervention in disease or illness, often viewed as Divinely caused, would somehow be either usurping the power of God, admitting to a lack of faith in His power, or to presume to understand God's will. Immanuel Jakobovits refers to this as the "…inner conflict between the essentially divine (and therefore providential) character of disease and the human efforts, through medical treatment, to mitigate or, if possible, to frustrate its effect."[184]

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[181] Of course, a couple's chance of fulfilling the requirement in the minimal number of attempts is only 50% anyway. I am grateful to Jonathan Kaplan for reminding me of this.
[182] Rosner (1991), 7.
[183] Ibid.
[184] Immanuel Jakobovits (1975), 2.

Jakobovits chronicles three approaches to this problem.[185] One approach is represented by an ancient sect of Judaism known as the Karaites, who did fear some or all of the concerns about usurping God's power and hence relied solely on faith and prayer to sustain them in times of illness or disease. "The second approach was simply to ask whether there was any less moral justification for curing illness, especially where it was caused by human negligence [as in the aforementioned passage], than for the application of water to the thirsty throat or of the plough to the virgin soil."[186] As there is a duty to do provide water to the thirsty person, this implies the duty to perform the former action as well. This approach is suggested by Rabbi Abraham Ibn Ezra, a famous biblical commentator, who argued that while some human intervention was justified, the passage in question limited that context to those of injuries inflicted by another in, e.g., a fight. Internal injuries (probably what we typically consider to be illness and disease) are left to God alone to heal.[187]

The third, and more widely accepted approach, was to acknowledge the "concept of disease as a divine visitation" while still affirming the justification of human intervention through a "divine sanction" to engage in healing.[188] Part of this sanction derives from the notion that as humans, we are both subject to the laws of the Divine and are partners with Him in the process of creation and sustenance.[189] "The

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[185] Ibid., 2-3.
[186] Ibid., 2.
[187] Feldman (1986), 17; Rosner (1991), 8.
[188] Immanuel Jakobovits (1975), 3.
[189] Feldman (1986), 16.

elaborate skill and ministrations of health-care people, and the sophisticated means and medicaments made use of, are ultimately an expression of God's inexorable blueprint. God afflicts and man, in fulfillment of a divine imperative, heals."[190] This is the view that ultimately prevailed, as Rosner states: "there is nearly universal acceptance that the sanctioning to the physician to heal is all-inclusive, encompassing all internal and external physical and mental illnesses. In fact, a commentary on the Talmud…specifically states that it is permitted to heal not only man-induced wounds but even heavenly-induced sicknesses and afflictions, i.e., all illnesses."[191]

The second biblical passage that is cited in regard to the mandate to heal is Leviticus 19:16, which commands that "thou shalt not stand idly by the blood of thy neighbor." According to Fred Rosner, "[t]he passage refers to the duties of human beings to their fellowmen and the moral principles which the sages expounded and applied to every phase of civil and criminal law."[192] What is interesting for our purposes here is to see how this biblical passage has been interpreted by both ancient and contemporary scholars to justify the mandate to heal. Rosner gives us a nice summary of the procedure. He refers to the writings of Maimonides, the great medieval rabbi and physician, to demonstrate this procedure. Rosner first cites the passage Maimonides uses in his code of law, and then interpolates from there.

Maimonides…states:

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[190] Ibid., 18.
[191] Rosner (1991), 8
[192] Ibid., 9.

> Whoever is able to save another and does not save him transgresses the commandment neither shalt thou stand idly by the blood of thy neighbor. Similarly, if one sees another drowning in the sea, or being attacked by bandits, or being attacked by a wild animal and is able to rescue him…and does not rescue him…he transgresses the injunction neither shalt thou stand idly by the blood of thy neighbor.
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> Such a case of drowning in the sea is considered as loss of one's body, and therefore, if one is obligated to save a whole body, one must certainly cure disease, which usually afflicts only one part of the body.[193]

Rosner here extrapolates the justification for a principle from a more specific set of instances.

Another passage that is cited as important for the permissibility of offering medical care is Deuteronomy 22:2, which includes the phrase, "And thou shalt return it to him," referring to lost property. Scholars have used this passage to argue for the requirement to aid others in life-threatening situations on the basis that in such instances that which one would be returning to another was his health or his body.[194]

Fred Rosner sums up the duty to heal from within the Jewish tradition in the following paragraph:

> If one asks why God granted physicians license and even mandate to heal the sick, one can offer the following explanation. A cardinal principle of Judaism is that life is of infinite value. The preservation of human life takes precedence over all commandments in the Bible except three: idolatry, murder, and incest. Life's value is absolute and supreme. Thus an old man or woman, a mentally retarded person, a

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[193] Ibid.

[194] Fred Rosner and J. David Bleich, *Jewish Bioethics* (New York: Hebrew Publishing Company, 1979), 23; Rosner (1991), 9.

> defective newborn, a dying cancer patient, and the like, all have the same right to life as you or I. In order to preserve a human life, the Sabbath and even the Day of Atonement may be desecrated, and all other rules and laws save the aforementioned three are suspended for the overriding consideration of saving a human life. He who saves one life is as if he saved a whole world. Even a few moments of life are worthwhile. Judaism is a "right-to-life" religion. This obligation to save lives is an individual as well as a communal obligation. Certainly a physician, who has knowledge and expertise far beyond that of a layperson, is obligated to use his medical skills to heal the sick and thereby prolong and preserve life.[195]

Given these biblical passages and the rabbis' interpretations of them, we now have the foundation for understanding that genetic screening is in fact permissible in some cases. This permission derives from two different sources: either genetic screening is a means to save someone's life, or screening is a means to engage in healing. Since both saving someone's life and engaging in healing are not simply permitted by required in Jewish law, using genetic screening to achieve these goals would be laudable. However, genetic screening does not always serve these purposes. Under what circumstances would genetic screening fall into these categories, and hence be permitted?

Genetic screening as a means to save someone's life seems to be a straightforward application of the aforementioned principles. This will be discussed further in the next section. The perspective of genetic screening as a means of healing, however, is a bit more complicated. To see how this concept is applied, one must understand "healing" in a broad sense. The reason that this is so is because in popular

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[195] Ibid., p. 10.

use, at least, the word "healing" typically corresponds to an end that is achieved; someone who is "healed" no longer has the ailment that was previously plaguing her. Genetic screening may not always lead to these same kinds of consequences, and yet the information may be beneficial for the patients. An example of this is genetic screening for TSD. Recall that there is no cure for Tay-Sachs Disease; as was discussed in the last chapter; the only hope for disease eradication is the prevention of the birth of affected children (either by preventing carriers from mating or through the abortion of affected fetuses). The eradication of disease is a project sanctioned by the observant Jewish community; this can be inferred from the focus on the duty to heal. We have looked at the passages that sanction human intervention into the disease process, even with the understanding that part of the cause of such a process may be divine. Relieving the individual patient of her ailment will require some knowledge of illness and the disease process, especially that which will be most effective in "curing" the individual of her sickness. Focusing on the individual and curing her ailments carries with it a correlative obligation to eradicate the disease that is afflicting her. This is because the duty to heal is the overriding consideration and is not restricted to individual instances of disease, but rather sanctions research into illness on the whole. The eradication of disease, then, is permitted, and in fact required, by the aforementioned biblical references. Since, at least at this point in medicine, the only way to eradicate Tay-Sachs disease from this community is to prevent its occurrence, Jewish law *prima facie* sanctions efforts in this vein. Since genetic screening for

carriers of the disease is one such effort, genetic screening may be permissible on the grounds that it is a way to heal individuals of their suffering.

As to the question of the time period most appropriate for screening, genetic testing shortly prior to marriage is one of the least disputed intervals among Jewish scholars. Testing individuals much earlier than that, for example, early in high school, is inadvisable for two reasons. First, as was discussed in the previous chapter, it takes two copies of the mutated gene to produce the disease. Carriers of (one copy of) TSD suffer no health complications. Hence, until the individual is contemplating marriage and its correlative obligation to procreate, such knowledge is not useful. A second reason not to screen individuals earlier is on account of the psychological effects such information may have on the teens. Rabbi Moshe Feinstein remarks that "…most young people are quite sensitive to nervous tension or psychological stress and, therefore, young men… or women… not yet contemplating marriage should not be screened for Tay-Sachs disease."[196] What Rabbi Feinstein seems to be referring to here is the process of maturation. Teenagers may be particularly "sensitive to nervous tension or psychological stress" because of both the pressures on them at that point in their lives (what to do with their lives, whether or not to pursue a college degree and if so, where, etc.), and because of the way that their emotions and psyches are developing at that point. We often hear about the influence of peer pressure at that age, and for a good reason: often our friends are what console us during these difficult

[196] Rosner (1991), 173.

periods. Hence, to add an additional burden, the knowledge that one is a carrier for a deadly disease, is both unnecessary and cruel. Hence, waiting until the individual is contemplating marriage, when the information gained from screening may have an impact, is preferable.[197]

Genetic Screening During Marriage But Prior to Conception

Of course, the aforementioned reasons for why it is inadvisable to screen for TSD early in one's life do not speak to the possibility of screening for TSD *later* in one's life. It is to that question that we turn in this section. The next logical step would be to screen for TSD after one has married but prior to the conception of any children. If screening is considered at this stage, the rabbis typically have had a further inquiry: for what purpose is screening being performed? Certainly, the eradication of disease through the prevention of the birth of Tay-Sachs afflicted children is still the broader goal, but the more specific intentions of the couples are important.

One reason why married couples may engage in testing prior to conceiving a child is simply to have information: to know if they are among those who risk a 1 in 4 chance of having a child afflicted with TSD. Many individuals find this knowledge helpful, whether the results are positive or negative. Certainly negative results may

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[197] In communities where the marriages are not arranged, but dating is permitted, then we might alter our recommendation to disclosure at an earlier point. I am still concerned about adding unnecessary burdens too early for them to be understood or even useful, but I recognize the danger in waiting too long, when emotional ties have already been formed and hence greater harm occurs because of the lateness of awareness. As with many such decisions, the right approach is a balancing act between the costs and the benefits.

alleviate the anxiety level of couples who are concerned about their risk for having affected children. But some even argue that the knowledge that one is at risk for transmitting the disease it also helpful; couples become more aware of the possible outcomes of having a child. Even if no other action is taken, many people find some relief in knowing the odds.

A second reason why married couples might engage in genetic screening for TSD prior to conception is to avoid the problem completely: if they find out that they are both carriers of the mutant gene, then they will refrain from having children. It is in this case where a couple's motive first takes on increased importance from the perspective of Jewish law. Remember that procreation is particularly important for this group of people: "He who does not engage in procreation is as if he engaged in murder." While having children is not the only reason for engaging in marriage, it is one of the most important obligations of a married couple. Hence, engaging in genetic screening for the purpose of not having children if the results come back positive is expressly prohibited by this group. Rosner cites J. David Bleich on this issue, who argues that:

> 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* [Jewish legal] viable alternative.[198]

Hence, screening for the possibility of not bearing children is prohibited.

Advances in medical technology, however, have made possible a middle ground between these two positions. Rather than engage in genetic screening simply for the purpose of information without the ability to alter one's conduct in light of that information, or rather than engage in screening for the purpose of making a drastic decision regarding one's progeny, another alternative is available. A couple may engage in screening to discover their carrier status, and then if the results come back positive, engage in conception that differs from the natural method: they could have children by means of assisted reproduction. Since it is having two copies of the affected gene that results in a child with TSD, assisted reproductive methods would have to ensure that this did not occur. One way of doing this is through artificial insemination by a donor (AID), where a woman would be inseminated with sperm that came from someone other than her husband who does not carry the gene. This would eliminate the risk for TSD because then only the woman would carry the mutated gene, and hence the child would be free from the disease (but may herself be a carrier). Another possibility involves in-vitro fertilization (IVF) where the woman's egg and the man's sperm are combined in a petri dish and then transferred to the woman's uterus once it has divided a number of times. Multiple embryos are routinely implanted in this procedure to increase the likelihood that one of them would "take" and implant itself in the uterine wall. What makes this technique particularly attractive for couples facing the risk of TSD is that such a procedure allows lab

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[198] Rosner (1991), 175.

technicians to implant only those embryos that were free from TSD.[199] Hence, assisted reproduction in this way also allows for some assurances regarding the alleviation of disease.

Before discussing whether or not either of these procedures would comprise viable options for the observant Jewish couple in lieu of conceiving naturally, we must determine whether or not such procedures are permitted at all. After all, if these technologies are prohibited generally, then even the best of intentions – prevention and hence eradication of TSD – may not be enough to justify their use. On the other hand, we have previously discussed instances where actions that were normally prohibited were "trumped" by other considerations and hence permitted in the service of some higher goal. That could happen here as well. Regardless, it is important to understand the perspectives on the technologies before evaluating them further.

Regarding AID, there are two conflicting schools of thought.[200] One school cites a number of Talmudic passages where an individual's parentage appears to have resulted from a means other than sexual intercourse between his parents: through impregnation via water in which a woman had bathed, or "linen on which a man other than her husband had lain" resulting in someone's impregnation. There are two primary concerns here: the status of the resulting child and whether or not the woman has violated a religious rule (against adultery, against incest, against premarital sex).

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[199] As Mary Ann Handel pointed out to me, this technology is very specialized and not widespread. However, the possibility does exist for the expansion of such technology, especially if there is a demand for the procedure by a portion of the population.

In each of these cases, the rabbis found judgment in favor of the woman in question, so that the religious rules that may have been violated had sexual intercourse taken place were not violated in this instance. In all of these cases, the rabbinic rulings supports the principle that "…the relationship between father and child is not necessarily dependant on physical intercourse between the parents, and that, on the other hand, the legal consequences of incest render a child illegitimate only if the forbidden union between the parents was natural."[201]

There is wide disagreement with these rulings, however, and contemporary rabbis almost universally condemn the practice of AID. This is primarily on account of three concerns: the prohibition against incest, the prohibition against adultery, and questions about genealogy that may lead to issues with inheritance.[202] The scholars fear that if a woman conceives a child through an anonymous sperm donation, then the resultant child, not knowing her parentage, may marry her brother. In such a case, the child will have committed incest, one of the three cardinal transgressions of Judaism. (Recall that any religious law may be circumvented to save a life except for the prohibitions against idolatry, murder and incest; these are the three "worst" crimes under Jewish law, and all are punishable by extreme measures.) A concern about adultery also arises because the sperm is not that of the husband's, and as a result the child may be considered a bastard, which has important legal consequences. Questions

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[200] Immanuel Jakobovits (1975), 246-248.
[201] Ibid., 247.
[202] Rosner and Bleich, 108-116.

about inheritance also wrinkle the picture, as the rabbis are uncertain to the claims of the child to the money and other assets of what today we would call the "social" father.

Immanuel Jakobovits also opposes AID, on more fundamental grounds than the above-mentioned, which are easily argued in either direction. Jakobovits opposes AID for "moral reasons": he is concerned about the possible precedent that allowing AID would set. He speaks of "…reducing human generation to stud-farming methods," and argues that this procedure

> …severs the link between procreation of children and marriage, indispensable to the maintenance of the family as the most basic and sacred unit of human society…Altogether, the generation of children would become arbitrary and mechanical, robbed of those mystic and intimately human qualities which make man a partner with God in the creative propagation of the race.[203]

Because of this severing of the family ties, some scholars worry that AID will lead to promiscuity and hence should be prohibited on these grounds.[204]

There is no clear conclusion from these varied sources as to the permissibility of AID. It is considered "by most rabbinic opinion to be an abomination and strictly prohibited,"[205] but given the divided opinions, Rosner suggests caution in the application of the general principles: "[s]ince many important legal and moral considerations which cannot be enunciated in the presentation of general principles

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[203] Immanuel Jakobovits (1975), 248-249.
[204] Ibid., Rosner and Bleich, 111.
[205] Rosner (1991), 96.

may weigh heavily upon the verdict in any given situation, it seems advisable to submit each individual case to rabbinic judgment, which, in turn, will be based upon expert medical advice and other prevailing circumstances."[206] Perhaps most important for our purposes is David Feldman's brief mention that "[n]one of the medically resourceful alternatives would be chosen, or permitted to be chosen, when conception and birth in the normal way are possible."[207] A question that must be addressed, then, is whether or not an exception would or could be made in the case of a couple facing the possibility of TSD. Since conception and birth are not the problem, but rather the constitution of the resulting child, it is doubtful that this procedure, contentious in and of itself, would be a viable option for these couples.

Homologous in-vitro fertilization[208] – IVF using the wife's ova and the husband's sperm -- does not carry with it the same problems that AID does: the sperm in question comes from the husband, so there are no problems regarding adultery for the women or questions of genealogy on the part of the child. Hence, the prohibitions against incest and the legal ramifications of illegitimacy do not arise in the case of IVF. However, IVF remains morally problematic for this group for three reasons: (1) as this procedure is conducted outside of the intimacy of the family bond, this similarly "severs the link between procreation and marriage" of which Immanuel

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[206] Ibid., 97.
[207] Feldman (1986), 75.
[208] From here on out, I will simply refer to homologous IVF as IVF.

Jakobovits speaks, so if AID is to be prohibited on those grounds, IVF will fare no better.

(2) The second major problem is the way in which the sperm is collected from the husband, as alluded to in chapter one.[209] This issue would also be raised in situations of artificial insemination with the husband's sperm – AIH. However, since the goal in cases of TSD is to prevent the birth of a Tay-Sachs afflicted child by making sure that both partners are not carriers of the mutation, AIH is not an option. If the husband is a carrier of the Tay-Sachs mutation, artificial insemination will not help.

Looking at the rulings regarding AIH, however, does assist us in the understanding the stakes involved in the procurement of semen. There is great concern in Jewish law to avoid the "improper emission of generative seed." While there is no clear biblical passage to which this prohibition refers, many relate this to the practice of "onanism," which was named for the main character in a Biblical story. In Genesis 38:7-10, we learn of Onan, whose brother had died and left his wife childless. According to the rules of levirate marriage, Onan was required to marry Tamar, his sister-in-law, for the purpose of having children and continuing his brother's line. He did marry her, but he apparently practiced coitus interruptus so that

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[209] See page 15.

Tamar never conceived. For this offense, God punished Onan with death, ostensibly because he "wasted" seed.[210]

Since semen procured for the purpose of inseminating his wife is not "wasted" in the same way, the rabbis cautiously permit the practice of AIH. What is at issue is how the semen can best be procured. Masturbation, the most common way to obtain semen today, is to be avoided at all costs. Instead, methods that more closely resemble the "natural" act of intercourse are preferred. For instance, the most desirable method of semen procurement is to retrieve the sample from the woman's vagina following sexual intercourse. Since this is logistically challenging in many cases, some authority figures sanction the use of a condom to procure the semen. Others, however, actually prefer coitus interruptus.[211] Regardless of the method, two important points are to be noted: "wasting" seed is to be avoided at all costs and is punishable by death, and that the procurement of semen in order to assist reproduction must be accomplished by the method that most closely resembles the "natural" act of sexual intercourse that is possible in the particular situation.[212]

(3) The third problem is the possible destruction of extra embryos is a problem

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[210] This is somewhat of an oversimplification of the story and its surrounding implications, but it is sufficient for our purposes. For a lengthy discussion of this incident, see Feldman (1968), 144-165.

[211] Rosner (1991), 95-97.

[212] Jonathan Kaplan suggested to me that it would be useful to be reminded here of the distinction between those who follow the traditions most closely and those who do not; alternative methods of semen procurement may be less of an anathema to couples that do not follow such orthodox traditions.

for some scholars in the Jewish tradition. In fact, this issue has the community divided. For our purposes, the terms "extra embryos" refer to embryos that were not implanted either because (1) they were simply extras or (2) because, after screening, it was determined that they carried two copies of the Tay-Sachs mutation and hence were deemed unsuitable for implantation. One source comments that "…untransplanted embryos have no standing and may be discarded."[213] The Talmud speaks of an embryo being "'mere water' within the first forty days of conception"[214] and hence can be destroyed. As another rabbi comments, "[t]o the extent there is an absolute [permission] to abort[215] a pre-40 days embryo, there would certainly be a dispensation to destroy or discard a preembryo (regardless of how many days had passed from fertilization) since its development has certainly not progressed to the 40-day point."[216] However, where the agreement seems to be is in the fact that an embryo conceived in vitro will not develop into a human being unless it is transplanted into the woman's uterus. For example, Rabbi Mordechai Eliyahu argues that: "'Fertilized ova that have been designated for transfer to a woman's uterus should not be destroyed, since a live fetus will develop from them, but fertilized ova that have not been

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[213] Richard V. Grazi and Joel B. Wolowelsky, "Preimplantation Sex Selection and Genetic Screening in Contemporary Jewish Law and Ethics," *Journal of Assisted Reproduction and Genetics* 9 no. 4 (1992): 319.
[214] Richard V. Grazi, *Be Fruitful and Multiply* (Jerusalem: Genesis Jerusalem Press, 1994), 181.
[215] Jewish views on the permissibility of abortion will be discussed in the next section.
[216] Yitzchok Breitowitz, "The Preembryo in Halacha," *Jewish Law – Articles*. September 26, 1998. <http://www.Jlaw.com/Articles/preemb.html>.

designated for transfer may be discarded.'"[217] Hence, the untransplanted embryo is not human, and "if there is no human fetal life outside the uterus, a superfluous fertilized ovum could be disposed of by any means, such as flushing down the drain. An alternative course of action would be to refrain from supplying nutrients to the ovum, thereby allowing it to perish."[218] What Rosner is identifying here is a distinction between a fertilized egg in a woman's uterus and a fertilized egg in a laboratory.[219] The crucial distinction is the potential for development. If science progresses to the point of the creation of an artificial womb, this distinction might be revisited.

This is, of course, different from those sources that argue that life begins at the moment of conception, when the sperm fertilizes the egg. Some argue on these grounds that the protection that is offered to the fetus extends back before the 40-day point. In IVF, technicians combine the sperm and egg in the petri dish; hence, despite the fact that the fertilized egg is not in a medium in which it can develop into a human being, conception has taken place. Hence, those who argue that life must be protected would not sanction the destruction of such an entity. Mackler cites J. David Bleich as opposing the destruction of viable embryos on the grounds that the distinction Rosner cites breaks down. "'[T]here are no obvious grounds for assuming that nascent human

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[217] Mordechai Eliyahu in Aaron L Mackler, "An Expanded Partnership with God? In Vitro Fertilization and Jewish Ethics," *Journal of Religious Ethics* 25 (1997): 290.
[218] Rosner (1991), 111.

life may be destroyed simply because it is not sheltered in its natural habitat, i.e., its development takes place outside the mothers womb.' He suggests that in vitro embryos that are viable should not be destroyed."[220]

Mackler suggests an alternative to these two views whereby unused embryos are permanently stored with the possibility of future transfer into a woman for gestation. He argues that this will respect all of the obligations regarding the status of embryos and the protection that some feel that they deserve. As recent events[221] demonstrate, however, this solution is less than ideal, as storage facilities are beginning to run out of room to hold all of the unused embryos. Mackler's suggestion seems simply to prolong the problem rather than to solve it.

Hence, the (im)permissibility of IVF seems to rest on the (im)permissibility of abortion, which is the topic of the next section.

Genetic Testing after Conception

It is possible that couples that are already pregnant would engage in genetic testing for the sole purpose of information gathering; that is, parents may want to know if the child they are expecting will be afflicted with TSD so that they can be

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[219] See also Moshe D. Tendler, "Rabbinic Comment: In Vitro Fertilization and Extrauterine Pregnancy ("Test-Tube" Baby)," *The Mount Sinai Journal of Medicine* 51, no. 1 (January-February 1984): 9.

[220] Mackler, 290.

[221] I am referring to the growing problem of lack of space for storage of extra embryos. For examples of the problem, see Sharon Lem, "Canada Lacks Embryo Law; Frozen Eggs Being Destroyed," *The Toronto Sun*, 24 July 1996, final edition, sec. News, p. 6; Reuter, "Brits Battle over Embryos," *The Toronto Sun*, 23 July 1996, final edition, sec. News, p. 8.

physically and psychologically prepared. As previously discussed, there would be little objection to testing if this were in fact the motivation.

However, many authorities would be concerned that results from such a test that indicated that the expectant mother was carrying a child with TSD would be used to justify abortion. To understand the implications of this, we must understand the views regarding the (im)permissibility of abortion in Jewish law.

Judaism has always permitted abortion in one particular circumstance: when the continuation of the pregnancy endangered the life of the mother. The defense of this practice can be traced to two principles: (1) that the fetus is not a "person" in the full sense until after birth, and (2) the fetus in such a case is viewed as a "pursuer" that is threatening the mother, who is then permitted to defend herself. I will briefly explain each idea below.

The fetus becomes a person, according to Jewish law, after it has been born. Until that point, it is considered to be a part of the mother and has no legal status of its own.[222] It is important to remember, however, that having no legal status does not automatically mean that the fetus has no moral status, either. Even if that moral status is less than that of the mother, certain moral considerations may be due to the fetus. Yet the fact that it is not a person with full moral status grants certain actions permissible that would otherwise be prohibited. One major scriptural basis grounding the different status between a fetus and a person is Exodus 21:22, where, as a result of

some sort of assault, a pregnant woman miscarries. The punishment levied on the offenders in this case is that they must pay some fine, as opposed to the penalty that would be appropriate for homicide, a capital crime. Hence, a fetus must be importantly different in status from persons in general.

This is not to say, however, that the fetus has *no* moral standing in Jewish law. On the contrary, Judaism is a life-affirming religion, with a principle respecting the sanctity of human life (which will be discussed in the next section). The "wanton destruction" of the embryo is never permitted, as the embryo is still potential life and has some significance.[223]

So what is the precise dividing line between "wanton destruction" and sanctioned disposal? One instance where abortion is clearly permitted is in the case of a threat to the mother's life. The passage from the Mishna most frequently cited is: "if a woman has [life-threatening] difficulty in childbirth, one dismembers the embryo within 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

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[222] Rosner (1991), 136; Feldman (1968), 254. The status of the child changes once it is partially born, and then again when it reaches the age of 30 days.

[223] J. David Bleich, "Abortion in Halahkic Literature" in Rosner and Bleich, 135. This point seems curiously at odds with the previously mentioned sanctioning of the disposal of embryos pre-40 days since their status is of "mere water." It could be that this source assumes that the entity does not really get "counted" as an embryo until the 40 days has passed. Or it could be that "wanton destruction" implies a complete lack of reasons for action, and as such it would not be justified. What this discrepancy points to is the difficulty of interpretation of ancient sources and the worldviews with which each authority figure approaches the problem.

life for another".[224] Some sources liken this to a case of self-defense, where we are permitted to kill someone who is mortally threatening us without the waiting for due process. Of course, an implication of this is that if the mother's life is threatened while pregnant – during labor, for example – from a cause *other* than the fetus, then abortion is not justified as a solution.[225] Only when the fetus is the cause of the mortal distress is abortion permitted. There is universal acceptance of abortion in this case; in fact, many sources argue that abortion is not merely permitted in such circumstances, but in fact is required to save the woman's life.[226]

From that point, however, the water becomes murkier. In traditional secular bioethics, therapeutic abortion has not been limited to cases of threats to the mother's life, but also included threats to her health. Authorities in Jewish bioethics differ on the permissibility of abortion in such circumstances. Given the difference in moral status between the fetus and the woman, however, most authorities claim that abortion is sometimes, even often, permitted when the woman's health is threatened.

To categorize the different approaches that sources have used to discuss this issue, David Feldman identifies one approach that "moves up" from certain principles and another that "moves down." That is, one approach begins with the assumption that abortion is "'akin to homicide,' and therefore permissible only in cases of

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[224] Feldman (1968), 275.
[225] Ibid., 281.
[226] See Feldman (1968), 275-284; Rosner (1991), 137, 145; Elliot N. Dorff, *Matters of Life and Death: A Jewish Approach to Modern Medical Ethics* (Philadelphia: Jewish Publication Society, 1998), 291.

corresponding gravity, such as saving the life of the mother."[227] This approach then works *down* from this strict perspective to one that acknowledges the legitimacy of abortion for other reasons, such as a threat to the woman's health and not just her life. The other approach "assumes no real prohibition against abortion at any time, except perhaps during the most advanced stage of pregnancy, and builds *up* from this lenient position to safeguard against indiscriminate abortion."[228] The first viewpoint, represented by Rabbi Unterman, looks to the danger involved to the woman were her pregnancy to continue. He includes in this assessment of danger challenges to mental health as well. Any form of instability that carries with it suicidal tendencies does constitute a life-or-death situation, and hence the principle should be extended this far. This is most commonly related to the principle of "mental anguish," where a person's psychological state is so severely affected by one of the proposed choices as to justify the selection of the alternative. Someone who is in such distress at the prospect of an upcoming child, for example, might do harm to herself or others, and hence would qualify as a life-or-death situation. These sources argue, then, that the notion that abortion is "akin to homicide," should be relaxed in these cases.

As for the other perspective, which does not recognize the strict legal interpretations of the first view, it still carries with it a recognition of the sanctity and value of human life, and an understanding of the fetus as a potential form of actual life. Hence, indiscriminate abortion is prohibited. After all, the fetus does retain some

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[227] Feldman (1968), 284.

moral status, and it is simply the consideration of the overriding status of the mother that outweighs the other's claim to life. However, given the absence of strict regulation as to the permissibility of abortion, when such an action is considered "…for a reason, even if it is a slim reason…then we have precedent and authority to permit it."[229]

There are a few specific concerns with which the sources have dealt that will be helpful for us to consider as they relate to issues involved with TSD. As to the woman who was distressed at the likelihood that her child may be deformed, because, for example, the mother had German measles or took Thalidomide during pregnancy, the rabbis traditionally have not permitted abortion in this instance. This is because of the uncertainty of the outcome; there is no guarantee that the child will be deformed.[230] This would require some sort of divine foreknowledge that humans lack. Hence, abortion is not permitted in these circumstances.[231]

With the advent of modern technology, of course, the issues change dramatically. Through mechanisms like ultrasound and amniocentesis parents are now much more sure of whether or not their children will be born with some abnormality. Hence, the argument that rests on the certainty of the outcome is diminished. That is, previously it was argued that women were prohibited from having an abortion because

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[228] Ibid.
[229] Ibid., 291.
[230] Ibid., 292.
[231] In instances where the mother would be so distraught at such a prospect as to pose a threat to herself or others, however, abortion would be permitted.

of a suspected abnormality with the fetus. Now that technology has allowed us to be more certain of the outcome, the argument about uncertainty no long holds. If abortion is still prohibited in this case, it must be because it is wrong to abort deformed fetuses, *not* because we are unsure that a deformed fetus will result. That is, in fact, the case here. If a woman was to have an amniocentesis performed for the purposes of aborting the fetus if an anomaly was detected, and such an abortion were prohibited, then the amniocentesis should be likewise prohibited. Engaging in such a procedure offers little in the way of solution and much in the way of heartache for these couples. It is on this basis that some rabbis argue against engaging in these procedures. So it is the case that the use of modern technology must be subjected to the principles and precedents in the same manner as other medical procedures.

As far as earlier intervention is concerned, there is some support for the notion that the fetus prior to 40 days is considered "mere water" and can be discarded or affected in ways not permitted of older fetuses.[232] Some consider the destruction of such an embryo not the taking of a life but rather the "destruction of seed," which carries with it different importance.[233] Even in the more strict interpretations, an early abortion is much less objectionable than a later one. This is understandable given the difference in moral status granted solely on the basis of development: the child that is born is closer to being a full person than is an early collection of undifferentiated cells.

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[232] Bleich, 142.
[233] Ibid., 146.

Some sources[234] do not grant full personhood to the child until she has reached the age of 30 days, given the high rate of infant mortality in the historical texts. A child that survives 30 days out of the womb is considered likely to develop and grow and hence is given full moral status.

With this as background, we can now turn to the question of the permissibility of abortion in cases of children with TSD. Assuming no other complicating factors, it is not the case that the woman's physical health is in jeopardy by carrying a TSD baby to term. Typically, there are no physical problems with the pregnancy, so the permissibility of abortion on the grounds of the threat to the mother's life do not apply here.

The question then revolves around the danger to the mother's health. For those sources that follow the strictest interpretation of law and precedent such that a danger to the mother's health is not a mitigating factor, abortion would not be permitted.

Many sources, however, do make an exception for women carrying a baby they know (through genetic testing) will have TSD. This is commonly accomplished through an appeal to the principle of mental anguish. According to this principle, an abortion is permitted if it can be demonstrated that the mother's mental health is in great jeopardy if she were to continue the pregnancy. The protection of the woman's

[234] See Rosner (1991), 139.

mental state[235] is affirmed because of the connection between mental health and physical health; one who is in a "state of hysteria" might very well "do physical harm to self or others."[236] Hence, certain cases of abortion have been justified according to this criterion: the mental anguish a mother may experience at the prospect of giving birth to a child who will degenerate before her eyes for a matter of 3-5 years may very well be a threat to her (or another's) physical health, and hence should be avoided.

It is solely with these considerations that a woman may abort a fetus with TSD. Either carrying such a child to term will produce such mental anguish in the mother that it would be destructive to her or to others, or else the fetus is viewed as a "pursuer" from whom the woman is justified in defending herself. So an abortion is possible for some women who discover that they are carrying a TSD-affected fetus, depending on the authority consulted and on the severity of the consequences that will result if she were to carry the child to term. Given the great variety in source interpretations, however, as well as the contingency of any claim of mitigation on the part of the woman, it is understandable why most rabbis recommend that testing for TSD be performed long before a woman is pregnant. However, for those that would permit a woman to have an abortion if the results came out positive for TSD, then genetic testing for this disease at this stage would be advised. For those who oppose

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[235] Betsy Postow suggested to me that the husband's mental state might be relevant here, and I agree. While it is not discussed in the literature, it seems to me that a man could be so distressed at the prospect of having another mouth to feed, for example, that the same risk of physical harm might ensue. Hence the principle of mental anguish ought to be applied in an egalitarian fashion.

abortion on these or other grounds, genetic testing at this stage would not be advised, since there is a good chance that distress would result from gaining information about which we could take no action. It is the case, as previously discussed, that genetic testing in order to be prepared for one's circumstances is, strictly speaking, allowed. Yet whether or not such action is advisable depends upon the amount of distress that might be experienced as a result of the information gained. While it is difficult to determine exactly how we will react to upsetting news, some indicators are better predictors than others about what to expect from others and from ourselves. These expectations must be taken into consideration when ascertaining the advisability of genetic testing.

Breast Cancer

An observant Jewish woman who is contemplating genetic testing for breast cancer would typically seek out her rabbi (or empower her husband to do so on her behalf) to determine whether or not such testing is acceptable according to Jewish law. Pronouncing an action acceptable under Jewish law does not require that it be carried out, but it does grant permission for its consideration, which otherwise would be lacking. This becomes especially important in a medical context, where the decision in question will likely affect the body of the individual. According to Jewish law, a person does not maintain complete sovereignty over her body; rather, her body belongs to God, and is simply on loan for the duration of her lifetime. Because of this

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[236] Feldman (1968), 286.

special relationship, every person is required to "take reasonable care of our bodies" and correspondingly to avoid any unnecessary harm.[237] Ascertaining exactly what it means to take "reasonable" care and avoid "unnecessary" harm is the task of the contemporary authorities.

So how would religious authorities determine the acceptability of breast cancer screening, given that there are obviously no specific guides on the subject in the ancient texts? The first step in assessing the acceptability of genetic testing for the mutations associated with breast cancer is to identify the rules and principles that would be relevant to this case. There are three fundamental principles that seem appropriate to apply to this case: (1) the sanctity of human life; (2) the principle of mental anguish; and (3) the idea of the body as belonging to God. I will discuss each of these in turn.

The principle of the sanctity of human life carries with it an obligation on the part of health care providers to heal whenever possible. Except for three cardinal transgressions (the prohibition against murder, idolatry and incest), it is permitted to override any religious obligation, including observance of the Sabbath, if it will save the life of oneself or another. This is because "…the overriding consideration in suspending religious laws is the intrinsic value of life, which transcends the moral worth of religious observance."[238] Hence, this principle takes *prima facie* precedence

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[237] Elliott N. Dorff, "Jewish Theological and Moral Reflections on Genetic Screening: The Case of BRCA1," *Health Matrix* 7, no. 65 (1997): 67.
[238] Immanuel Jakobovits (1975), pp. 47-48

over all the others; if a course of action can save a life, then that is the action that must be performed.[239]

Given this focus on the value of the life of the individual (which, of course, has certain implications for end-of-life treatment decisions), one thing that must be ascertained is whether or not testing for the mutations associated with breast cancer falls under the scope of this principle. Certainly the regular breast cancer screening procedures (self breast exams, yearly clinical exams, mammography) coincide with the goal of saving life, as the purpose of those procedures is to detect cancer early so that effective treatment may be offered and hence will help to prolong the life of the individual. Genetic testing for breast cancer mutations may accomplish a similar goal. A woman who has tested positive for one or more of the mutations will be aware of the need to exercise increased vigilance for signs and symptoms of the disease. It is also possible that she will engage in a clinical trial of a prophylactic medication, or even go to the extent of having a prophylactic mastectomy and/or oopherectomy on account of the information she receives from a genetic test. All of these measures seem to correspond to an emphasis on the intrinsic value of life.

However, one must remember that the opposite is also possible. I mean two things by this. First, it is possible that the test results will come back negative, and that

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[239] Note that this principle was operating implicitly in the discussion of abortion in the previous section. Individuals are permitted to do whatever is necessary to save the life of someone who is being "pursued" or who is in danger from another. The fetus, which has diminished moral status, retains some amount of protection from this principle, as it guards against "wanton destruction" of even potential life.

such a finding may dangerously encourage women to become lax in their self or clinical breast exams. This would run counter to the goal of the value of life. While this is certainly possible, it is with the second meaning that I am more concerned. It is possible that the psychological burden of a positive test result might be so severe as to impair an individual's experience with living. Knowing that one has a significantly increased likelihood of developing cancer – perhaps even the same cancer that killed her mother and sister – is a harm that must be considered when deciding on the advisability of testing. An interesting thing to note about the principle of the sanctity of life is that nowhere does it speak to the quality of the life that is preserved – a bone of contention with some euthanasia and physician-assisted suicide advocates. Regardless, even if these negative results develop as a result of finding out that one is at increased risk for developing breast cancer, insofar as this information is likely to lead to saving the life of this woman, there is nothing in the sanctity of life principle alone that speaks against having the test performed.

This quality assessment is apparently addressed, however, with the principle of mental anguish, which was discussed in the last section. Recall that according to this principle (in the previously-mentioned context), an abortion is permitted if it can be demonstrated that the mother's mental health is in great jeopardy if she were to continue the pregnancy. The protection of the woman's mental state is affirmed because of the connection between mental health and physical health; one who is in a

"state of hysteria" might very well "do physical harm to self or others."[240] Given this context for evaluating the importance of maintaining mental health when contemplating a medical decision, it is necessary to ask whether or not the fears previously mentioned regarding genetic testing for mutations associated with breast cancer would qualify under this principle. Certainly it is possible that the information gained from genetic testing would negatively affect someone's mental health. The question then becomes one of breadth: how broadly can the principle of mental anguish be applied before it becomes meaningless? This is a problem, of course, because *any* difficult decision carries with it some degree of mental anguish, some measure of being unsettled by the choice that has to be made. At what point does the distress become sufficiently severe to warrant an overriding status? Fred Rosner notes that "[p]sychiatric indication for abortion must be certified by competent medical opinion or by previous experiences of mental illness in the mother, such as a postpartum nervous breakdown."[241] From this, it seems as though the circumstances must be grave indeed to warrant the inclusion of this principle into the decision process. If that is the case, however, then the applicability of the rule is severely limited. Without clear evidence that the woman will have some serious breakdown as a result of the information she may receive from genetic testing, then there is no reason to override the principle of the sanctity of human life.[242] And yet mental

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[240] Feldman (1968), 286.
[241] Rosner, (1991), 145.
[242] The primacy of this principle is further defended in chapter five.

distress manifests itself in various forms, and is often quite harmful to many individuals on multiple levels. We have no indication, however, that Jewish law allows for this sort of consideration in the decision-making process.

The final principle that is of concern when discussing the permissibility of breast cancer testing is that the body belongs ultimately to God. The rules that cover the ways in which we care for our bodies follow from this overarching principle. There are rules that require Jews to take "reasonable care" of their bodies, to avoid "unnecessary risk," and to take positive steps to "maintain good health" whenever possible.[243] Fred Rosner interprets this to mean that a person "…is entrusted with her body and may use but not abuse it. She is commanded to care for her body and soul and do all that is necessary to protect and preserve both."[244]

The idea that the body is on loan to an individual, then, seems to sanction genetic testing for the purposes of information gathering insofar as the information is useful and important in saving the life or protecting the health of the individual. While this course of action also coincides with the principle of the sanctity of human life, it is brought into specific relief here. So, for example, a woman who discovers that she is at an increased risk of developing breast cancer may become more vigilant about the warning signs and hence her cancer may be detected earlier, thus saving her life. If Jews are commanded to do what they can to care for and preserve the body that is simply on loan to them, learning susceptibility information aids in that service. In

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[243] Dorff (1997), 67.

fact, one might make the argument that if sufficient treatment options are available for a particular affliction, engaging in testing for that disease is not merely permissible, but is mandatory. This follows directly from the notion that we are commanded to do whatever we can to preserve these bodies that are on loan to us. Certainly this seems to be the attitude society has taken in regards to the condition phenylketonuria (PKU). Infant testing is mandated by law in most states because the condition is largely manageable with a particular diet plan started almost immediately upon the child's birth. This is an example of an affliction where the therapy offered is sufficiently effective and accessible, and the test itself has a sufficiently low degree of risk involved, such that testing is required. Certainly the benefit-to-burden ratio needs to be assessed in each case, but the model is clear. The requirement to take "reasonable care" of our bodies in Jewish law clearly sanctions following health regimens to the extent we are able -- we ought to eat nutritionally-advantageous foods and get regular exercise – so that our body is being preserved as well as we are able. Seeking medical attention when it is necessary is also important, both for acute and chronic conditions. With the advent of genetic medicine, the injunction to seek medical care takes on a new twist. If a genetic test were developed that enabled us to know that we were at significant risk for heart disease, for example, which we know can be combated by eating sensibly and engaging in a regular exercise program, then taking "reasonable

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[244] Rosner (1991), 149.

care" of our bodies might include both having the test done and, subsequently, following the recommended course of action.

The situation is a bit less clear with genetic testing for the genes associated with breast cancer, since there is little therapy currently available for those who discover that they are at particular risk for developing the disease. However, learning which diseases pose special threats to individuals may not only increase their vigilance regarding signs and symptoms of the disease, but may also cause them to take proactive measures, such as engaging in prophylactic treatment interventions or not having children to avoid passing the gene to future generations.

One example of such engagement is the woman who chooses to take a more proactive role in relation to her risk for developing breast cancer and opts for a prophylactic mastectomy and/or oophorectomy. This act may indeed save the woman's life…or it may not. A prophylactic mastectomy does reduce the woman's risk of getting breast cancer, but not all the way to zero; there is still a chance that she will develop the disease in remaining tissues. Furthermore, recall that there is no guarantee that a woman who tests positive for one of the mutations will in fact develop breast cancer. So if the woman never develops the disease, it is possible that this disfiguring surgery was, in some sense wasted. (Of course, it is also possible that she did not develop breast cancer *because* she had the surgery!) Regardless, this speaks to an important issue: how much evidence is "enough" to justify an action? The rules in Jewish law regarding the treatment of the body are specific; both temporary measures

like the use of cosmetics and the more permanent measure of cosmetic surgery are permitted on the grounds that we are beautifying ourselves and hence further dignifying the bodies that God has loaned to us.[245] The proposed body alteration in this case, of course, does not involve beautification, but rather the opposite: intentional deformity. And yet the removal of a cancerous breast from an affected individual is clearly sanctioned. This action is justified in Jewish law by the positive obligation to preserve life and health, and insofar as the removal of the tissue coincides with this goal, then the action is permitted. Intentional deformity, then, would be permitted in the case of *actual* breast cancer, but it is unclear to me if it would be likewise permitted in the case of the *susceptibility* to breast cancer.

Rabbi Dorff utilizes the previously mentioned principles to argue for an obligation for a woman at risk for the mutations to be tested. He offers two grounds for this obligation: the duty to preserve life and health, which requires increased vigilance on the part of the woman if she tests positively for the mutations and, secondly, because such a test "opens up the possibility … of a radical mastectomy in an effort to prevent breast cancer."[246] However, he offers no further defense of the mastectomy, and hence it is still unclear to me that such an action would be permitted, much less required.

A final issue that must be considered in relation to the woman's decision to undergo a prophylactic mastectomy relates to the issue of probabilities. As previously

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[245] Dorff, (1998), 267-272.

discussed, it is not certain that the woman will not develop breast cancer if she has the surgery, nor is it certain that she will develop the cancer if she refuses this course of treatment. Hence, the degree of uncertainty to which each alternative is tied will be important in the woman's decision process. For example, while it is the case that she might still develop breast cancer even if she has the mastectomy, the probability of her doing so is drastically reduced. Depending upon how the surgery would affect her psychologically, this course of action may carry with it the greatest benefit. On the other hand, if she were so psychologically burdened by the surgery that knowing that she still would retain some chance of developing the disease would be even more of a harm, then the probability of her developing breast cancer takes on a greater importance. What this underscores is the need to evaluate each individual's situation separately, with an understanding of the probabilities as well as how this will be influenced by her concerns and predilections.

Colorectal Cancer

There are many similarities between the issues involved in colorectal cancer and those that are involved with the other diseases mentioned. The applicability of the notion that the body belongs to God and is on loan to humans, for us to care for during our lifetime, is one notable similarity between breast cancer and colon cancer. The principle of mental anguish, discussed in relation to both TSD and breast cancer, will

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[246] Dorff (1997), 89.

apply here as well. Hence, much of that which was previously used to justify decisions in Jewish law will apply in this context as well.

However, there are unique features of colorectal cancer that make it an interesting subject for discussion. One main difference between colorectal cancer and breast cancer, for example, is the rate of prevalence of the diseases, as discussed in chapter two. Not only is colorectal cancer less common than breast cancer, but the implication of the genetic test is importantly different: individuals who have the genetic mutation associated with colorectal cancer have an increased likelihood of developing the disease, but how likely that development is is unclear. While a positive result of mutation testing for BRCA1 or BRCA2 mutations indicated a strong likelihood that the individual would develop breast cancer, and even more so for the Ashkenazi Jewish population where carriers of one of the mutations are at three times the risk for developing breast cancer as is the general population.[247] The situation is more vague with colorectal cancer. This is important because with the difference in probability of developing the disease comes a different set of considerations in assessing the risk of participation in genetic testing.

It is also significant that the clinical screening examinations for signs and symptoms of colorectal cancer are much more invasive and uncomfortable than those for breast cancer. This is important because, in some senses, it raises the stakes for genetic testing: if it were the case that a negative result from genetic testing would

[247] Fodor et al., 45.

mean that individuals could participate in fewer invasive examinations, and that the testing does not carry with it any additional burdens, then this is a compelling reason to engage in testing. Since roughly 15% of the cases of colorectal cancer diagnosed annually have a hereditary component, this information could indeed be significant.[248] In fact, though, there are additional burdens with this, as with all, genetic testing: the risk to an individual's insurance coverage, and the risk that that the patient will find out information about her family members that the family members may not want to know. Furthermore, there are dangers associated with testing that are similar to those discussed in relation to breast cancer: individuals who find that they do *not* have the mutation associated with colorectal cancer may become lax in getting recommended clinical exams. This is especially dangerous for those at risk for colorectal cancer since the only way to detect the disease is through the invasive exams. All of this must be weighed in a cost/benefit analysis of genetic testing for colorectal cancer. Since the recommended course of action for a negative test result – that annual colonoscopies that are recommended for those with a family history of early-onset colorectal cancer can be reduced to a colonoscopy every two years – is, in some ways, only a slight benefit, many would argue that the burdens incurred by genetic testing outweigh the benefits. In this section, I will focus on individuals who share these concerns and, as a result, desire not to engage in genetic testing, despite the recommendations of their health care providers.

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[248] Laken et al., 79.

There are three principles in Jewish law that explicitly relate to genetic testing for colorectal cancer, but because of these varied consequences, I contend that the closest analogy to this issue in Jewish law is the concept of risk. The other two principles, the principle of mental anguish and that of the individual as a caretaker of her body, will be discussed in relation to the issue of risk. Assessing how much risk an individual is permitted to – or even should – take will be appropriate for the patient who is considering not engaging in genetic screening because of some or all of the abovementioned factors. It is important to note here that while risk is involved both in engaging in screening and in refraining from screening, more risk to an individual's health is at stake when an individual refrains from engaging in genetic testing. This is because the additional information that would be available to the individual as a result of the test would be absent. Hence, unless otherwise noted, the risk discussed in this chapter refers to that which the individual incurs by refraining from engaging in genetic testing for the mutations associated with colorectal cancer.

According to Jewish bioethicist Benjamin Freedman, the general attitude towards risk is that "…risks must be counterbalanced by proportional gains, so that even the greatest risks are allowable under extreme conditions."[249] To begin with, Freedman emphasizes the role of the individual as the caretaker of his or her body. As discussed in the section on breast cancer, an individual's body belongs to God and is on loan for the duration of his or her lifetime. Any acceptable risk to this body, says

Freedman, must coincide with the goal of the individual acting as a reasonable caretaker of this body. Some risk may be allowable – for example, occasionally ordering pizza with extra cheese – but such a risk is relatively minor. In an attempt to ascertain how much risk is allowable in a medical context, Freedman discusses three principles that define and classify "allowable risk." According to the first principle, an individual may risk life in order to lengthen life.[250] For example, if there is one last treatment for a dying man that has a chance at saving his life, but also has a chance of killing him if it does not work, the Jew is permitted, but not required, to participate in the treatment and hence assume the risk. Presumably this is on account of one of the principles previously mentioned, that of the sanctity of life. Since life is sacred in Judaism and we are commanded to do whatever we can to save a life, then the benefit of taking on a risky procedure that has some chance of saving someone's life overrides the possibility that it might cause death. The attempt to save a life is what is crucial here.

Given this focus on the sanctity of life, it does not appear as though taking on the risk by not engaging in genetic testing would be sanctioned according to this principle. Knowledge that one has a genetic mutation that puts her at increased risk for developing colorectal cancer could assist her in saving her life by stimulating her

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[249] Benjamin Freedman, *Duty and Healing: Foundations of a Jewish Bioethic* (New York: Routledge, 1999), 262.
[250] Freedman, 262.

to engage in more frequent clinical exams,[251] to become more vigilant about the warning signs, etc. Hence, if there is a way to sanction refraining from engaging in genetic testing for colorectal cancer, it must be justified according to another principle.

The second principle Freedman mentions is "risking pain and life for quality of life."[252] An understanding of this principle includes knowledge of Jewish attitudes towards pain and suffering. While a detailed discussion of this is beyond the scope of this work, suffice it to say that, unlike some in other religious traditions, pain and suffering are not to be sought or endured for some means of salvation or soul-building. Rather, pain is to be alleviated wherever possible, even when such alleviation carries with it some level of risk.

Quality of life assessments, however, are not exclusively concerned with pain and suffering. In his discussion of cosmetic surgery, Freedman investigates whether or not an individual is permitted to undergo some "self-wounding" in order to produce a better appearance. He argues that this is justified in Jewish law because "…a person is permitted to undergo a degree of self-wounding and pain on behalf of that which he or she judges to be a greater good."[253] Of course, the interpretation comes with figuring out exactly what constitutes the "greater good." If one holds that the burdens

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[251] In the event that an individual would voluntarily engage in more frequent clinical exams without the external stimulus provided by genetic testing, then the benefit of testing is lessened. However, given the onerous nature of clinical examinations for colorectal cancer (colonoscopies, etc.) it seems to me that such compliance would be unlikely without some other form of encouragement.

[252] Freedman, 279.

[253] Ibid., 294.

of screening for mutations associated with colorectal cancer outweigh the benefits, then it seems like the greater good to be served here might indicate that an individual should not be tested. The principle of mental anguish seems relevant here as well: the severity of the mental distress caused by the possible consequences of finding out the testing information is important to consider. If, psychologically, the burdens significantly outweigh the benefits, then this is another justification for refraining from testing. Suppose that the individual does engage in testing and finds out that he or she carries one of these mutations. Despite the regulations previously discussed, it is possible that employers or insurance companies may learn of this data, and that would in turn affect not just the individual, but her family as well. That is, there is a threat that if he or she learns that he or she carries the mutation, so will the insurance company. The insurers may then exclude coverage of colorectal cancer treatment not only for herself, but also for her children, etc. This is a burden that must be considered when contemplating testing.

Freedman discusses risk in relation to occupational hazards, and argues that an individual may take increasing risk as her economic situation becomes more desperate.[254] For an individual who is concerned about losing insurance coverage as a result of a positive result from genetic testing, it is possible to argue that her economic constraints are sufficiently severe to justify taking such risk. Considering that any information gained from a genetic test also gives information about my family

[254] Ibid., 297.

members, the concern about insurance coverage for everyone becomes even weightier. Hence, it may be possible to justify refraining from screening on economic grounds. Freedman specifically argues, though, that this principle cannot be restricted to occupational considerations, since "[p]ersons are more than just economic units. Rather, it [the principle] must be understood as encompassing both occupations and any other important social role (e.g. marriage, filial duty) that person occupies or plans to occupy."[255] If this is the case, however, then it seems as though the principle leads to contradictory rulings. Considerations of my social role, for example, as a parent, seem to argue for the injunction to be tested. This is because testing is a course of action that may result in saving or prolonging my life, and my obligations to my children seem to require that this action be undertaken. My children depend on me to be here to care for them.

On the other hand, a genetic test reveals information about my children just as it does about me. Perhaps we could argue that my obligations as a parent require that I not engage in testing because doing so might result in a series of bad consequences: the cancellation of my insurance policy, making my children uninsurable when they apply for coverage, or raising of the premiums to a point where I would be unable to pay, which would be detrimental to the health care of my children; gaining information about my family members regardless of whether or not they want to know the information, etc. There is a minimal ranking of principles in Judaism; first and

[255] Ibid., 299.

foremost, we are commanded to do what we can in order to save a life. The problem is that even this principle is not absolute; previously in this section we looked at actions that could be undertaken which had some chance of risking life in favor of some other goal (ending pain and suffering, for example). So there is no clear way to adjudicate between these conflicting principles, or between conflicting actions that seem to be justified by a particular principle. This is one of the key problems with using Jewish bioethics as a moral guide, and it will be discussed in more detail later.

The third and final principle Freedman discusses in relation to risk is in regard to the threshold of risk and the notion that "God protects fools."[256] While there are many interpretations of this principle and the scope is quite large, Freedman focuses on one in particular. "This view understands the principle as granting the reasonable caretaker permission to engage in activities that the general population have come to accept despite the (relatively improbable) risks they might entail."[257] In order for the risky behavior to be sanctioned, says Freedman, two conditions must hold: (1) the risk must be improbable; and (2) "it must be an activity widely (although not necessarily universally) engaged in, without its participants particularly noticing the minor risks to which they are exposed."[258] There is risk involved in not engaging in genetic testing: an individual may have a particular mutation whose discovery could lead to extra vigilance for the symptoms of cancer, or she might be able to engage in some sort of

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[256] Ibid., 300.
[257] Ibid., 305.
[258] Freedman, p. 306.

prophylactic therapy. A negative result from genetic testing might alleviate the psychological worry of individuals, and hence not having the test done would enable the individual to continue to fear that he "has the gene." However, there is also risk involved in engaging in genetic testing for colorectal cancer. A positive test result may result in insurance and/or economic problems for the individual and his/her family. Test results will give information about other family members who may not share the desire to know of their risk. Negative test results may cause an individual to become lax in getting clinical exams, which could have a detrimental effect on her health.

It is difficult to determine how "improbable" these risks are, and hence whether or not this action would be permissible for Jewish law. It seems to me that the probability of the various outcomes will vary by each situation and hence must be addressed accordingly. More interesting, I think, is the idea of the risky activity being one that people generally engage in without a recognition of the kinds of risk they are engendering by their action. Since mutations run in families, those individuals often are aware of their risk: they have a father, or a sister, or a grandparent, who developed the disease. But is the general public aware of their risk of getting colon cancer? It is unclear. Certainly one interpretation of the fact that fewer people engage in routine colonoscopies suggests that the general population is not aware of its risk. The interesting thing is that the "risky" activity referred to here is *living*, and omitting genetic testing does not change that. So the question for our purposes becomes: Is the

risk of developing colorectal cancer too great to justify living without the knowledge of whether or not one carries a genetic mutation associated with that disease? It is unclear that these principles give us any guidance in relation to this problem. The genetic test itself has a low level of risk (it has the same risk as any simple blood test, or even less than that if a cheek swab is sufficient for analysis). The risk involved is in obtaining the results from the test. Giving the current state of public misunderstanding about genetics and the results of genetic testing, some would argue that given the uncertain nature of the information gained from the test for mutations associated with colon cancer, the risk is actually greater from having the test done than from simply continuing to visit one's doctor to get regular clinical evaluations.

Regardless, from the principles mentioned associated with risk, and given the varying probabilities associated with the information gained from this genetic test, it is unclear whether or not Jewish law would sanction genetic testing for colorectal cancer. My sense is that it would be permitted but not required, and I contend that this is not enough. In a sense, we're back to square one: trying to decide whether or not to engage in testing. Nothing that has been said here gives us a sufficient action guide to help us make the decision of what to do in this situation. What it does, as I will specify in the next section, is to function as side constraints on action that narrows the range of choices, but gives no positive guidance to help the individual make a decision. In order to prove useful to actors, an ethical theory must help us to narrow the choices of

action in which we can engage, and it is not clear to me that Jewish bioethics alone accomplishes this.

Problems with Jewish Bioethics

The principles and rules that have been discussed in this chapter are intended to serve as action guides for the observant Jewish community. The individual Jew who is facing a treatment decision approaches his or her rabbi to discover both which principles are appropriate for his/her situation, as well as how to apply those rules to arrive at a decision. So it is the assessment of the relevant principles and rules that are intended to assist the individual in making a treatment decision that is sanctioned by Jewish law.

Some might object that it is unfair to collapse rules and principles into one entity, as I have done throughout this work. Jean Grimshaw, for example, argues that rules and principles are importantly different. According to her interpretation, the guides that I have described in Jewish law would be rules, not principles. "A rule specifies or forbids a certain sort of action, and to follow a rule is to accept a guideline for one's conduct whose purpose is to eliminate the need for reflection, except in marginal or problematic cases."[259] A principle, on the other hand, invites reflection, and can best be expressed in the form "Consider….".[260]

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[259] Jean Grimshaw, *Philosophy and Feminist Thinking* (Minneapolis: University of Minnesota Press, 1986), 207.
[260] Ibid.

It is not clear to me, however, that such a distinction is tenable when we look at the model of Jewish law. The proper domain of rules that Grimshaw specifies, that of serving as guides for decision-making, only makes sense in terms of specific cases, and the application of those ideas will require reflection. Traditionally, that has been the role that the authority figures have assumed, presumably because they were better equipped in some way to specify the range of acceptable action. The rules in question must be general in order to be widely applicable. Yet it is this breadth of application that is the limitation of these rules.

Perhaps an example will help to clarify this point. Grimshaw uses as an example the shared belief by both of her parents that it is wrong for a man and a woman "to live (i.e. sleep) together if they are not married."[261] This shared belief resulted in different actions in relation to Grimshaw's sister, who apparently was doing this very thing. Her father refused to visit his daughter's house for fear that such a visit might be construed as "condoning" the practice, while her mother did visit her child and grandchildren despite maintaining the belief that her daughter's practice was wrong. Grimshaw argues that what is exemplified in this case is that her mother and father share a rule ("'Don't sleep with someone to whom you are not married,'") but did not share principles. Grimshaw argues that her father's principle was: "'Consider whether your behaviour will condone that which you think to be morally wrong.' My mother also had this principle, but she had another one too: 'Consider

[261] Ibid., 209 – 210.

whether your behaviour will stand in the way of maintaining care and relationships.' This principle overrode the other…"[262]

This case is not as clear-cut as it seems. Suppose that we grant Grimshaw the fact that her parents shared the rule in question: Don't sleep with someone to whom you are not married. Her parents followed this rule, as much as we can tell: they weren't sleeping with anyone but each other. The problem was with what the *daughter* was doing, and there is no indication that she shared this rule of her parents – in fact, it is relatively clear that she explicitly *rejected* this rule. If the sole function of a rule is to specify or forbid a sort of action to "eliminate the need for reflection," then this did its job…for those who accepted it. Grimshaw's parents were not having extramarital sex.

The problem, of course, is that the case in question required her parents to consider their actions towards someone who violated this rule of theirs, without specifying why anyone should accept this rule in the first place. To be more precise, the rule that specified or forbade action in this case would have to go something like this: Don't sleep with someone to whom you are not married, and don't perform any action that might be interpreted as approval of such behavior. This rule is better because it applies to situations like Grimshaw's sister's, where a choice in action had to be made.

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[262] Grimshaw, p. 209.

What is evident, of course, is that the rule/principle distinction has collapsed. What Grimshaw called the "principle" that her parents shared I have turned into a rule. I contend that something like this happens whenever we look at an actual case, and this is important: rules and principles are supposed to aid our decision-making process, and our decisions only matter when they are about real cases. Reflection is a necessary part of the moral life, and it is unlikely that a distinction between the overtly reflective and non-reflective portions of a decision will do any work for us when we have to make a decision. Hence, I will continue to use the terms "principle" and "rule" interchangeably.

It is not clear to me, however, that these rules and principles *do* serve as appropriate action guides for the individual patient. Knowing that we are required to do whatever is necessary to save life and preserve health gives us a good starting point to initiate the discussion. But in light of the various options open to the patient, this principle is rarely sufficient to serve as an action guide alone. Many different courses of action might coincide with the goal of saving life or preserving health, especially if the latter is understood to include mental health in its definition. Instead, this principle seems to serve as either a side constraint on any proposed action, or, alternatively, the principle gives us a general orientation according to which we should approach particular problems.

If that is the case, then perhaps the other rules and principles that are specified by the authorities for particular cases do help to shape an individual's decision. That

argument seems plausible when we look to some of the ethical issues involved in TSD. A couple that is concerned about their risk of having a child affected by TSD might initially consider not having children as a response to this concern. That is, there is a range of possible action open to the couple concerned about its risk for having a child with TSD that includes not having children in the first place. The principle that specifies the duty to procreate, however, rules out this option. That is, this principle in Jewish bioethics removes this action from the range of those possible for the couple because if they are committed to following the demands of the tradition, they must procreate. Once again, this is a limiting agent for the decision-maker; in effect, this principle serves as a boundary within which a decision must be made. The boundary is specified by the applicable rules or principles – actions on one side (outside?) of the boundary are impermissible, and actions on the other side (inside?) are permissible.

This is useful, of course: a moral theory ought to limit our range of choices. My argument is that Jewish bioethics does not limit them *enough*. I am not advocating that a moral theory ought to only prescribe one or two right actions, and leave no room for whim or choice on the part of the individual. What I am saying is that a moral theory ought to do more than simply serve as rough guidelines; it should give us some mechanism by which we can wade through the possible actions so that we can decide on the right action for us.

We could make the same argument for both breast and colorectal cancers. Suppose a woman is trying to decide whether or not to engage in genetic testing for

either of these diseases. The principle that the body belongs to God serves as a limiting agent, that is, as a constraint on action: she is prohibited from engaging in action that intentionally destroys the body, and is permitted to engage in measures of beautification. Furthermore she is aware of the value of life and that she is to do what is necessary to take "reasonable care" of the body while it is in her possession. How this translates into the decision about whether or not to engage in testing, though, is unclear. Getting information that may be useful to save her life is desirable under Jewish law. But if such knowledge causes some or all of the harms previously mentioned, then such suffering is to be avoided. Once again, the general rules and principles serve as side constraints, but do not further assist the woman in making a decision.

There is an image in my mind that corresponds to the methodology employed by Jewish bioethics. Starting with the range of possible action for an individual, I envision a series of concentric circles whose boundaries represent the principles in Jewish bioethics. The outermost circle's perimeter represents the principle of the sanctity of life. The inside of the circle represents the range of action in which the decision-maker is still permitted to engage. With each decision handed down by the rabbis, the relevant rules and principles make the circle's boundary, and hence the range of permissible action, a bit smaller. The requirement to have children, for example, further limits the choices for the couple concerned about the risk of having offspring with TSD. These are, then, rules of exclusion of sorts: by informing

believers of which practices are not permitted under Jewish law, the authorities are limiting the range of actions.

Part of what I have in mind here is suggested by Robert Nozick in his discussion of "moral constraints."[263] Nozick discusses a way to incorporate important moral considerations in some way other than making them part of the overall goal of the moral theory. Nozick is specifically responding to critics of utilitarianism who are concerned about possible rights violations, and who thus argue that utilitarianism is defeated on these grounds. Instead, Nozick suggests that the utilitarian can incorporate the protection of rights of the individual as "…side constraints to safeguard the inviolability of others."[264] One can still seek to maximize the good as a goal of a moral theory, and yet be protected against the unwanted consequences of rights violations by adhering to the side constraints. Specifically, Nozick argues that "[t]he side-constraint view forbids you to violate these moral constraints in the pursuit of your goals…."[265]

Insofar as the side constraints do not suggest a positive direction for action – note, for example, this view says nothing about any obligation to maximize an individual's rights – this corresponds to my suggestions about traditional Jewish bioethics. I propose to call these *negative* action guides, since no positive action is required from such constraints but instead our action is restricted. In Nozick's schema, then, utilitarianism itself serves as the *positive* action guide that actually gives

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[263] Robert Nozick, *Anarchy, State, and Utopia* (New York: Basic Books Inc., 1974), 28-33. I am grateful to Glenn Graber for reminding me of this distinction.
[264] Ibid., 33.

direction for what action should be chosen. My ethical basis for a positive action guide, as I will argue in the next chapter, is an ethic of care.

Before getting to that discussion, however, I want to be clear about the difficulties with Jewish bioethics as a representation of rules of exclusion, and of the general principled approach. There are at least two problems with this approach. The first problem is with the principles themselves, and the second is with their application. One problem with the rules is, frankly, that they do not limit the range of action enough. The rules and principles are general enough to ensure that they apply to many different situations, and yet are too general to serve as real action guides. According to my analogy, what happens is that the center of the circle gets somewhat smaller, but not so small that a reasonable range of choices is apparent for the decision-maker. Instead, there are many choices still available to the individual, and it is unclear which option is the best for her situation. The duty to heal, for example, is important and justifies a range of action, but that range is alarmingly wide. Such a duty would be consistent with a variety of actions, some of which may in fact be contradictory. For example, the duty to heal is consistent with engaging in genetic screening for disease risk information, not engaging in genetic screening on account of the negative consequences that will be contradictory to the goal of healing if they result, engaging in means of assisted reproduction as a form of "healing" the childlessness of couples, not engaging in means of assisted reproduction if couples are

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[265] Ibid., 29.

capable of conceiving naturally, etc. So this rule must be specified either with other rules or else with more detail on how best it applies to the case at hand. Regardless, it involves a good deal of interpretation for it to be useful to a patient making a decision.

This relates to the second problem with this method, which is the process of application itself. Often this is where the rabbi figures most prominently, as it is his responsibility to interpret the texts and precedent in order to apply it to the case at hand. However, there are many courses of action that coincide with the precedents, and hence the rabbi must make a recommendation based on what he feels is most appropriate for the individual patient. How this decision is accomplished is unclear, and there is some indication that such a procedure is necessarily idiosyncratic. As was demonstrated in the discussion on abortion, for example, the interpretations of the ancient texts differ according to the authority figure reading them. Consulting two different rabbis, then, could result in two different sets of recommendations through which the patient would need to sort. There is no obvious way to adjudicate between these conflicting interpretations, and no way to choose among the different "circles" of action that would correspond to each one.

There is little in the method described that would sufficiently aid the individual in making her decision, then. She would receive some information about proscribed action, and learn of the constraints upon her decision-making, but would be given little positive direction in terms of making her choice. I contend that an ethic of care would

serve to better assist the individual in such circumstances, and in the next chapter I demonstrate how this will be an improvement on this methodology.

CHAPTER FOUR

ETHIC OF CARE

Some of the problems I have identified in chapter three are not exclusive to Jewish bioethics. One problem often cited with appeals to principles in general is that the approach may fail to adequately consider context.[266] For example, in a Kantian framework, our obligation never to lie may lead to the consequence that the Nazis learn of our hidden Jewish compatriots, an action that strikes many of us as simply wrong. This principle does not require that we actually *inform* the Nazis of the occupants of the attic, of course, but our silence in response to questioning may speak volumes. A carefully orchestrated lie, on the other hand, might set the villains on an alternate course that would result in a more favorable consequence. A more complete assessment of the context would help to alleviate this shortcoming; it is significant that the result of my honesty will be that innocent people will die, and any moral decision must somehow take this into account.[267]

A common reply to this objection to traditional moral theory is that such an analysis does not do justice to the theories mentioned.[268] Just as understanding that

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[266] For those that do, like act utilitarianism, they do so specifically in service to a principle – in this case, the principle of utility.

[267] Of course, a Kantian is not concerned with consequences, but rather with intent or motive. However, it is this focus on intent and disregard for consequences that strike many people as inadequate. An analysis of the context will include a discussion of these important consequences, while a strictly deontological approach will ignore them.

[268] This reply has been personally suggested to me by Glenn Graber, Robert Arnold, and Baruch Brody, just to name a few.

the obligation not to lie is not the same thing as requiring full disclosure of the truth, so too can a rich conception of the theory in question be seen as incorporating context. In the context of Nazi Germany, for example, "spilling your guts" and telling the Gestapo the location of the hidden Jews would be exactly the wrong action for a Kantian, as such an action would not be universalizable – it leads to an inconsistency. That is, if full disclosure of the truth was universalized, then there would be no such thing as hiding, since hiding is necessarily connected to nondisclosure. Hence, taking account of the context is essential for knowing what it is that the principle in question specifies.

The same defense can also be said for utilitarianism, or for most forms of consequentialism, for that matter. Ascertaining which action promotes the greatest benefit for the greatest number of people while minimizing the negative effects for the greatest number of people requires us to look at the context in which the action is occurring. Only by understanding who is involved in the problem, what each person or group stands to gain or lose by the proposed action, and the various ways in which each participant might be affected can the consequences of an action truly be assessed and an action then chosen.

I will grant these points to the arguers, and yet still a problem remains. The context is important in each case – that is true. But the reason that the context plays a role is simply in the specification of the applicable rule or principle. This makes sense because that is the goal of these theories: to perform only that action that is

universalizable, or to choose that action that has the best consequences overall. Hence, context is relevant only insofar as it is necessary to accomplish these goals. If there is an element, or a series of elements, in the context that do not contribute to these goals, they will not be included in the assessment of the moral worth of an action.

Yet often it is these very features that gave rise to the dilemma in the first place, or that make the right choice so very difficult to see. Suppose that Helga is the woman hiding Jews in her attic when the Nazis come calling. What was not mentioned previously, but is, I contend, morally significant, is that the Nazi at the door is also her childhood sweetheart, Franz, whom she had planned to marry before the war began. Her feelings for him are divided on account of the kind of man she thought him to be compared to the evidence of the kind of man he is, via joining the Nazis. She wants to trust that he would do the right thing and not harm the Jews if she tells him of their location, as she wants desperately to believe that she had not been so wrong about his character. And yet the stakes are awfully high.

The morally right action in this situation likely does not change; she ought to put aside her desire to trust Franz and to test their love because the consequences, both for herself and others, are too great. The utilitarian calculus still clearly weighs on the side of nondisclosure. For the deontologist, it is not clear that such considerations are relevant at all, given the fact that we are prohibited from lying, regardless of the reason. And yet this relationship causes Helga moral distress. Of course there would still be a dilemma without this complication – the dilemma with which this chapter

began, in fact. But it seems like it is a different dilemma now, or at least one that is more complicated. Aspects of the context that are significant get ignored or marginalized with these traditional approaches.

A famous example of where the right act would be different because of such complications can be found in Plato's *Euthyphro*.[269] In this dialogue, Socrates meets Euthyphro who is bringing charges against a murderer. In this case, the murderer also happens to be Euthyphro's father. Socrates asks Euthyphro whether his father killed a relative or a stranger because Socrates assumed that he would not prosecute his father for the murder of a stranger.[270] One of the things that this case exemplifies is the importance of context to a situation; the mere fact that Euthyphro's father killed someone seemed to be an insufficient reason to bring his father to trial, Socrates assumed. It is significant that the murderer was his father, and this relationship changed the morality of the action of bringing suit.

I contend that the same holds true for Jewish bioethics, especially in the arena of genetic medicine. It is significant that a prophylactic radical mastectomy is major, disfiguring surgery with only some indication of benefit. It is significant that genetic testing for breast cancer predominantly affects women, who often have a different relationship with medicine than do men. Furthermore, the relationships in which the woman is engaged are significant. It is important to be clear here: the process that I am

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[269] Plato, *Euthyphro*, trans. Lane Cooper, in *Plato: The Complete Dialogues*, eds. Edith Hamilton and Huntington Cairns (Princeton: Princeton University Press, 1989). All references will denote original line numbers of the text.

concerned with is that of determining the morally permissible actions of a situation. Once that is accomplished, there will be further decisions made about which of the options is "best" for the person, and often these further decisions are made on non-moral grounds. What I am arguing here is that the sorts of considerations on which I have been focusing are not simply important to the later decisions, but in fact matter to the moral permissibility of action. Even the most careful weighing of the principles and obligations involved does not take into account the richness of context for which I have been arguing. Finally, solving moral problems in this way assumes that medical decision-making is exclusively rational: the rabbis say that action A is permitted and action B prohibited, hence I will perform action A. As was discussed in the previous chapter, it is mistaken to assume that the principles always give a determinate answer, and hence it is the rabbis who must step in and specify the appropriate action. Without a detailed analysis of how this specification works, it may appear that such decisions are devoid of emotions and simply emerge from the principles themselves. It is not clear to me that decision-making[271] happens in this way, and an ethic that serves as an action guide must include a more realistic assessment of the process.

I contend that an ethic of care and responsibility, as initially described by Carol Gilligan, will fill in the gaps suggested at the end of the previous chapter, and give a better focus to the decision-making process. Specifically, what I argue is that the

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[270] Plato *Euthyphro* 4A-B.

rabbis are actually using the ethic of care when they apply the principles and precedents to cases that are presented to them, and so an understanding of this perspective is crucial. In this chapter, then, I will first explain what the care ethic is and how it differs from traditional ethics of justice. I will then explore how we might apply such a perspective to the specific decisions in genetic medicine that serve as the exemplars in this work. This is the kind of process in which the rabbis are already engaged. I will address the specific ways in which I think that the principles of Jewish bioethics and the orientation of caring work together in the final section.

The Ethic of Care

Originally suggested by Carol Gilligan in response to studies on moral decision-making published by the psychologist Lawrence Kohlberg, an ethic of care encompasses aspects of moral decision-making additional to the traditional approaches. Traditionally, moral theorists have advocated procedures according to which individuals ought to make decisions based on rules or principles that are more general than the specific case at hand and that could, and should, be applied to all cases across the board. For instance, Kantian theorists argue that all moral action must be universalizable and must respect individuals as rational agents with ends and goals of their own. When making a moral decision, we should perform an action that respects an individual's intrinsic worth and which could be performed by any agent in

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[271] When I refer to decision-making in this way, I am referring to the process by which we determine what the morally right course of action is, not necessarily whether or not we do the morally correct thing.

similar circumstances. So when making a decision about breast cancer screening, then, a Kantian would ask us to consider what action best preserves the woman's (and those individuals with whom she interacts, we can presume) status as an end-in-herself, and hence to consider what action could be universalizable. These general principles are applied to the specific case to determine morally justifiable action. The task is then to identify particular features of the proposed action that would fall under the "jurisdiction" of the principles, hold them up to the test, and then proceed from this analysis. If the proposed action fails to abide by one of these principles, an alternative action should be performed.

It is a fact, though, that much of our moral life depends on experience. It is in real situations that moral questions emerge, and we depend on experience to tell us when a proposed action requires separate justification. Since so much of our moral life depends on subjective experience, care ethicists claim that conditions are rarely "sufficiently similar" to justify universal principles.[272] Furthermore, because the application of general principles requires a certain amount of abstraction – eliciting only the parts of the proposed action that fall under the guise of the general principles – there will be much that is in the context of the moral problem that will not be addressed by such an approach. It is this failure to appreciate the richness of detail in a moral problem that leads to one major criticism of this approach by care ethicists. As Nel Noddings argues: "In doing this [abstracting from context], we often lose the very

[272] Noddings (1984), 5.

qualities or factors that gave rise to the moral question in the situation. That condition which makes the situation different and thereby induces general moral puzzlement cannot be satisfied by the application of principles developed in situations of sameness."[273]

An ethic of care has as its focus the goal of preserving and maintaining relationships, as it recognizes that our moral lives consist in interactions with other people. We are all interrelated in important ways, and the recognition of this is an essential part of the moral life. Hence, care ethicists suggest that in order to make a morally sound decision, our thought process must include the others with whom we are in contact, and must explicitly address how our actions will affect them.

Of course, an objector will maintain, Kantian ethics and, for example, utilitarianism, also include this connection between people as a part of the decision-making process. Our actions must be universalizable according to Kant, so that it must be possible for everyone to act just as we have. The universalizability of the Kantian maxims depend upon the rules being able to be held simultaneously, or at least depends on the rules not contradicting each other. The very nature of this principle of non-contradiction presumes an interaction with others who may face similar conflicts. In fact, Kant's requirement that we treat individuals as ends in themselves who set their own goals and values demands that we respect the dignity of others. The utilitarian will address this issue even more specifically; a utilitarian must

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[273] Ibid., 85.

include the effect that an action will have on all who might be affected by it when considering whether or not a proposed course is morally justified. What is different, however, is the focus. A utilitarian must consider how her action affects others as well as herself, but she is still the primary agent, that is, the one who must act. So if it is the case that a proposed course of action leads to the best consequences for the greatest number of people but a few have to suffer greatly, then this course may be justified according to utilitarianism.

It is not clear that we could make the same judgments from within care ethics. A proposed course of action that makes even a few people with whom I am in a relationship worse off is a primary concern for me in my deliberations, and may on balance prove to be the wrong decision. This at least partly arises because of the primary focus on connection of individuals, rather than on the separation of one moral agent from another as seems to be the focus of ethics of justice. Those operating with the latter perspective "…assume separation" from others and only later begin "…to explore parameters of connection," while those who operate from within an ethic of care first "…assume connection" and only later begin "…to explore parameters of separation."[274] This is important because the very orientations lead us to different actions largely because they produce "…different images of self and of relationships."[275] According to Gilligan, the central insight in the ethic of care is that

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[274] Gilligan (1982), 38.
[275] Ibid.

the self and other are interdependent[276], and it is this realization that leads to moral action. So, unlike the traditional ethics of justice, an ethic of care makes no sharp distinctions between self and other. "My day-to-day interactions with other persons create a web of reciprocal caring,"[277] and it is the recognition of this web that binds us to each other, that constrains and determines our moral action.

This distinction, between the demarcation of self and other that is characteristic of ethics of justice and that of the interconnectedness of individuals that is the focus of the ethic of care, is an important difference between the two approaches to morality because this distinction shapes the priorities of the ethics. That is, this distinction gives rise to different foci which are dependent on the different understandings of the relationship between individuals. Joan Tronto argues that we must begin from the assumption that humans are interdependent, and when we do so "…the terms for our moral discussion must shift. Rather than assuming that any and every threat to autonomy is beyond discussion, the interpersonal point of view raises questions about how to resolve these problems. Shifting the assumptions we make about people changes the terms of what issues our moral theories must resolve."[278] For example, instead of our moral theory attempting to resolve the problem with rights violations for

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[276] Ibid., 74.
[277] Rita Manning, "Just Caring," in *Explorations in Feminist Ethics: Theory and Practice*, eds. Eve Browning Cole and Susan Coultrap-McQuinn (Bloomington: Indiana University Press: 1992), 46.
[278] Joan C. Tronto, *Moral Boundaries: A Political Argument for an Ethic of Care* (New York: Routledge, 1993), 163-164.

which some authors criticize utilitarianism, now our moral theory must attempt to resolve the problem with individuals acting in disregard of their interdependence.

In fact, Tronto argues that it doesn't make much sense to think of individuals as separate, autonomous beings. We all are, at some point in our lives, in a position to need care from others. This is to be in a vulnerable place, and this alone "belies the myth that we are always autonomous."[279] Care theorists share with justice theorists a concern about the possibilities of abuse that may arise with such vulnerability, but they deal with this issue in very different ways. According to Gilligan:

> The morality of rights is predicated on equality and centered on the understanding of fairness, while the ethic of responsibility relies on the concept of equity, the recognition of differences in need. While the ethic of rights is a manifestation of equal respect, balancing the claims of other and self, the ethic of responsibility rests on an understanding that gives rise to compassion and care.[280]

This focus on relationships and the ties we have with others originates from the notion that we are all bound up in a web of caring, where my interests and objectives are inextricably linked to yours, and where ethical action arises from an acknowledgment of this interconnectedness. Part of this recognition involves understanding the embeddedness of the self. Who I am cannot be sharply distanced from others, as it is my interactions with others that has and continues to shape me into the person I am now. The fundamental fact of connection is integral to my self-concept, and continued interaction sustains my identity.

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[279] Ibid., 134-135.
[280] Gilligan (1982), 164-165.

Because of this focus on the network of carers of whom I am but one part, the traditional concept of autonomy will not apply. This is an important difference between an ethic of care and an ethic of justice, and hence it is worthwhile to investigate how this distinction plays out. To replace the notion of an atomistic decision-maker, who may consider others in her decision process but ultimately is only responsible for herself, Sarah Hoagland proposes the concept of "autokoenony," from the Greek words for "self" and "community."[281] This concept of an individual is "not essentially *defined* in terms of another" but instead is "both separate and connected." That is:

> What I mean by "autokoenony" is the "self in community." The self in community involves each of us making choices; it involves each of us having a self-conscious sense of ourselves as moral agents in a community of other self-conscious moral agents….Thus, being autokoenonous does not involve isolation, nor does it mean not being influenced by or not depending on others….An autokoenonous being is one who is aware of her self as one among others within a community that forms her ground of be-ing, one who makes her decisions in consideration of her limitations as well as in consideration of the agendas and perceptions of others. She does not merge with others, nor does she estrange herself; she *interacts* with others in situations.[282]

This definition works nicely with the conceptions Noddings proposes, where an individual undergoes motivational displacement towards the other but does not completely lose herself in the needs or goals of the other. This is important if one is to be able to care for another: the individual must be competent to meet the needs of the

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[281] Sarah Lucia Hoagland, *Lesbian Ethics* (Palo Alto: Institute of Lesbian Studies, 1988), 145.
[282] Ibid.

other individual. Hence, the moral work of weaving an identity is part of the process of caring: knowing the limitations placed on me by the responsibility I have to care for others and yet knowing what my needs and goals are shape how I view my moral agency.

So what does it mean to care? Caring involves many things, such that it is impossible, and undesirable, to make lists of criteria or categories of caring.[283] At the very least, caring requires some action by the one caring on behalf of the one who is cared-for.[284] This points to an important realization: "…caring is not simply a cerebral concern, or a character trait, but the concern of living, active humans engaged in the processes of everyday living. Care is both a practice and a disposition."[285] The disposition evolves from what Noddings calls a "relation of natural caring" that is not simply a matter of projecting myself onto the object of care, but rather involves an engrossment with the other.[286] Noddings compares this relationship to the one of mother and child, where the mother shares the infant's feelings, as is exemplified by the impulse to comfort the child even before she ascertains what is causing his distress. When this happens, when the individual becomes truly receptive to the other, Noddings argues that there is a fundamental motivational shift; my motivational energy is now shared with the other.[287] Once this shift has taken place, "[t]he one-

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[283] Noddings (1984), 9-12.
[284] Ibid., 10.
[285] Tronto, 104.
[286] Noddings (1984), 30-31.
[287] Noddings (1984), 33.

caring assumes a dual perspective and can see things from both her own pole and that of the cared-for."[288]

To be more precise, Joan Tronto and Berenice Fisher have developed four "analytically separate, but interconnected" phases of caring, which speak to both the disposition and the actions necessary to maintain an ethic of care. The four phases are[289]:

(1) Caring about: It is in this phase where moral agents first recognize that care is necessary. "It involves noting the existence of a need and making an assessment that this need should be met."

(2) Taking care of: This phase involves the agent "…assuming some responsibility for the identified need and determining how to respond to it." Inasmuch as this phase involves the recognition that someone can act to address these unmet needs, both agency and responsibility are involved in this phase. It is in this phase that Tronto and Fisher's definition of caring becomes important. Caring is not simply a "cerebral concern" but instead "implicitly suggests that it will lead to some type of action…to care implies more than simply a passing interest or fancy buy instead the acceptance of some form of burden."[290] Determining whether or not I am the person to meet those needs is the function of the next phase.

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[288] Noddings (1984), 63.
[289] Tronto, 106-108.
[290] Ibid., 102-103.

(3) Care giving: In this phase is located the direct meeting of the needs for care, which almost always requires that care-givers come into direct contact with those who are in need of caring.[291] Tronto argues that responsibility rests on a number of factors – if an action or omission of ours resulted in the need for care, then we must give the care.[292] Or maybe we have a responsibility to care simply because we recognize the need.[293] The appropriate objects of our caring will depend on "political motivations, cultural practices, and individual psychology" in addition to "perceived gender roles…class, family status" and race.[294] Tronto argues that we are better served by a flexible notion of responsibility than by continuing to use the concept of obligation.[295]

(4) Care receiving: In this phase it is recognized that "…the object of care will respond to the care it receives." This is an important part of caring because it provides the only way that we know that caring needs have actually been

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[291] Tronto notes here that providing money is usually more a form of "taking care" than of "care giving." In fact, she argues that the illusion that giving money is a rich form of caring, converting care to dollars and cents, directly points to the undervaluing of care giving in our society.
[292] Tronto, 132.
[293] It must be noted, of course, that this is not a complete theory as I have presented it; a person can recognize all sorts of needs that are beyond her capacity and/or obligation for which she ought to take responsibility. I am grateful to Betsy Postow for suggesting this to me.
[294] Tronto, 132-133.
[295] Ibid., 133.

> met, and this is crucial for maintaining the ability to assess how adequately care has been provided.

Corresponding to these phases are four "ethical elements of care" that arise from the action that is taken in each of these phases. Corresponding to the first phase is the element of attentiveness, where we suspend our own needs to be attentive to the needs of others. According to this, then, ignorance is a form of "moral evil."[296] Knowing what the other needs, however, is not an easy task. Lawrence Blum comments:

> Understanding the needs, interests, and welfare of another person, and understanding the relationship between oneself and that other, requires a stance toward that person informed by care, love, empathy, compassion, and emotional sensitivity. It involves, for example, the ability to see the other as different in her own right, rather than viewing her through a simple projection of what one would feel if one were in her situation.[297]

To really care for others, then, involves more than just putting myself into another's shoes. To care for others includes listening to what the other needs, and recognizing that this may very well be something different from what I would assess that she needed based on my interpretation of the situation. Caring may require that I act very differently from what I would want in a situation, or from what I think the one cared-for *should* want. Ideally, if the motivational shift takes place, then my desire to meet the needs of the cared-for will arise naturally.

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[296] Ibid., 127-128.
[297] Lawrence A. Blum, "Gilligan and Kohlberg: Implications for Moral Theory," Mary Jeanne Larrabee, ed, *An Ethic of Care*, New York: Routledge, 1993, 51.

Corresponding to the second phase is the element of responsibility, where we assume the role of the one who can give the care.[298] This is where the motivational shift becomes apparent, as it is on account of this that we take responsibility for meeting the needs of the cared-for.

The third element, then, is competence, as one must be competent to give the kind of care necessary, or else the action is not really caring.[299] If all I do to meet the needs of the other is to offer the care that I would need in that situation because I do not have the ability or skills to offer what the cared-for really requires, then I am not caring; instead, I am doing something like "transferring." Furthermore, if all I do is offer money so that someone else can provide the goods or services, then I am also not truly caring. What I am doing is enabling someone else to care, and this is a commendable action in the instances when I am incompetent to give care myself. I should not, however, assume that this provision means that I am caring, because that is simply not the case.

The final element is responsiveness of the care-receiver to the one who is giving care.[300] It is this element that demonstrates the success of the caring, and it is this element that alerts us to a potential problem in caring if, for example, I have simply transferred my values and needs onto the person of the cared-for rather than

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[298] Tronto, 131.
[299] Tronto, 133.
[300] Tronto, 134.

cared for her as is appropriate for her in this case. So this element alerts us to insufficient or inadequate care as well.

By acknowledging these elements and completing the four phases of caring, Tronto and Fisher propose that we have completed an act of caring. Often this process is more difficult than it appears, and conflicts in caring do arise. For example, sometimes what the cared-for needs is in direct opposition to what someone else may need, and hence there is a moral dilemma. But when conflicts in caring arise, the approach to solving them is quite different from the procedures in traditional ethics of justice. In cases of a conflict, the agent "…does not decide by formula, nor by a process of strict 'rational decision-making.' [Instead] she turns away from the abstract and back to the person for whom she cares. [A decision] is right or wrong according to how faithfully it was rooted in caring – that is, in a genuine response to the perceived needs of others."[301] So to evaluate whether or not a decision that I reached was the right one, I look less to the actual outcome of the decision and more to the process. As Noddings argues: "…[T]he test of my caring is not wholly in how things turn out; the primary test lies in an examination of what I considered, how fully I received the other, and whether the free pursuit of his projects is partly a result of the completion of my caring in him."[302]

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[301] Noddings (1984), 53. Noddings here is referring to a specific (and realistic) example of a conflict between a woman caring for her child and caring for her husband. The needs of all the participants are important, and an assessment of all of those needs must be a part of the process.

[302] Noddings (1984), 81.

This "turning back towards the person for whom she cares" does not mean that rationality is not utilized at all. Noddings comments:

> Instrumental thinking may, of course, enhance caring; that is, I may use my reasoning powers to figure out what to do once I have committed myself to doing something. But clearly, rationality (in its objective form) does not of necessity mark either the initial impulse or the action that is undertaken. If I care enough, I may do something wild and desperate in behalf of the other – something that has only the tiniest probability of success, and that only in my own subjective view. Hence, in caring, my rational powers are not diminished but they are enrolled in the service of my engrossment in the other. What I will do is subordinate to my commitment to do something.[303]

So rationality does have a role in the ethic of care, but it is a very different one from the role it has in an ethic of justice. Instead of appealing to overarching principles and rules and rationally determining which course of action best fits in with those principles, in cases of conflict the individual who cares returns back to her initial focus on the needs of the cared for, and then proceeds from an understanding of what that entails. She could, of course, be wrong in her estimation, but as previously mentioned, the process of caring is more important than the product. This is because it is through the process of caring that we ascertain and meet the needs of the other much more than is evidenced by simply looking at the product of such deliberation. The differently-focused methodology is what is important, and ascertaining success or failure will appeal to the degree to which the individual has tried to meet the needs of the cared-for.

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[303] Ibid., 35-36.

This is also not to say that an ethic of care is inherently and completely devoid of principles. It is simply the case that the principles that operate here (that it is right to sustain human relationships, for example) are different from those that are important in an ethic of justice,[304] and also perhaps have a subordinate role to play. It is not in achieving correspondence with principles that is important, but rather in caring for others.

This different focus will result in a different kind of thinking, according to Allison Jaggar.

> Justice thinking is impersonal and general because it regards both moral subjects and the objects of their moral concern in terms of their moral status as representatives of humanity or as beings capable of pleasure and pain rather than in terms of their concrete specificity; care thinking is personal and particularized in that both carers and those cared-for regard each other as unique, irreplaceable individuals.[305]

This difference in thinking, then, will result in an ethic more focused on individuals, and more responsive to the needs of those for whom we care.

Caring and Genetic Disease

Jews are commanded to do what they can to preserve life and health, yet how that gets applied to real treatment decisions is far from clear. What we get instead is an overall framework by which decisions get made: preserve life and health whenever

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[304] Patricia Ward Scaltsas, "Do Feminist Ethics Counter Feminist Aims?" in *Explorations in Feminist Ethics: Theory and Practice*, eds. Eve Browning Cole and Susan Coultrap-McQuinn (Bloomington: Indiana University Press, 1992), 17.

possible. Even the more specific principles discussed in this case, such as the notion that one's body belongs to God and that mental anguish is a mitigating factor in some circumstances, fail to serve as sufficient action guides in treatment decisions. When a woman approaches her rabbi uncertain about whether or not to engage in genetic testing, the rabbi has much work to do in the way of applying these general principles to her particular case. Precedent may help here, but with many of the issues in genetics, technology is requiring us to embark upon new ground. Hence, it may be the case that genetic testing is permitted, or it may even be obligatory, as Rabbi Dorff argues. How is a specific rabbi to proceed to assist a specific woman?

This focus on the individuals with whom we are in relationships will help us in approaching these issues, and in fact these are the kinds of considerations that the rabbis deliberate. One issue present in all three cases discussed in the previous chapters is the importance of the knowledge gained from engaging in genetic testing. In order to make a decision that corresponds to the constraints of Jewish law,[306] it is important to determine the motive or purpose for engaging in testing. For example, many authorities would prohibit a couple from engaging in genetic screening if the purpose of such testing was to abort a fetus that had Tay-Sachs disease. If, instead, the purpose of engaging in genetic screening was simply to gain knowledge so that the

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[305] Allison M. Jaggar, "Caring as a Feminist Practice of Moral Reason," in *Justice and Care: Essential Readings in Feminist Ethics*, ed. Virginia Held (Boulder: Westview Press, Inc., 1995), 191.

[306] It is possible that the constraints of Jewish law could be contrary to caring. For a discussion of such conflict, see chapter five.

couple could be prepared for the different demands and needs of their child, then testing would almost universally be permitted. Certainly in the case of genetic screening for the genes associated with breast cancer, assessing the benefits and burdens associated with the knowledge gained is crucial for understanding the (im)permissibility of engaging in screening procedures. This is because the assessment of the moral (im)permissibility of an action depends upon how it affects the important relationships in which the woman is involved. She must maintain her integrity, but also meet the needs of the others for whom she cares in order to be a genuinely caring individual. Yet traditional Jewish bioethics will weigh in on her decision as well. As with TSD, the principle of mental anguish would serve as a guide to determine under what circumstances screening would be sanctioned. A woman who has lost two immediate family members to breast cancer may suffer more from not knowing whether or not she carries the gene associated with the disease than she would from learning the results that she does in fact carry the mutation. Finally, as previously discussed, the information itself had important value in the case of colon cancer screening. Individuals might benefit from results of such screening because certain results would justify a reduction in the frequency with which they had to submit to invasive clinical examinations; alternatively, it was from the information gained that he or she might become lax in heeding the warning signs altogether.

What the ethic of care will do for these individuals is to refocus the discussion in terms of maintaining and preserving relationships rather than in identifying rules or

principles. To see how this works, we will begin by discussing some of the ethical issues that arose with TSD, and then move on to breast cancer and colon cancer.

Tay-Sachs Screening

A married couple's obligation to procreate is important in Judaism, but this obligation also is importantly vague. Authority figures have interpreted various passages to conclude that the commandment has been filled when the union results in a boy and a girl; however, given the uncertainty of life it is recommended that the couple have more children "just in case." Hence, it is prohibited for a couple to choose not to have children, apart from any medical inability that might be present.

Yet for those who are concerned about their risk for having a Tay-Sachs afflicted child, these guides are insufficient at best. It is not difficult to imagine a couple that wants nothing more than to have many healthy children, but who are both carriers of TSD and hence know that they are at risk for producing Tay-Sachs afflicted children. Whether or not they undergo genetic testing (and, perhaps more importantly, *when* they undergo genetic testing) seems to be more a function of their unique situation than it is a matter of conforming to principles. Aside from those in the ultra-Orthodox community or those involved with Dor Y'shorim's program, many contemporary Jews are simply unaware of their risk for TSD, or do not consider this issue prior to marriage. So while genetic testing prior to marriage -- with the corresponding understanding that two carriers will not go on to marry – may be the most desirable approach towards testing from an ethical standpoint, it may not always

be possible. Perhaps education on such subjects was not available to the couple, or because testing was prohibitively expensive or distant from their location they may not have been able to engage in testing. It may well be the case that the subject does not arise until the couple is already pregnant, at which time different considerations come into play. Or if it does arise prior to marriage, the couple may not be willing to change their life plans in accordance with the test results. Aside from the communities that still engage in arranged marriages (and perhaps even within those), the desire to marry another individual is often the culmination of a long-term relationship whose ties cannot be severed so easily.

The right decision for couples like these seems to be one that is responsive to the needs and desires of the people involved. They would need to consider what it would mean to care for a child like this, what it would mean to be in relationships with others in this situation and, perhaps most importantly, what it would mean to care for each other in such a situation. It is a fact that different people would deal with this situation in different ways. For some people, caring for a special-needs child is simply more than they can bear, while for others, it is an opportunity to express their love to those who desperately need it. The rule that says that a married couple must have children fails to capture the sentiments that go into such a course of action. What is at issue here, presumably, is not the desire to have children, but rather how best to fulfill this desire given the particular set of circumstances at hand. With some exceptions, parents do not desire or care for their children because they have an obligation to do

so, say from some ethical prescription. Rather, they care for their children because of a set of feelings they have about them or because they are in a special relationship with them that they are not in with other people's children.

Some would argue here that other ethical theories, such as utilitarianism, could meet these needs in relation to the family in question. Utilitarians would take account of possibilities and risk, as well as the idea that different people evaluate different circumstances differently. Ascertaining the morally right action in a particular situation relies both on the consequences of such a decision on all those affected as well as a determination of how the proposed action fits in with our life plan or other goals – hence, non-moral considerations are relevant as well.

I will grant that that the outcome, that is, the decision eventually chosen, may be the same for an ethic of care and utilitarianism in this case. What is different, however, is the process by which such a decision is reached. Consequences of a proposed action are not evaluated according to utility, but rather according to how well an action maintains or continues the relevant relationships. To enter into a caring relationship is to take responsibility for meeting the needs of the other as well as meeting the needs of oneself, and a decision such as this is simply a concrete manifestation of the commitments made in the context of the relationship. Those who care have an obligation to meet the needs of the other in a way very different from that of utilitarians. In fact, the very life plan and values that we hold emerge from this commitment to caring, and hence the assessment of how best to meet these goals is an

affirmation of the dedication we have to our moral ideals. To care genuinely involves more than simply choosing the best outcome, but instead requires the engagement in a particular kind of process along the way.

It is this relationship of caring that is crucial for moral decision-making. Recognizing what it takes to maintain the relationship between spouses will, and should, factor into a decision about whether or not to abort a pregnancy that will result in a child with TSD. Recognizing what it would mean to care for such a child is also important. Recall the four phases of caring and their associated ethical elements proposed by Tronto and Fisher. An individual must be able to work through all of the phases if she is to truly care for another. The crucial point here is that not everyone will be competent to care for such a child. For those who are not, according to this schema, despite the best of intentions, it is impossible for them to truly give care to the recipient. "When a 'carer' can no longer respond adequately to the demands in her sphere of activity, she has to turn to those adjacent to her in a chain of caring. The people to whom she addresses her request are then obligated to respond to her, just as she is obligated to respond to those who address her."[307] Noddings here does not specify what the response must entail, but simply that those with whom the couple is engaged in caring must respond. It is conceivable that the caring response to the couple is the one that respects their decision to terminate a TSD pregnancy and then to act as a support system for them after making such a choice.

It is also important to remember that a crucial part of the caring relationship is the cared-for's response to the caring. Recall that it was on account of this that Noddings argued that we could not really care for those distant from us, like starving children in Africa, since they could not respond to that caring in a way that would be meaningful to us. This seems to have significant implications for children with TSD who, after a certain point, will not be able to respond to caring at all (except at the most rudimentary physical level). In such a circumstance, I argue that the truly caring response by parents would be not to subject a child to the pain associated with this degenerative disease by not bringing them into the world in the first place.[308] These considerations must be balanced with other considerations, to be sure, but it is an option that must be considered.

A couple's decision to take advantage of any of the assisted reproduction techniques would also be assisted by the use of an ethic of care. Some methods of combating infertility are clearly permissible (AIH, for example) given the importance of procreation in the Jewish tradition. The permissibility of using other techniques, such as IVF, when infertility is not a problem is a bit more complicated. Authorities have ruled in both directions. Yet if we include in our decision-making process an

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[307] Nel Noddings, "In Defense of Caring," *Journal of Clinical Ethics* 3, no. 1 (Spring 1992): 17.

[308] It may also be possible to justify this kind of caring response simply on account of the suffering that the child would endure, regardless of considerations of his or her ability to respond to care. Because this action may contradict other important principles in Jewish bioethics that have not been discussed here, I will leave this consideration aside.

assessment of what it would mean to care for the individuals involved, we may have more guidance into what is the right decision for them. A couple that desperately wants to have children but is concerned about bringing a child with TSD into the world has predilections that seem to coincide with Jewish law. A boy and a girl child are considered sufficient to fulfill the commandment to procreate so long as they live long enough to reproduce themselves. A child with TSD will not. Hence, having a child with TSD does not assist the couple in fulfilling the commandment. To help the couple conceive children free from this disorder, then, is both the caring response and the one that seems in sync with religious prescriptions.

In fact, I contend that this is the preferable choice for couples that are committed to upholding Jewish law. After having and caring for one or perhaps more children with TSD, it is easy to imagine the emotional, psychological, and physical distress that a couple would suffer. It is possible that under such conditions, the stress would be so great as to be destructive to their relationship and/or destructive to their ability to create or care for other children. Given the focus on procreation in Jewish law, this situation is to be avoided. Hence, utilizing a procedure such as IVF which includes the couple's own genetic material (and hence avoids many of the concerns that accompany donated material) is the most ethically sound way to solve this dilemma.[309] This is the caring response to the couple that desires to comply with Jewish law and procreate but does not feel capable of caring for a child with TSD.

Remember that the way to evaluate whether or not we did the right thing according to an ethic of care is not only to evaluate the outcome, but also to assess how well we cared for others during the process.[310] Hence, we will need to appeal to context, to the unique features of each situation, before we can know what it means to care for this particular couple. The rules and principles involved can serve as a boundary, but do little to guide us to action. The caring response, then, will vary from couple to couple, from situation to situation.

Finally, the duty to heal that is important in Judaism can be interpreted in a number of ways. As previously discussed, it was this principle that justified the physician's profession and gave certain obligations to those who were competent to engage in such practices. With TSD, no "healing" in the traditional sense can take place; there is no cure for TSD, and little that physicians can do to ease the discomforts of these children and their families. I contend that this duty to heal can be interpreted in a broader way to include caring and compassionate responses to individuals as a part of the process. While we cannot offer a cure to the parents of children with TSD, we can care for them: we can offer our assistance in sitting with the child, in preparing meals for the family, in offering a sympathetic ear or a shoulder to cry on. Since we now know that spiritual and emotional healing are important in

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[309] I will grant, however, that IVF is far from perfect. It is expensive, cumbersome, and unreliable, but may yet present the best possibilities for couples like these.

[310] However, if the outcome flouts Jewish law, it may be rejected. What will hopefully become very clear in chapter five is that I am not advocating a pure care ethic, but rather a hybrid theory, where caring and principle-application are combined.

physical healing, it stands to reason that the duty to heal can and should be extended in this way. Since this demonstrates that healing includes non-physical aspects, then applying this expanded notion of healing to TSD is plausible. Caring for the parents of Tay-Sachs afflicted children is a form of healing, and one that many (although not all) of us are competent to engage in. This suggests one way in which principles and caring can be combined; I will address this issue more fully later in this chapter.

Breast Cancer Screening

How would the perspective of an ethic of care change the way we answered the woman's initial question of whether or not she should be tested for one of the mutations associated with breast cancer? Certainly we would investigate what religious principles apply to her situation; after all, this is still a member of the observant Jewish community, and the tenets of her tradition are important to her. But an important difference is that the discussion wouldn't stop there. The woman would also consider how having this test performed would affect those whom she cares about and those who care about her. One implication of a genetic test, of course, is that she will receive information not just about herself, but also about her relatives: if she has one of the mutations in BRCA1 or BRCA2, then it is likely that her sisters and daughters do as well. As mentioned before, her family members may be uninterested in learning their own risk, and hence this knowledge could be a burden for the woman. If, for example, her sister resents her for finding out this information in the first place, regardless of the reason, the woman will consider that in her calculation. She may, of

course, have the test done and simply not inform her sister, but she will learn something about their shared genes regardless of the nondisclosure. Since keeping this information to herself may psychologically affect her – and her subsequent relationship with her sister – this must be considered. The primary focus here is on preserving and nurturing relationships, and if finding out the information from this test would likely harm an important relationship, then the woman might think twice before agreeing to be tested.

Similar points can be made in reference to the woman's daughters, but perhaps arguing from the other direction: the information gained might prove to be a real benefit to her children, as they can be vigilant early on for signs and symptoms and perhaps participate in experimental preventive therapies. Recognizing the connection she has with her daughters in this particular way might guide her towards getting the test done. Keep in mind her motivation here: it is because of the nurturing relationship that the woman considers her daughters here, not simply because of an obligation. Recall that "[t]he first thing we must do as 'carer-thinkers' is to recognize that our dilemmas are not ours alone. They must be referred to a community or network of 'carers'"[311] and recipients of care. This involves not only the consideration of others in our decision-making, but also using others to help us achieve a resolution to the conflict at hand. Often solutions can best be generated by working with others, and

[311] Noddings (1992), 17.

given the fundamental assumption of connection with which the care ethic operates, it is reasonable to assume that it will take others to help us decide what to do.

We could further detail the ways in which having the test performed could affect the relationship she has with her family (how will a positive test result and a decision to have a mastectomy affect her relationship with her husband, for example), but it is crucial to remember that the woman is not only concerned about her family. Rather, as one who is engaged in the process of caring, she is connected to many people. If having this test done will provide valuable information for researchers who will then be able to help women in her daughter's generation, even if she tests negative for the gene, then that will be considered as well. Some of her daughters' friends might be benefited from the knowledge that she provided, and as this will enrich the lives of those she cares for, this facet is important.

This type of reasoning is also useful when we expand the decision from the question of genetic testing to the one of the woman considering a radical mastectomy as prophylaxis. Considering how such surgery will affect the relationship the woman has with her husband, with her daughters, with her coworkers, and with her friends

will all be important. If her self-esteem[312] will be so lowered by this procedure as to put some or all of those relationships in jeopardy, then it is clear that that is not the right action for her, regardless of the fact that it has some, maybe even a good, chance of prolonging her life.[313] Recall that there was some debate within the principles of the tradition as to whether or not this qualified as a life saving procedure; here, the decision process is made a bit clearer.

Notice the difference in language here. Gone is a specific reference to the woman's "right" to have the test done, or to the "obligation" she has to make the decision for herself.[314] With an ethic of care, we get a different construction of the moral problem. The discussion shifts from a consideration of conflicting rights to one

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[312] I do not mean to imply here that we ought to evaluate such considerations in a vacuum. Perhaps the woman's self-esteem is lowered because of expectations of beauty that have been perpetuated by a patriarchal society – expectations which I would clearly want to reject. It is possible, however, that the woman's self-esteem issues are the result of the importance of bodily integrity to her, a consideration that deserves further investigation. What is required for a genuinely caring response is to understand the depth of the commitment by the woman and to subsequently ascertain what her commitments require from me, as the one-caring.

[313] In instances where a mastectomy is crucial for saving the life of the woman, it may be the case that, according to the ethic of care, she should have the operation regardless of these types of concerns about her relationships. In immediate life-saving instances, we would need to evaluate the harm to relationships that would ensue because of her death. Regardless, the issue here is a question of prophylaxis, and hence the immediate life-saving consideration is not an issue.

[314] See Gilligan (1982), 21; Carol Gilligan "Moral Orientation and Moral Development," in *Women and Moral Theory*, eds. Eva Feder Kittay and Diana T. Meyers (Savage, MD: Rowman and Littlefield Publishers, Inc.: 1987), 23; Thomas E. Hill Jr., "The Importance of Autonomy," in *Women and Moral Theory*, eds. Eva Feder Kittay and Diana T. Meyers (Savage, MD: Rowman and Littlefield Publishers, Inc., 1987), 134.

of conflicting responsibilities.[315] Of course, a woman's ability to make the decision for herself must be assumed – further consideration by the woman is moot if someone else is making the decision for her. And for such foundational concepts, traditional Jewish bioethics serves her well. She learns that testing is permitted based on the grounds that the Jew has a duty to save someone's life and to care for one's body. But that is a far cry from making the decision to engage in testing or not. When it is time to decide what is the right thing to do, the context becomes increasingly important.

Consider further the traditional role of the woman in Judaism: her primary obligation and concern is for the family. Traditionally, caring for individuals and maintaining relationships have been her domain. In such a context, the language of rights and obligations is replaced here by words of emotion and compassion. As Hume remarks, morality arises from our sentiments, our feelings about what is right and wrong. I endorse this view, as it nicely captures the notion that reason alone does not account for our moral dispositions. Caring often involves putting oneself in the place of the other, as only in this way can she truly understand the needs of the one cared-for.

Colon Cancer Screening

Focusing on caring and relationships is exactly what the individual who is considering not being screened for colorectal cancer is doing for the following reasons. She is evaluating how the options available to her coincide with her goals of

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[315] Gilligan (1982), 19.

maintaining the important relationships in her life. Recall that the decisions in colorectal cancer screening revolved around the issue of risk, and specifically the amount of risk that an individual was permitted to assume. Freedman argued that any risk undertaken by the individual must be counterbalanced by proportional gains. Ascertaining the benefit-to-burden ratio of not being screened, then, was one key factor in deciding if that course of action was allowable under Jewish law. However, Judaism gave little guidance as to how such an assessment is to be made. What features of the decision are relevant to an assessment of the proportionality of the risk? It is difficult to see which details are important to consider and which are not, as well as how to rank them.

Making such an assessment is, and should be, an exercise of caring for the individual. Understanding whether or not the risk is proportionate with the proposed gain from an action requires more than simply weighing the consequences and choosing that option that benefits the most as would be required by consequentialism or ensuring that the action could be universalizable as required by deontology. These schemes are still too general for the individual and fail to take account of the intuitions of the patient. A decision either way in this case could result in significant harm to those whom the patient cares about (if, as a result of screening, she loses her health insurance which in turn affects her children, for example) and that is more important to her than the benefits that might accrue to others. Our feelings of partiality are

important and give rise to the "natural sentiment of caring" of which Noddings speaks. Any moral decision-making process must take account of this.

Hence, the choices made by the individual who is considering screening for colorectal cancer depend on how her decision could affect the important relationships in her life: whether or not the responsibility she has to her family requires her to make certain choices, both on account of economic and social considerations; how others who cared for her would be affected by a decision not to engage in testing, etc. Once again, Jewish bioethics serves as a useful limiting factor: any risk assumed by the individual must coincide with her acting as a reasonable caretaker of her body. Yet many actions would be acceptable under this schema, and hence it gives little real guidance to the individual who is unsure of what course of action to choose.

Consider the three instances of allowable risk that Freedman discusses. A Jew is allowed to risk life to lengthen life, risk pain and life for quality of life, and engage in some amount of risk on account of the fact that "God protects fools." The quality of life assessment that is mentioned in the second instance is important in our discussion of colorectal cancer screening. For the purpose of improving the quality of life, individuals are permitted to engage in some self-wounding. But the very assessment of quality of life is contingent upon many factors, some of the most important of which are the relationships one has with friends and family. Recall that part of the assessment of the quality of life determination included the notion that risky action could be taken if it was in pursuit of some greater good. Clearly a greater

good for many individuals is the well-being of those about whom one cares, and hence this would help to determine the level of risk that is appropriate to be taken. Again, considerations of one's social role are important: a woman's role as a mother restricts her in certain ways, but leaves many others open to her. How she best meets that responsibility must be understood in terms of an ethic of care.

Within the range of acceptable action that is specified by Jewish bioethics, then, an ethic of care serves as a better action guide for individuals as it provides a framework for moral decision-making. An ethic of care gives the decision-maker a goal to focus on – preserving and nurturing relationships – that is both useful as an action guide as well as not too limiting on the patient's ability to choose from among options.

Combining Principles and Caring

What an ethic of care cannot do, however, is to completely replace the principles that are inherent in Jewish bioethics. We saw the reason for this in the initial discussion with the patient who was considering screening for one of the mutations associated with breast cancer. Because of the way in which I defined the community with which I am dealing, by definition these individuals are committed to their religion in some way and may mold their action accordingly. That is, these patients are concerned with performing those actions that are sanctioned by Jewish law and strive to avoid those choices that would contravene such principles. Hence, any decision

about which action to perform must include an assessment of the Jewish legal requirements that pertain to the situation.

What I have been arguing all along, then, is that such an assessment is important, but it is simply not a sufficient enough action guide. The principles involved in Jewish bioethics do serve an important role: they guide the individual away from action that is proscribed and towards action that is permissible. The problem, however, is that given the general nature of the principles and the vast array of options open to an individual at any given time, the principles of Jewish bioethics do not give enough of an action guide to be useful for a patient. Instead, it serves to narrow the playing field, so to speak, without doing much positive work of helping the individual to choose an option. I am not arguing that a moral theory must always indicate a specific action and leave no room for individual discretion or whim. What I am saying is that a moral theory ought to specify a narrow-enough range of acceptable action so that an individual's choice is made easier. I do not intend the resultant choice to be trivial, but rather a theory ought to present a reasonable range of choices for the individual from the vast number of those initially available. It is not clear to me that an application of the principles of traditional Jewish bioethics alone can do that.

Traditionally, it is at this point that the rabbis entered the picture as authority figures, whose task it was to interpret these vague principles using both precedent and a knowledge of the individual and her situation. However, such an application is problematic on a number of levels. First, identifying appropriate precedents will

require the authorities to abstract the features of the situation that make it sufficiently similar to others such that the paradigm matches. As previously discussed, such abstraction often obfuscates the very complexities of the situation that made it a moral dilemma in the first place.

Furthermore, it is not clear according to what scheme the rabbis will help the individual to decide what action to choose. Apart from precedent application, the authorities typically use their knowledge of the individual to arrive at a course of action. Many sources speak of the individual nature of this, such that a patient is encouraged to seek out *her* rabbi for such a consultation, as only he knows her and her family and hence can arrive at a decision that is well-informed. I contend that this focus on the relationship between the individual and the rabbi whom she seeks out to assist her with her dilemma arises because of an understanding of the fundamental connectedness of individuals. The rabbis know that any decision reached in these situations will inevitably affect other family members and individuals about whom the patient cares. Reaching a good moral decision, then, will require accessing the process of caring of which Nodding speaks: a good moral decision is evaluated not only according to the resultant action, but also according to how faithful the participants were to the process of caring when making the decision.

Hence, since the focus on the individual situation of the patient is already a part of decision-making in Jewish bioethics, coupling this focus with an ethic of care should work quite nicely. In fact, I argue that many authorities are doing this already,

whether or not they are aware of or can name this distinct focus of their procedure. If not, it will not take much work to incorporate this ethic into the already-existing schema. Given the importance of the family and community in Judaism, incorporating an ethic whose primary focus is these important relationships will complement the structure well.

There is precedent for combining principles and an ethic of care, although they are combined in different ways from the one that I am suggesting. Regardless, thinking about these examples will be illuminating. Chris Crittenden remarks that principles in and of themselves are "neither principles of care nor of justice;" what is important, then, is what the principles are and what one does with them.[316] In fact, Crittenden argues that there are seven "principles of care" that correspond to the traditional principles of justice.[317] He does this at least partly to demonstrate that it is not the structure of the moral tenet that is important (principle vs. rule, for example) but rather the character and use of the principle. According to Crittenden, any principle that furthers the oppression of women is an anathema, regardless of its origin.

Feminist philosopher Rita Manning also finds a place for the combination of principles and caring. In fact, Manning argues that "rules and rights" serve the same purpose that I have argued principles do in Jewish bioethics. I argued that the

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[316] Chris Crittenden, "The Principles of Care," *Women and Politics* 22, no. 2 (2001): 81-105.
[317] Ibid., 84.

principles and rules served as useful side constraints on action, or as limiting factors which narrowed the range of acceptable choices, yet failed to provide sufficient direction as action guides. Manning goes a step further: rules and rights serve as moral minimums, and as such are required in conjunction with an ethic of care.

> …[T]he rules do not have a life of their own, but are guides. They help us to formulate a caring response because they speak to us of what most of us would want as a caring response in a similar situation. If the one needing care does not want the response suggested by the appropriate rule, we should listen to them very carefully and be willing to ignore the rule.[318]

This view may also be useful in addressing a common criticism of care ethics, that of "moral myopia": caring only occurs for those who are closest to us and those who are morally more distant from us do not benefit from our caring actions. Hence, we are nearsighted in the sense that we only care for those in our "inner circle" and do not address the (sometimes grievous) moral problems that affect those far away from us. One response to this is to point to the network of relationships in which we are involved. Even if one agrees with Noddings that it is impossible to truly care about those at a distance from us – the starving children in Somalia, for example – both because we are not able to provide the real care that they need and because they cannot respond in kind, one is not committed to a view of morality as localized and narcissistic. Rather, envision the network of those with whom we are connected as a spider's web, with us at the center. Those I am competent to care for are on the

spindles that are closest to me. Yet my caring for them facilitates their caring for those close to them, etc. Hence, since we are all somewhere on this web of interconnectedness, the children in Somalia *will* be cared for, just not directly by me.[319]

Manning suggests another way to combat this objection. Extreme moral myopia is centered around the notion that we only care for those who can help us in some way, or who are directly related to us: our family and closest friends, one could suppose. It is more difficult to care for others who are not a part of this inner circle, and hence we treat others with a certain amount of distance. This leads to the attitude that caring for helpless others is "someone else's job," since my responsibility is exclusively to those in my immediate radius. Rules and rights, according to Manning, help to guard against this to an extent. Manning argues:

> In a world infamous for its lack of caring, we need tools of persuasion to protect the helpless. This is one of the roles that rules and rights fill….Rules and rights provide a minimum below which none should fall and beyond which behavior is morally condemned. Rules provide a minimum standard for morality. Rights provide a measure of protection for the helpless.[320]

Hence, incorporating principles into an ethic of care may guard against the problem of distance as a challenge to morality.

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[318] Manning, 51. This may very well hold for the hybrid theory that I am proposing as well. This will be discussed in greater detail in chapter five.
[319] Recall that "caring" is a technical term, and does not merely refer to a "fellow feeling" we may have with those who are suffering. It is in this technical way that I cannot care for the children, but others can.
[320] Manning, 50.

Another common criticism of the care ethic is that the one who cares is vulnerable to self-sacrifice and abuse. One must be on careful guard against completely losing one's own goals and needs in the process of fulfilling the needs and desires of others. To help to ensure that this problem does not come to fruition, Crittenden posits a principle that requires the caregiver to first care for herself before caring for others.[321] This is not inherently counter to the ethic of care, and plays an important role in the moral life of the caregiver.

So far I have been arguing about why combining principles and the ethic of care are not incompatible with the motives of care. There is nothing inherently contradictory between the notion of care and that of principles, but rather it is which principles are used and the manner in which they are applied that is important. There are some that suggest that principles themselves cannot stand alone, and require some other element for a complete moral theory. As Lawrence A. Blum argues:

> …[W]hat it takes to bring such principles to bear on individual situations involves qualities of character and sensibilities which are themselves moral, and which go beyond the straightforward process of consulting a principle and then conforming one's will and action to it….[K]nowing that the particular situation which the agent is facing is one which calls for the particular principle in question and knowing how to apply the principle in question are capacities which, in the domain of personal relations (and perhaps elsewhere too), are intimately connected with care for individual persons. Such particularized, caring understanding is integral to an adequate meeting of the agent's moral responsibilities and cannot be generated from universal principle alone.[322]

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[321] Crittenden, 99.
[322] Blum, 59.

This provides more evidence that such a combination of principles and the ethic of care make sense for Jewish bioethics. This speaks to the issue of application, and argues that only by already having more (moral) information at hand will such an assessment of the role of principles be achieved. And since such application requires an additional moral assessment, given an individual's "natural feeling of caring" and the focus on the family and the community in Judaism, adding an ethic of care is useful for this group of people.

So the combination of a principled approach with one centered around caring and relationships is a nice fit. Both are useful in shaping the individual's decision in a medical context. The principles lay a general foundation upon which the work of preserving relationships can build.

Objections

Some may object that by introducing an ethic of care, I have not aided traditional Jewish bioethics as an action guide; rather, I have simply made things worse by making it more general. Instead of having discrete principles to guide our decisions, now we have to look at relationships and figure out how to preserve those. My reply is that looking at the context involved in the decision may make the process more complicated, but it also adds a particular focus that had been lacking. The presumably arbitrary nature of principle application can be addressed somewhat by a focus on the caring and compassion that are already present in Judaism.

A common objection to care ethics in general is that it is insufficient as an action guide when used alone because it fails to give a universal guide (such as the principle of utility) for agents to follow. Remember, however, that I am not suggesting we adopt care theory *in place of* traditional Jewish bioethics, but rather that we augment the traditional schema with this alternative approach. This will allow for a richer moral theory on both counts.

Some might argue that I am doing nothing new here. That is, Judaism already emphasizes the importance of family and familial relationships, and so introducing care theory into this tradition is redundant. In fact, it is this understanding of relationships that drew me to this project. What the traditional schema does not typically do is to focus on the needs of the relationship in the way that care theory does. Instead, it focuses on our obligation to those in the family – the duty we have to our children, etc. What this project suggests is a way to bring to the surface elements that already exist in Jewish bioethics. It is crucial to maintaining these important ties – not because we are obligated to, but because that is what it means to care for others and be cared for by them. Only then can we act in a way that is true to ourselves and our convictions.

Finally, there is a difficulty that I have not yet addressed. Augmenting Jewish bioethics with an ethic of care gives an individual a more specific action guide when facing a moral question. But what happens when the action guide conflicts with the principles? That is, suppose the principle in Jewish law that requires us to act to save a

life is the one that is appropriate in a given situation. Then suppose a situation where caring for an individual patient will require us to act in direct opposition to that guide. Perhaps a concrete example will be useful here, and will demonstrate how incorporating an ethic of care into traditional Jewish bioethics may alter moral decision-making.

Consider the woman who refuses a radical mastectomy despite the fact that such a course of treatment has the best chance of saving her life. Such an action seems to directly counter the principle of the sanctity of human life that is crucial in Judaism, and hence it is the rabbi's role to counsel the woman against this course of action. On the other hand, perhaps caring for the woman in question would require us to support her position: when we consider her reasons for refusing surgery, let us presume, we are convinced that the caring response to her problem is to support her right to refuse treatment. Now, however, there is a clear instance of conflict: the caring response is in direct opposition to the response prescribed by the principles of Jewish bioethics. Our initial appeal to Jewish bioethics to narrow the sphere of action is itself in conflict with caring. Now what?

I contend that the way to understand such instances of conflict is to analyze them from a larger perspective, which is the task of the next chapter. Specifically, understanding the framework of principle and rule application that is the hallmark of Jewish bioethics includes an understanding of the values and priorities of this group of people. Comparing their values and priorities with the values and priorities of the

physicians doing the genetic testing will be illuminating. For one thing, such a comparison will suggest a scheme of dealing with the aforementioned conflicts: I will show that agreement and disagreement can be assessed in terms of degrees, and any instance of conflict must be further refined considering this analysis.

Finally, the other issue that has not been adequately discussed yet is the impact of dissent: dissent by those who reject the recommendations of the authority figures, and dissent among the authority figures themselves. What is the moral significance of the fact that two different rabbis may well give two very different recommendations to a woman considering breast cancer screening? As the answer to this question is fundamentally grounded in the analysis of values and priorities mentioned previously, this will also be discussed in chapter five. Once those issues are clear, I will suggest some future directions of research for those interested in this project, as well as specifying what consistency will require in future decisions.

CHAPTER FIVE

CONFLICT AND RESOLUTION

So far in this project I have focused on specific applications of more general ideas in order to support my thesis. That is, instead of looking at genetic medicine in general, I focused on three specific genetic diseases and the ethical issues associated with each. Then, rather than looking at Jewish bioethics in general, I focused on the particular rules and principles that could be consistently applied to the moral questions that patients with one of the three diseases might face, and then pointed out problems with that approach. Finally, in my discussion of the care ethic, I related it specifically to the group of observant Jews with whom my project is concerned and described how the ethic is both an appropriate orientation for this group, as well as how it offers a better action guide to the individuals involved in moral decision-making.

These very practical efforts, however, have led me into a sort of a trap: there will be instances when my augmented form of Jewish bioethics fails to specify a morally right course of action, specifically when the principles of Jewish bioethics and the action suggested by care ethics conflict. I have defended the notion that Jewish bioethics and care ethics can work together because the rules and principles of the traditional schema lead one to an optimally acceptable action, while care ethics offers the appropriate focus for moral agents when making a decision. Yet in instances of conflict, it seems, this proposal breaks down.

I contend that this is not a fatal flaw for my project. What is necessary to solve this problem is a broader understanding of the values and priorities of the group in question. Specifically, by understanding what the observant Jews in my project view as important – in fact, by creating a moral taxonomy of such values – we will be empowered to solve such an apparently fundamental objection. My first objective in this chapter, then, is to elucidate such a taxonomy and then to use it to answer the objection suggested at the end of the last chapter.

Once that has been accomplished and this conflict has been resolved, however, my problems will not end. In fact, a larger issue may arise from rubble of the former one. The moral taxonomy that I specified from the observant Jewish communities mentioned may indeed conflict with the values and priorities of the scientists and clinicians engaged in genetic medicine. What is the appropriate resolution of these conflicts in moral priority? I will describe and then analyze what I judge to be the motivational goals and values of the scientists and researchers, and then suggest both similarities and differences between these and the goals of my augmented Jewish bioethics. I then will suggest ways that these two groups of people can find common moral ground. What will become apparent is that it is unlikely that real instances of irresolvable conflict will arise, since, as I have argued, care ethics are a part of the application process of the principles of Jewish bioethics. I will explain how the rules and principles might be thought to conflict, and then defend the notion that in fact the two approaches work together in a complementary fashion. Finally, this chapter

concludes the discussion of this project with a recapitulation of the progress that I made and the claims that I defended.

Values and Priorities of the Jewish Community

Judaism is a religion that focuses on the present rather than the future. Social action is crucial for committed Jews, as it is through such interaction with individuals that morally right action can be initiated. Morally right action is pursued not for some goal of life after death, nor for any future rewards,[323] but because of a general requirement to act according to the laws of God. While an action may be performed in order to please God or to win God's favor, it is not because of a fear for one's eternal existence that the committed Jew engages in morally right action. Rather, the way we act towards one another determines the nature of our character, and it is this that motivates the committed Jew. The goal is to be the best kind of person we can be, the kind of person whose actions are pleasing in the eyes of God. In other words, our goal in life is to live a life of holiness.[324]

Our choices determine our character, but there is a core upon which such choices imprint, and that is that the human is created in the divine image. While there is debate over which feature of humans reflects this divine image,[325] it is this notion that divides the human from animals. This doctrine is more than merely descriptive,

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[323] There is a concept of the "world to come" in Judaism, but the character and origin of such a concept is still debated. For a discussion on the after life in Judaism see Toby Schonfeld, "The Afterlife in Judaism, Including Christian Influences," working paper, University of North Carolina at Chapel Hill, Chapel Hill, NC, May 1994.
[324] Dorff (1998), 26.

however; it is also prescriptive. According to Elliot Dorff, "…because human beings are created in God's image, we affront God when we insult another person."[326] Being created in the divine image, then, serves as a moral foundation for action. If we are all alike in this fundamental way, then any differential treatment must be on account of actions that we perform rather than on account of a difference in intrinsic moral worth. We must treat others with respect for what they are: images of God.[327]

The goal of living a life of holiness also specifies ways in which we are to view our bodies. Unlike Christianity, according to Judaism the body is "morally neutral and potentially good."[328] This means that bodily pleasure is "God-given and not to be shunned, for to do so would be an act of ingratitude toward our Creator. The body, in other words, can and should give us pleasure to the extent that such pleasure enables us to live a life of holiness."[329]

This is important to consider in relation to the duty to preserve life and health that is one of the primary moral requirements in Judaism. What we see here is that this principle is not important simply because life itself is sacred and of infinite value, but also because an individual who is in pain or suffering is unable to pursue the life of holiness that God desires. Dorff cites the following passage by Maimonides to support this view:

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[325] Ibid., 18.
[326] Ibid., 19.
[327] Ibid., 20.
[328] Ibid., 24.
[329] Ibid.

> He who regulates his life in accordance with the laws of medicine with the sole motive of maintaining a sound and vigorous physique and begetting children to do his work and labor for his benefit is not following the right course. A man should aim to maintain physical health and vigor in order that his soul may be upright, in a condition to know God…Whoever throughout his life follows this course will be continually serving God, even while engaged in business and even during cohabitation, because his purpose in all that he does will be to satisfy his needs so as to have a sound body with which to serve God. Even when he sleeps and seeks repose to calm his mind and rest his body so as not to fall sick and be incapacitated from serving God, his sleep is service of the Almighty.[330]

Understanding this foundation is crucial for understanding the values and priorities that committed Jews place on varieties of right action. The individual has an obligation to engage in that action that is pleasing to God, or, more importantly, an obligation to refrain from action that is displeasing to God. But the attribution of "pleasing" and "displeasing" does not directly correspond to the specific precepts and laws that are specified by the ancient sources. In chapter three I discussed the principle of mental anguish, according to which some laws were permitted to be broken in order to save a life. For example, there is the case of the individual who was so distressed at the prospect of following the dietary restrictions that the rabbis sanctioned his transgression of this obligation. This was because the well-being of the individual took priority over strict obligation to ritual law. Another example of such a violation was the woman in labor who desired that a lamp be lit, despite the Sabbath prohibitions on the kindling of fire. This was similarly allowed on the grounds that the laboring woman's need, even if not a physical one, caused a certain amount of mental

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[330] Ibid., 26.

anguish that the rabbis determined might be detrimental to her health and/or the health of others – in this case, her child.

What we see here, then, is an indication that there is an implicit ordering of obligations or requirements for the individual. There are many actions that an individual is morally compelled to perform,[331] and yet some of those obligations may be circumvented or even transgressed in the service of some higher goal. This goal, I contend, is that of being the "right" kind of person: one who cares for others as well as herself, one who tries to live her life according to the rules set forth in the various codes of law, and one who participates in the religious and ritual life that is a part of her tradition and hence attempts to live a life of holiness.[332]

The first step in the creation of our moral taxonomy is the recognition that health and life take precedence over any purely religious obligation. For example, while adults are required to fast from food and drink on the Day of Atonement, individuals whose health would be put at risk by this action are not required to engage in this action. This is the principle that is exemplified in the previous cases of the man transgressing the dietary restrictions and the woman breaking the laws of the Sabbath: their health took precedence over observance of the religious laws. This is especially interesting in these cases because the threat to health described is mental or apparent,

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[331] Here I am referring to the 614 good deeds, or mitzvoth, that the Jew is required to perform during her lifetime.

[332] It is possible, of course, that these goals may conflict, or that the pursuit of such goals could lead to conflicting actions. It is the task of the remainder of this chapter to discuss the resolution of such conflicts.

depending on the interpretation. The laboring woman did not require light to physically accomplish her task, and neither did those who were assisting her. Yet her perception of such a need was sufficient for the rabbis to rule in her favor.

So the priority of life and health is of crucial importance. It is also from here that the mandate to heal is derived. There is a famous saying from the Talmud that reads: "If you save one life, it is as if you have saved the whole world." Hence we are permitted some transgression of the rituals or laws in order to save a life ourselves, or in the service of healing. For example, Immanuel Jakobovits discusses how it is permissible to ignore the observance of the Sabbath and other religious observances in order to save a life, except for the three cardinal transgressions of idolatry, incest, and murder.[333]

This last bit is crucial because it further defines our relationships to one another. Previously we only discussed an individual transgressing the religious laws in order to preserve her own mental or physical health. With the discussion about the mandate to heal, however, we learn of the importance of our responsibility to others. No longer are we simply permitted to transgress our obligations if our health is in jeopardy, but we are also given that permission if we can help someone whose life or health is in jeopardy. This is a key move because it speaks to our fundamental interconnectedness as individuals. This is one way to see how the individual is not isolated in the community, but rather is joined to others in an important way.

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[333] Immanuel Jakobovits (1975), 42-58.

Other principles that were discussed in relation to the specific concerns raised by genetic medicine can be generalized into our taxonomy as well. For example, in the discussion of risk in relation to screening for colorectal cancer, we learned that an individual was permitted to engage in certain risky behaviors in order to save or prolong life, in order to improve quality of life, and in pursuit of a goal that has a low level of risk and/or that many people engage in, heedless of the risk involved. This discussion of risk gives us more of an insight into the priorities in Judaism once again because of the kinds of things for which failing to meet obligations can be justified. Important to this discussion was an understanding that an individual's body belongs to God and is simply on loan to her, and hence she is obliged to act as a "reasonable" caretaker and avoid unnecessary harm to this property that is entrusted to her. The amount of risk that is permissible for an individual to take is assessed in terms of the larger goal: the more likely an action is to save someone's life, for example, the more risk you are permitted to assume in its pursuit. The more improbable the risk and subsequent harm to the individual, the more likely it is that you will be permitted to engage in that action.

It is important to remember here that there is no sanction, divine or otherwise, for failing to achieve one's ends. A good faith pursuit of a life that is in accordance with the laws set down is sufficient for morally right action. There is no fear that one will go to Hell or be punished in some way if, for example, one inadvertently transgresses a doctrine or fails to save the life of an individual despite repeated

attempts. Instead, the focus is on how to live a good life apart from any concern about punishment.

The case of screening for the genes associated with breast cancer also reveals this priority of the sanctity of human life and the preservation of health. Once again the body as property was important, as was the principle of mental anguish: mental health is to be considered in addition to simply physical health. This became especially important in the case of the individual who was considering forgoing life-sustaining therapy in favor of some other course of action.

It is with the case of Tay-Sachs disease that we see the greatest evidence of a prioritizing of moral principles at work. It is still true that human life is sacred and individuals are instructed to do whatever they can in order to preserve that life. Yet with a fatal genetic disorder such as TSD, other considerations become important. For example, other religious prescriptions and prohibitions must be considered for a couple that is considering some method of assisted reproduction to avoid TSD. The prohibition against spilling seed, the obligation to procreate, and even rules about incest and infidelity become important in such cases. Their importance and relevance to the decision must be weighed according to what is at stake in each case. For example, the prohibition against "spilling of seed" is important, and usually justifies an absolute prohibition on condoms or other barrier forms of birth control. In certain circumstances, however, condom use is permitted: if, for example, that is the only way to harvest an ejaculate for the purpose of artificial insemination. It is possible that such

a permission is forthcoming because such an action does not properly fall under the rubric of "wasting seed," since it is for the purpose of procreation. However, it is also possible that permission is forthcoming because such an action occurs in the service of a "higher" goal – in this case, the goal of procreation. Yet such permission is only afforded on a case-by-case basis; the presumption is in favor of a prohibition unless the specific situation warrants special consideration. Hence, the priority is clear.

From what has been said, then, it appears that the moral taxonomy of Jewish bioethics consists of a series of prima facie obligations, all of which have relatively equal import, plus two overarching principles: the sanctity of human life, and the duty to preserve life and health. All other principles or duties (the requirement to ease suffering, the obligation to procreate, etc.) either stem from these two principles or are subsumed under them. While the lower-level prima facie principles can be overridden, it seems that the two overarching principles take precedence over all the others.

Since these two principles are the most important, it is worthwhile to spend some time figuring out why. Why are the sanctity of life and the preservation of health privileged over all the other principles? It is not because the punishment levied for transgressing the principles is any worse than for transgressing a number of other requirements. It is also not because Judaism is a vitalist tradition, as is apparent from the permissibility of abortion and the permissibility of certain risky behaviors that might endanger one's life. So why are these principles privileged?

I contend that there are two fundamental reasons why these principles have a privileged position over all the others. The first stems from the recognition that Judaism is a tradition focused on the present, rather than on the future. There is a rich tradition of accounts of individuals acting in accordance with the ways of life that are pleasing to God, as well as accounts of the ill that befalls such individuals when they fail to live such a life. This is partly on account of the fact that our bodies belong to God, and hence we must do what is necessary to care for and preserve what is on loan to us, until such time as God is ready to take it back. Furthermore, because the primary concern in Judaism is living a life of holiness, and because this is our only chance to better the world in which we live, it makes sense that we are required to do what we can to preserve our lives here on earth so that we can accomplish that goal.[334] Hence, the lack of a certain afterlife is one reason that principles regarding the sanctity of human life and the preservation of such life are of crucial importance. We must be alive and well in order to pursue the goal of holiness.

The second reason that these principles occupy a privileged position is because of the focus on the family and on the community that was mentioned at the beginning of this project. The community is very important in this tradition: individuals are instructed to choose marriage partners from others within the community, religious obligations are carried out and rites of passage are celebrated within the community, and assistance in times of need comes from the community. While the community is

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[334] See Dorff (1998), 26.

more than simply the sum of its members, sustaining those members remains an important component for the continuity of the community. The principles and rules of Judaism help to specify our relationship to one another, and our actions in the community are representative of this. It is a fact that these principles require each of us to care for other community members in some way. Part of caring for others includes a recognition that we are all important and importantly different, something that is captured by the notion that we are all created in the divine image and the principle of the sanctity of human life. We are each valuable, and our value cannot be compared or replaced.

Furthermore, caring for individuals includes providing for others in their time of need, and that is the sentiment that is captured by the principle that requires us to preserve life and health. We are to do what we can for each other because that is what morality requires. Babies are born in Judaism with a clean slate, and hence the development of character is similar to the process described by Aristotle, where we are responsible for the kind of person we become on account of our choices, which are also augmented by environment and the influence of others. We are the kind of people we are, then, by the choices we make and the actions we perform. Being the best kind of people, those who are pleasing to God, and achieving a life of holiness means performing those actions that caring people perform. Hence, the priority of these two principles is also supported by the kinds of relationships we have with one another.

From what has been said, it should be evident that these principles are foundational in the life of the observant Jew. The principle of the sanctity of life is important not only because we are created in the divine image and hence are intrinsically valuable, but also because we must be alive in order to fulfill God's commandments and achieve a life of holiness. The principle that specifies our duty to preserve life and health, then, does so in recognition of the fact that we must preserve or restore our ability to perform God's commandments and pursue the life of holiness whenever possible. And because it is this principle that is also fundamental to our relationship to others, it is important to consider this in relation to how we act in our community. No other principle (e.g. the obligation to procreate, the principle of mental anguish, etc.) is as foundational to the life and well-being of the individual as are the two specified here.

Conflicts with Caring

With this in mind, we are prepared to discuss the issues of potential conflict between rules and principles and the prescriptions of an ethic of care. Suppose, for example, that the woman considering a radical mastectomy decides, for good reason, not to go through with the surgery. Further suppose that when we analyze the situation, we agree that the caring response is to honor her wishes and support her. Yet the principles of the sanctity of human life and the mandate to heal strongly suggest another action: insofar as the mastectomy has a good chance of saving her life, there is reason to assume that Jewish authority figures would counsel the woman that she is

required to undergo this surgery. Hence, the caring response seems to conflict with the action suggested by Jewish law.

What I propose here is that the adjudication of such conflicts must be accomplished from an understanding of the overall importance of these principles. This is where the perspective of care ethics does not conflict with the traditional schema, but rather enhances it. There is a chance, of course, that the principles and the application of the care ethic lead to an instance of apparent conflict rather than real conflict. This result occurs because of a failure to understand the principles richly. An example here may help to demonstrate this point. We have previously mentioned that the requirement to preserve a person's life and health includes mental health as well as physical health. In the scenario provided regarding the mastectomy, one can assume that it was something other than the individual's concern for her physical health that prompted her decision. Perhaps she has a psychological commitment to her bodily integrity that precludes even potentially life-saving physical deformity, or perhaps she has an understandable fear of surgery that stems from both the risks involved as well as a personal experience with loved ones dying on the operating table. Regardless, her quality of life would be severely compromised by engaging in the surgery, we can assume, and quality of life considerations are important in Jewish bioethics. Recall that in the assessment of risk, we discussed that it was permissible to risk life for quality of life, and that seems to be what is at issue here. A rich interpretation of the principles includes an acknowledgement of the motivations behind the principles and

will lead to a more warranted application of the principle. This procedure will likely illuminate and resolve any conflict that is merely apparent. And in this understanding of the case, it is not at all clear that the principles of Jewish bioethics in fact do suggest a different course of action than the one suggested by care ethics. Hence, as I have argued all along, the authority figures' interpretations of the principles required an acknowledgement of the overall context in which the decision was taking place, and it is this that the care ethic has provided for them.

However, there might be instances of real conflict, not merely apparent conflict. What are we to do in those instances? I contend that the right course of action for that individual will once again depend on the context. I stipulated initially that the group of people on whom this project would focus were those who would seek out the rulings of Jewish bioethics when making a medical decision. I deliberately avoided referring to a particular organized group, such as Orthodox Jews, both because of the diversity among such groups and because of the difficulty with such limitations. Because, then, these individuals have various commitments and are in fact only united by the fact that they seek guidance from Jewish sources when making a medical decision, we know little about the rest of their commitments. More importantly, we do not know the extent of their commitment to the guidance that they receive from the authority figures. For some individuals, we can assume, this information will be factored in with all of the other relevant considerations, and not carry any more or any

less moral weight than other considerations. For others, this information will be the primary ground for making a moral choice.

The point is that the amount of moral weight that these principles have for the individual must be considered. If an individual ranks consideration of her family higher than adherence to principles, for example, then this instance of conflict will be solved in favor of an ethic of care rather than in favor of the principles. She may choose the option that best keeps her family's interest in mind because that is also the option that is good for her. This determination that her family's interests are very important in the decision process is not necessarily a rejection of autonomy, but even if it is, that is acceptable to a woman whose ethical framework is the ethic of care. Recall that it is a fundamental realization in this ethic that the self is not a separate and separable entity but rather is inextricably connected to others.

On the other hand, perhaps what this example demonstrates is that real, irresolvable conflict is unlikely to occur. If, as I contend, an ethic of care really has become part of the rabbis' application of the principles to the individual case, then in fact a care ethic serves to underscore the fundamental values of this community, regardless of their commitments. The point is that since these two approaches complement each other rather than stand in opposition to one another, real conflict is unlikely. This possibility will be discussed shortly.

In the event that an occasion of conflict does arise, however, the overall idea is that the woman would need to ascertain where her commitments lie in order to

determine how to solve the conflict. And insofar as each person will have different commitments and different levels of commitment, such an assessment must occur on an individual basis, based on the context of the situation. The values and priorities of the individual must be employed in interpreting the principles of Jewish bioethics and used to weigh the various commitments of the individual against each other.

What I suspect, however, is that if we understand the rules and principles in Jewish bioethics in the way that I have previously argued, that is, according to the values and priorities which the principles represent, then conflict will either be easily resolved or will turn out to be merely apparent in the first place. If the principles exist in order to afford individuals the opportunity to have a rich and fulfilling life, and if they include a recognition of the importance of the community in the development of the individual, then in fact courses of action specified by care ethics and those specified by Jewish bioethics will rarely conflict. This will require a broader interpretation of the principles, to be sure, but will yet be true to the foundations and spirit of the principles. Understanding the importance and value of individuals to the Jewish tradition will require a correlative understanding of the regulations that specify the ways in which we should treat one another: we should act according to the notion that human life is valuable, and hence we ought to do what is in our power to preserve it. The woman's act of refusing a radical mastectomy may first appear to counter this goal of preserving life. But when we understand her reasons to include a fundamentally different idea of what her life means, and of what such surgery would

mean to her quality of life, I would argue that the principle that requires us to recognize the value in human life carries with it a recognition that the individual is the only one qualified to make the determination about the value of her own particular life. Preserving life and health includes mental health as well as physical, and that might be the most important factor in this case.

This interpretation of the rules and principles does not run counter to the tradition of Jewish bioethics. In fact, I would argue that it is in better harmony with it than would be a rigid application of the principles to the case. Recall that traditionally, the authorities made their rulings based on particular cases; the model of casuistry applied here. My quarrel was with the lack of apparent clarity in how the rulings were applied to individual cases, not with the focus on cases themselves. In fact, I argued that moral dilemmas can only be solved from within the context of particular cases, and that care ethics helps us to specify the right action for individual patients. This is in fact what the authorities do when presented with an individual with a decision to make: they try and determine how particular rules and principles can be made to fit with the individual's goals and values, and this is the process of caring that I have described. The importance of the individual case for traditional Jewish bioethics cannot be underestimated, as it stems from the fundamental importance of the individual in relation to her community. Hence, keeping this foundation in mind when evaluating a situation of apparent conflict will help the decision-makers to achieve some sort of resolution.

Values and Priorities of Researchers and Clinicians in Genetic Medicine

"Cracking the code" of the human genome has been hailed by the public as one of the most important advances in science and medicine in the history of the discipline. The scientists and clinicians who have been involved with or benefit from the project are just as excited as the public, if not even more so. This is because of the promised benefits of genetic research. Understanding the human genome will give insight into causal mechanisms of disease, which may then suggest treatment interventions for these ailments. Indeed, the cure for cancer and the key to longevity may be found within the human genome.

It will be useful for us to specify and analyze the values and priorities of those involved in genetic medicine in order to compare and contrast them with those of the observant Jewish communities of whom I have been speaking. There are five aspects of genetic research that are of value to clinicians and researchers. The first is that understanding the human genome will increase our knowledge of disease and illness. This is important for a number of reasons, which comprise the other four values held by this group. Such knowledge may allow clinicians to (2) save lives, by leading to (3) the development of cures for disease or methods of symptom suppression, which will lead to improved care for patients. Of course, some researchers simply (4) value knowledge for knowledge's sake, because understanding more about the world we live in and the role that individuals play is one of the great mysteries. Finally, some researchers (5) value the economic potential that the human genome brings, either by

patenting this new knowledge (gene sequences, etc.) or by developing products that are in high demand in our market economy.

This list of values is neither exhaustive nor mutually exclusive, and there is a good deal of overlap among them. A clinician could be interested in knowledge for the sake of knowledge, and yet simultaneously recognize the benefit to patients that will result from her investigations. In fact, this idea that understanding the human genome may get us one step closer to solving a great mystery should not be underestimated as a value.[335] It is from such an orientation that we get the clinician who is a problem-solver, one whose role it is to get to the root of the problem and then propose a way to deal with the mystery. We encourage our medical students to take on such a role, where medicine is a sort of discovery into the nature of disease and injury, and where the practitioner has an array of armaments at her disposal with which to attack the offending entity.

We encourage this role of the clinician-as-problem-solver because it furthers goals with which we largely agree. That is, solving the "problem" of heart disease, for example, will result in saving lives, or at least in helping patients. These are goals with which we resonate. Corresponding goals of increasing an individual's quality of life or decreasing her amount of suffering are also noble. Understanding the character of

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[335] Nor, of course, should it be overestimated, as such overconfidence in genetics might discourage a researcher from pursuing other research that might more quickly or directly benefit patients. I am grateful to Glenn Graber for pointing this out to me.

disease or injury is also necessary for the more fundamental goal of the physician – to do no harm.

Given that genetics is the science of heredity, researchers in this field have an even greater opportunity to achieve the goals or continue the values that were previously mentioned. Now they have the opportunity not simply to cure disease in one generation, but to carry that through to multiple generations. We can manipulate our basic building blocks, our genes, to eliminate undesirable traits and to promote traits that confer some sort of social advantage.[336] If one of our goals is to help patients, then certainly we would not want to limit our investigation to those procedures that fix deleterious genes, but we also want to give individuals every possible opportunity to succeed, and this can be achieved through genetic manipulation as well.

Or would we? One thing that is clear is that there is a certain amount of paternalism involved in many analyses of what it means to help people. Certainly there are degrees of such knowledge: we are hard-pressed to understand why anyone would be hesitant to eradicate lethal traits like TSD[337] while we are much more dubious of efforts to enhance individual characteristics. Yet paternalism in any form must be subject to scrutiny. One relevant instance of the problem with paternalism is

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[336] Mahowald, 2. This claim may be a bit bold, but the spirit of the thought is valid.
[337] However, there may be some reason to be concerned about such manipulation, as discussed previously in relation to things like heterozygotic advantage and the like. Regardless, after a cost-benefit analysis is performed, many would still argue that disease eradication takes priority.

when a patient refuses treatment that is otherwise indicated, or when a family requests the continuation of an apparently "futile" treatment. It is in these instances that we see some of the problems with paternalism, notably that the physician is not always correct in her estimation of what is in the best interests of the patient.

The same kind of reasoning holds true for genetic medicine. As previously discussed, the information gained from genetic research is of value to the clinicians and researchers for many reasons. Regardless of which one – or how many – of those reasons hold in a particular case, the information is always of value for clinicians. Such information can assist them in caring for the patient, in developing future cures or other treatment alternatives, etc.

This points to the first main difference between the values of the researchers and that of the community of which I have been speaking. While the information gained from research is always of value to the researchers, the same information may be a disvalue for patients. A good example of such a conflict is the case of the woman considering genetic testing for one of the mutations associated with breast cancer. The information gained from the test would give her physician knowledge about her risk of breast cancer that might change the way in which he cares for her: perhaps she ought to come in for clinical exams every six months instead of yearly, or perhaps she ought to have a mammogram earlier than the normally recommended time. These actions coincide with the goal of helping patients, and perhaps even with saving her life.

It is not clear, however, that such information would likewise be valuable for the woman herself. As previously discussed, she may have compelling reasons not to find out the information: perhaps it would lead to more psychological distress for her or her family members; perhaps it would harm the relationship that she has with others insofar as gaining this information about herself would also give her information about her siblings and children, etc. Especially if it is clear that the woman would take no action given positive or negative test results, it is not at all certain that engaging in testing for the purpose of gaining information is a value to her.

This leads us to the second major area of conflict between the interests of those doing genetic medicine and those of this group of observant Jews, and this is a difference in priorities. Given the context of values previously discussed, it is understandable that the priority of genetics is to cure disease, or to understand the human genome so that diseases can be eradicated and individuals can live longer, healthier lives. The priorities of the observant Jewish community, on the other hand, are to live a life of holiness and to be the "right" kind of people in whatever time we are given. These priorities may conflict, as living the life of holiness may include performing actions that are contrary to the goals of those involved in genetics. For example, the woman considering testing for a genetic susceptibility to breast cancer may find that other things important in her life take precedence over finding out this information. Since the goals are different for this group than for the group doing genetic medicine, the value of engaging in such a test must be evaluated accordingly

by all parties. The focus is on living a life that is pleasing to God, and curing disease or manipulating the genome is desirable only insofar as it assists the individual in achieving this goal.

In the previous two cases, we mentioned the impact that the family has on an individual's decision, and discussed how other considerations might supersede those specified by the geneticists. This points to the third major difference in values between those doing genetic medicine and the members of the group of observant Jews. While the family is important for both groups, its importance stems from completely different foci. For the geneticists, families are important as the foundation for the science of heredity. That is, it is through the study of pedigrees and inheritance that genetics is understood, and hence the family is an important locus of information. For the group of observant Jews, on the other hand, family is important for entirely different reasons. The family is the locus of morality, where caring occurs and where our obligations to one another are both first learned and best applied. The role of the family is initially to model and shape appropriate relationships and then to enable individuals to pursue relationships with others – it serves as the foundation for ethical interaction with others. The family, then, does not have only instrumental value for this group, but rather has intrinsic value as well. This intrinsic value stems from the notion that we are all created in the divine image and as such we are required to respect one another as individuals. The interactions we have with one another, then, is supposed to presuppose this value.

The question then becomes: is there a way to solve these conflicts so that the two groups can find common moral ground? I argue that there is, and that is the subject of the next section.

Conflict Resolution and Harmonious Living

The first conflict in values and priorities is in some ways the most difficult, that of the differing value of information. Part of the problem here is that information is almost always viewed as a value to individuals, whether in the context of genetics or otherwise. For example, there are obstetricians who refuse to care for women who decline the triple-screen early in their second trimester simply because the physician feels that the information from this test is valuable to them.[338] Furthermore, with the transition in medicine from an ethic of paternalism to one of autonomy, we now find ourselves counseling physicians on how to deliver information in a compassionate manner without being patronizing or holding too much back. With this as a model, then, it is no wonder that information is viewed as especially important in medicine, with individuals more often than not erring on the side of caution by having as much information as possible.

It is important to note that the disvalue that may attributed by the Jewish community is not because of the information itself, but rather the different priorities and goals that this group has. It makes sense that in a field that depends on previous information in order to build knowledge, researchers will always value information.

Yet when the focus changes, as in this instance, then so does the value of the information.

This also explains the fact that the information will likely differ in value depending on the individual and her situation. For a couple that is concerned about their risk of having a child born with TSD, the information about their risk may very well be beneficial. This could be because they are willing to abort an affected fetus, or because they are willing and able to engage in one of the alternative methods of reproduction, or simply because they want to be physically and psychologically prepared for their child.

What we see, then, is that the conflict that may result between those doing genetic medicine and the patients involved occurs not because of the information itself but rather with the use of such information. Because this is the case, I do not think that this conflict is irresolvable. What a solution requires is some measure of understanding both on the part of the clinicians and on the part of the patients. The kind of understanding I have in mind will be described below.

Bioethicists have been attempting to bring clinicians to an understanding about patient values almost since the discipline began. One hallmark of respecting patient autonomy is in recognizing that patients may have different values than the clinician and this may result in differing ideas regarding treatment options. A treatment that is

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[338] I know this from personal experience. When one considers the lack of reliability of this test, it makes this position even more suspect.

recommended and seems perfectly reasonable to a physician may be absolutely out of the question for a patient with different values and goals. Respecting an individual's right to refuse treatment, then, includes an appreciation for, but not necessarily an agreement with, the patient's values.

We have attempted to accomplish this understanding on the part of the physician on a number of fronts: through different models of the physician-patient relationship,[339] through a detailed discussion of "futile" treatment and a subsequent undermining of the fact-value distinction,[340] and through descriptive accounts that explain different religious beliefs and cultural notions of patients so that an understanding can be reached.[341] What all of these approaches have attempted to do is to give clinicians reasons why patients might disagree with their treatment recommendations. The idea seems to be that if the clinicians understood the reasoning of the patients they would be more likely to accept their decisions, if not agree with them.

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[339] For example, see Ezekiel J. Emanuel and Linda L. Emanuel, "Four Models of the Physician-Patient Relationship," *Journal of the American Medical Association* 267, no. 16 (April 22/29, 1992): 2221-2226.

[340] The fact-value distinction refers to the notion that objective, scientific facts (i.e. lab results, prognoses, etc.) can be separated from the value judgments that people make about diseases, patients, and patient care. For an extensive discussion of this distinction and how and why it can be undermined, see Susan B. Rubin *When Doctors Say No: The Battleground of Medical Futility* (Bloomington: Indiana University Press, 1998).

[341] For example, see Anne Fadiman, *The Spirit Catches You and You Fall Down* (New York: The Noonday Press, 1997).

Insofar as this model has merit,[342] I contend that it is applicable in the instances of conflict with which we are concerned here. Recall that what is different about the value of information is the goals that each party has. Getting the clinicians to understand that this group of people has different goals for their lives and for the role of medicine and healing is crucial to resolving potential conflicts. It is possible to reach such an understanding in ways similar to those discussed above: educating physicians about the priorities of this group will not only elucidate differences from "traditional" medicine but will also give them an understanding of the reasons why certain treatment options may not be acceptable. In some ways, then, this group represents another instance of the overall importance of understanding patient values. And since not every member of the observant Jewish community will view the information in exactly the same way, approaching each case on an individual basis seems to be the best way to proceed.

It is important to remember, however, that this conversation must not be one-sided. It is equally important for the patients in these cases to understand the modus operandi of the clinicians as well. Sometimes the physicians get "demonized" because it is presumed that they do not, and cannot, understand the differing values of the

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[342] This is not to say that this method is the best available, or even better than some alternatives. I am concerned, for example, with the presumption that a detailed list of reasons must always be given for such decisions to be acceptable; that is, I am suspicious of the notion that demonstrations of rationality always trump other considerations. However, as this method has been influential and is currently the operant paradigm, I think it is still useful for conflict resolution. Other methods may be better, but this one still works.

patients, and I think this is a mistake. Such assumptions lead to further conflict, not to resolution. Hence, continuing to appreciate the role of the clinician as a scientist, as one who has ostensibly good motives (to help patients), or as one whose role it is to solve mysteries, will be beneficial to the patient. The problem-solving mentality might be an asset here; what is necessary is a recasting of the problem.

Hence, this conflict can be resolved by engaging in a conversation about the goals of each party. There is a dual responsibility here: it is the responsibility of the clinicians to explain why the treatment they are suggesting is recommended, and what values and goals that presupposes, and it is the responsibility of the patients to explain what their goals and values are so that treatment can be evaluated accordingly. Again, this is not likely to result in total coincidence of values (although that is possible); instead, what will result is an increased understanding of where each party is "coming from" so that they can continue together on a course of action. In fact, a bit more may be necessary here: some overlap of values may be required for the physician and patient to agree on a course of action. A common goal might be reached, even if not all of the values are shared by all of the parties.

It should be evident, then, that the conversation model that I am suggesting will work to elucidate the different priorities that each group has, in addition to the differing value of information. In fact, it is not at all clear that these two issues are really separable. The different priorities held by each group – living a life of holiness for the observant Jews and saving lives and solving mysteries for the genetic

researchers – largely determines the differing importance of information for each group. By making these priorities clear and bringing them out into the open, different alternatives may present themselves and other courses of action will be better understood in terms of the larger worldviews of the two groups.

The final difficulty that might lead to conflict that was previously mentioned was the difference in importance that the family holds for each group. The genetic researchers value family primarily because this is how they get their information, and because the information that they are able to determine has medical implications for other family members. The observant Jewish community, on the other hand, places family at the center of importance for an entirely different reason: their tradition and community center around the family, and it is through interactions with family members that ethical behavior is first derived.

It is not entirely clear to me that this difference in focus on the family will always, or even most of the time, result in conflict between these two groups. Instead, I contend that these two views can be complementary, where finding out information about family members may indeed help both clinicians and the patient himself to care for the other individuals. However, in cases where conflict does arise from such different priorities, I argue that this must be resolved in favor of the patient. For example, once again consider the woman debating about genetic screening for her susceptibility to breast cancer. It is true that information gained about her risk would give her and her physician important information about her family members as well.

But also important to this woman was what caring for her family involves, and this included the recognition that gaining such information might be harmful to her relationships. Insofar as preserving her relationships is one of her most important goals, it was not clear that receiving this information was the best course of action for her.

It is true that getting such information could be helpful for the clinicians. Not only does it indicate certain courses of action involved in caring for the patient and her family, but also the information would be important scientifically – the more that we learn about the way that mutations are inherited in families, the better we can get about predicting diseases and combating them by prevention and treatment alternatives. The problem is that these goals are not always the goals of the patients – medicine is many things to many people. And while it is true that if *every* patient and her family refused[343] to engage in genetic testing we would get no data about inheritance and the development of diseases on account of mutations, it does not seem as though we are in immediate danger of such a consequence. In fact, if anything, the

[343] It would also be significant if every member of a genetically significant sub-population refused to engage in testing, as our research might be skewed. However, the points that I make regarding the unlikelihood of this consequence for the general population hold here as well…for the most part. I am reminded of the problems with screening for sickle-cell anemia, however, where the problems with screening were almost exclusively caused by poor handling of the situation by the public and by the medical community. If this fear, that our research would be affected by certain groups failing to cooperate with screening, is real, then society should be willing to take the necessary steps to ensure that such discriminatory and negative consequences do not occur again. We have an opportunity here to learn from our mistakes, and we ought to do so.

frequency with which society seeks out "genetic" answers to their problems suggests that scientists will be well supplied with data. The public relies more and more on genetic information to give them answers to their questions, and hence it is possible that given our current state of knowledge about treatment, genetic science is being overused.

Hence, what I propose is that in instances where family considerations make it such that engaging in testing or in some treatment alternative is not the best course of action for the patient because of her other goals and priorities, the clinician should respect this decision and the reasons behind it. Some information may be lost, but something else important may be gained: trust in the provider-patient relationship.

The conflicts, then, that may have arisen because of the different values and priorities of the groups in question do not seem to be insurmountable after all. In fact, some amount of conflict is useful, as can be evidenced in this case: conflicts give the parties an opportunity to reach a greater understanding of each other such that a resolution can be found that will meet everyone's needs.

Conclusion

Thus, it is the case that these two groups, the clinicians/researchers and observant Jewish patients, can turn an instance of conflict into one of mutual understanding. More can be gained from such a productive encounter than is likely to be lost. Yet it is only through an understanding of the various goals and priorities of each group by the other that middle ground can be reached.

Understanding the values and priorities of the observant Jewish community is not just useful for those who are treating them, however. Such an understanding helps all of us to appreciate the role that medicine and healing have within the tradition. This is at least partly because other religious groups have weighed in on issues in medicine, and understanding how one group has approached these issues may prove illuminating for other groups. It is also generally useful to understand how a person's religious beliefs can impact all areas of her life, including medical decision-making. In this case, insofar as medicine restores an individual to her capacity to fulfill God's commandments, to care for others and be cared for by them, and in general to live a life of holiness, medicine is an important part of her life. Yet its value must be understood in terms of the larger goal, that of being the kind of person that she and God want her to be.

Part of being the right kind of person, I have argued, is being one who does not simply follow the principles and rules as they have been interpreted for her, but also one who cares for others and is cared for by them. This is important because not only is the family the center of the community in Judaism, but it also has practical value: it speaks to the actual experience of individuals. Medical decisions, especially life-changing decisions, impact more than just the patient, but also her family, friends, coworkers, etc. An approach that serves as a guide to ethical action must take this into account.

An ethic of care is particularly useful for this group because of the focus on family. In fact, when authority figures interpreted past decisions to apply to present cases, often the application of the appropriate rule was done in order to include considerations of the individual's loved ones. The problem, of course, was that the very determination of the relevant principles and rules was difficult to understand in its abstraction from the particular case, and in the way in which it often failed to offer specific direction for the agents. The rules and principles, I argued, served as side constraints on action, or were general guidelines within which a course of action could be chosen. For greater assistance in determining a course of action, an ethic of care is necessary to augment traditional Jewish bioethics.

This is not to say, however, that the traditional schema is unimportant, or is even second in importance to care ethics. Instead, I have argued that they are in fact used together, first to narrow the range of acceptable action and then to specify the right action from the choices that remain. The difference between the negative and positive action guides I have specified may be the difference between principles of obligation and principles of responsibility. The precedents that have been set by previous rabbinical decisions are illustrative and demonstrative, but perhaps not prescriptive for the reasons previously mentioned. Yet ascertaining how authorities in the past have interpreted the ancient laws and scripture and applied it to problems like the current problem is an important step for those who are concerned with aligning their actions with the demands of their religious tradition.

The three cases in genetic medicine that I discussed presented certain challenges for the observant Jewish community, but offered new opportunities as well. As we increase our understanding of the human genome and the ways in which it is responsible for the development of who we are, investigating the relationship between that genetic identity and the other ways in which we identify ourselves – woman, Jew, American, etc. – will become increasingly important. I focused on these specific genetic disorders because they are particularly prevalent in the Ashkenazi Jewish community, but I think that the analysis provided here could easily be exported to other issues in genetics, and, indeed, other issues in bioethics – and perhaps moral choices in other areas of life as well. Discovering my predisposition for developing heart disease will, of course, still tell me information about the same risk in my children, and hence many of the issues discussed here will apply.

Because of the wide-ranging implications of this, it is unclear where this discussion should stop. Another line of investigation would be to demonstrate how other genetic issues are related to the kinds of differences in values and understandings that I mentioned here. It also would be interesting to investigate the juxtaposition of genetics and other religious traditions to see if a similar approach would hold. I suspect that a focus on caring for individuals will be evident across religious and cultural barriers, but this is a claim that must be defended in a larger work. One thing is clear, however, and that is that as religion is an important part of people's lives, and as the science of genetics has made us confront important issues about ourselves and

our relationships to others, understanding the relationships between these foci for individuals will be integral to any complete understanding of medical decision-making in the future.

BIBLIOGRAPHY

Abeliovich, Dvorah, Luna Kaduri, Israela Lerer, Naomi Weinberg, Gail Amir, Michal Sagi, Joel Zlotogora, Normal Heching and Tamar Peretz. "The Founder Mutations 185delAG and 5382insC in BRCA1 and 6174delT in BRCA2 Appear in 60% of Ovarian Cancer and 30% of Early-Onset Breast Cancer Patients Among Ashkenazi Women." *American Journal of Human Genetics* 60 (1997): 505-514.

Abraham, Abraham S. "Euthanasia." In *Medicine and Jewish Law*, Vol. 1, edited by Fred Rosner. Northvale: Jason Aronson Inc., 1990.

_____. *The Comprehensive Guide to Medical Halacha*. New York: Feldheim, 1990.

Abrahamson, John, Roxana Moslehi, Danny Vesprini, Beth Karlan, David Fishman, David Smotkin, Yehuda Ben David, Haim Biran, Abbie Fields, Jean-Sebastien Brunet and Steven A. Narod. "No Association of the *I1307K APC* Allele with Ovarian Cancer Risk in Ashkenazi Jews." *Cancer Research* 58 (July 15, 1998): 2919-2922.

Abuelo, Dianne N., Judith Rosenstein, and Michael Sheff. "Tay-Sachs Disease: Knowledge and Attitudes of the Rabbinical Community." *Rhode Island Medical Journal* 68 (May 1985): 225-226.

Berman, David B., Josephine Wagner-Costalas, David C. Schultz, Henry T. Lynch, Mary Daly, and Andrew K. Godwin. "Two Distinct Origins of a Common BRCA1 Mutation in Breast-Ovarian Cancer Families: A Genetic Study of 15 185delAG-Mutation Kindreds." *American Journal of Human Genetics* 58 (1996): 1166-1176.

Bishop, Jerry E. and Michael Waldholz. *Genome*. New York: Simon and Schuster, 1990.

Bishop, Laura Jane and Mary Carrington Coutts. "Religious Perspectives on Bioethics, Part I." *Kennedy Institute of Ethics Journal* 4, no. 2 (1994): 155-183.

Blum, Lawrence A. "Gilligan and Kohlberg: Implications for Moral Theory." In *An Ethic of Care*, edited by Mary Jeanne Larrabee. New York: Routledge, 1993.

Breitowitz, Yitzchok. "The Preembryo in Halacha." *Jewish Law – Articles*. September 26, 1998. <http://www.Jlaw.com/Articles/preemb.html>.

Brennan, Samantha. "Recent Work in Feminist Ethics." *Ethics* 109 (July 1999): 858-893.

Brody, Baruch A. "The Use of Halakhic Material in Discussions of Medical Ethics." *The Journal of Medicine and Philosophy* 8, no. 3 (August 1983): 317-328.

"Cancer Facts." *National Cancer Institute.* Fact Sheet 3.62. June 30, 1999. <http://198.77.70.12/3_62.htm>.

Chase, Gary A. "The TSD Gene Among Ashkenazic Jews: Founder Effect and Genetic Drift." In *Progress in Clinical and Biological Research*. Edited by George J. Brewer, Vincent P. Eijsvoogel, Robert Grover, Kurt Hirschhorn, Seymour S. Kety, Sidney Udenfriend, and Jonathan W. Uhr. Vol. 1. *Tay-Sachs Disease: Screening and Prevention*, edited by Michael M. Kaback. New York: Alan R. Liss, 1977: 107-110.

Chase, Gary A. and V.A .McKusick, "Founder Effect in Tay-Sachs Disease." *American Journal of Human Genetics* 24 (1972): 339-347.

Cohen, Debra Nussbaum. "Jewish Ethicists Voice Concerns Over Gender-Selection Technology." *JTA Daily News Bulletin* 30 October 1998.

"Colon and Rectum Cancer." *American Cancer Society.* Cancer Resource Center. April 22, 2001. <http://www3.cancer.org/cancerinfo/load_cont.asp?st=ds&ct=10&language=english>.

Copel, Joshua A., and Ray O. Bahado-Singh. "Prenatal Screening for Down's Syndrome – A Search for the Family's Values." *The New England Journal of Medicine* 341, no. 7 (August 12, 1999): 521-2.

Crittenden, Chris. "The Principles of Care." *Women and Politics* 22, no. 2 (2001): 81-105.

Devilee, P. "*BRCA1* and *BRCA2* Testing: Weighing the Demand against the Benefits." *American Journal of Human Genetics* 64 (April 1999): 943 – 948.

Dorff, Elliot N. "Jewish Theological and Moral Reflections on Genetic Screening: The Case of BRCA1." *Health Matrix* 7, no. 65 (1997): 65-96.

_____. *Matters of Life and Death: A Jewish Approach to Modern Medical Ethics*. Philadelphia: Jewish Publication Society, 1998.

Durfy, Sharon J., Deborah J. Bowen, Anne McTiernan, Jen Sporleder, and Wylie Burke. "Attitudes and Interest in Genetic Testing for Breast and Ovarian Cancer Susceptibility in Diverse Groups of Women in Western Washington." *Cancer Epidemiology, Biomarkers and Prevention* 8, no. 4, part 2 (April 1999): 369-375.

Edelson, Paul J. "The Tay-Sachs Disease Screening Program in the U.S. as a Model for the Control of Genetic Disease: An Historical Overview." *Health Matrix* 7, no. 125 (1997): 125-133.

Eisenberg, Vered H., and Joseph G. Schenker. "The ethical, legal and religious aspects of preembryo research." *European Journal of Obstetrics & Gynecology and Reproductive Biology* 75 (1997): 11-24.

Emanuel, Ezekiel J. and Linda L. Emanuel. "Four Models of the Physician-Patient Relationship." *Journal of the American Medical Association* 267, no. 16 (April 22/29, 1992): 2221-2226.

"Employment Discrimination." *National Human Genome Research Institute.* March 2000. Issue Update. September 26, 2000. <http://www.nhgri.nih.gov/Policy_and_public_affairs/Legislation/99upemp.htm>.

"Facts About Lung Cancer." *American Lung Association*. May 16, 2000. <http://www.lungusa.org/diseases/lungcanc.html>.

Fadiman, Anne. *The Spirit Catches You and You Fall Down.* New York: The Noonday Press, 1997.

Feldman, David M. *Birth Control in Jewish Law*. New York: New York University Press, 1968.

_____. *Health and Medicine in the Jewish Tradition*. New York: Crossroad, 1986.

Fodor, Flora, Ainsley Weston, Ira J. Bleiweiss, Leslie D. McCurdy, Mary M. Walsh, Paul I. Tartter, Steven T. Brower and Christine M. Eng. "Frequency and Carrier Risk Associated with Common BRCA1 and BRCA2 Mutations in Ashkenazi Jewish Breast Cancer Patients." *American Journal of Human Genetics* 63 (1998): 45-51.

Ford, D., D. F. Easton, and J. Peto. "Estimates of the Gene Frequency of BRCA1 and its Contribution to Breast and Ovarian Cancer Incidence." *American Journal of Human Genetics* 57 (1995): 1457-1462.

Frank, Isaac. "Understanding Jewish Biomedical Ethics: Reflections on the Papers." *The Journal of Medicine and Philosophy* 8, no. 3 (August 1983): 207-216.

Freedman, Benjamin. *Duty and Healing: Foundations of a Jewish Bioethic*. New York: Routledge, 1999.

Friedman, Lois C., John A. Webb, C. Sue Richards, and Sharon E. Plon. "Psychological and Behavioral Factors Associated with Colorectal Cancer Screening Among Ashkenazim." *Preventive Medicine* 29, no. 2 (1999): 119-125.

Friedman, Marilyn. "Care and Context in Moral Reasoning." In *Women and Moral Theory*, edited by Eva Feder Kittay and Diana T. Meyers. Savage, MD: Rowman and Littlefield, Inc.: 1987

Froberg, Debra J. and Robert L. Kane. "Methodology for Measuring Health-State Preferences – I: Measurement Strategies." *Journal of Clinical Epidemiology* 42, no. 4 (1989): 345-354.

Ganzfried, Solomon. *Kitzur Shulhan Arukh* (Code of Jewish Law). Ann. rev. ed. Translated by Hyman E. Goldin. New York: Hebrew Publishing Company, 1996.

Gelehrter, Thomas D., Francis M. Collins, and David Ginsburg. *Principles of Medical Genetics*. 2d ed. Baltimore: Williams and Wilkins, 1998.

Gilligan, Carol. *In A Different Voice*. Cambridge: Harvard University Press, 1982.

_____. "Moral Orientation and Moral Development." In *Women and Moral Theory*, edited by Eva Feder Kittay and Diana T. Meyers. Savage, MD: Rowman and Littlefield Publishers, 1987: 19-36.

Goldberg, David J. and John D. Rayner. *The Jewish People*. New York: Penguin Books, 1989.

Goldgar, David E. and Philip R. Reilly. "A Common BRCA1 Mutation in the Ashkenazim." *Nature Genetics* 11 (October 1995): 113-114.

Goodman, Madeline J. and Lenn E. Goodman. "The Overselling of Genetic Anxiety." *The Hastings Center Report* (October 1992): 20-27.

Gravel, Roy A., Barbara L. Triggs-Raine and Don J. Mahuran. "Biochemistry and Genetics of Tay-Sachs Disease." *The Canadian Journal of Neurological Sciences* 18 (1991): 419 - 423.

Grazi, Richard V, ed. *Be Fruitful and Multiply*. Jerusalem: Genesis Jerusalem Press, 1994.

Grazi, Richard V. and Joel B. Wolowelsky. "Preimplantation Sex Selection and Genetic Screening in Contemporary Jewish Law and Ethics." *Journal of Assisted Reproduction and Genetics* 9, no. 4 (1992): 318-322.

Greene, Velvl. "Ethical Issues in Community Health." In *Science in the Light of Torah*, edited by Herman Branover and Ilana Coven Attia. Northvale: Jason Aronson Inc., 1994.

Grimshaw, Jean. *Philosophy and Feminist Thinking*. Minneapolis: University of Minnesota Press, 1986.

Hamilton, Diane. "A Nursing Challenge: Adult-Onset Tay-Sachs Disease." *Archives of Psychiatric Nursing* 5, no. 6 (December 1991): 382-385.

Hanen, Marsha and Kai Nielsen, eds. *Science, Morality and Feminist Theory*. Calgary: The University of Calgary Press, 1987.

Hartage, Patricia, Jeffrey P. Struewing, Sholom Wacholder, Lawrence C. Brody, and Margaret A. Tucker. "The Prevalence of Common *BRCA1* and *BRCA2* Mutations among Ashkenazi Jews." *American Journal of Human Genetics* 64 (April 1999): 963 – 970.

Hartmann, L. C., D. J. Schaid, J. E. Woods, T. P. Crotty, J. L. Myers, P. G. Arnold, P. M. Petty, T. A. Sellers, J. L. Johnson, S. K. McDonnell, M. H. Frost, and R. B. Jenkins. "Efficacy of Bilateral Prophylactic Mastectomy in Women with a Family History of Breast Cancer" *New England Journal of Medicine* 340, no. 2 (January 14, 1999): 77-84.

"Health Insurance Discrimination." National Human Genome Research Institute. August 2000. Issue Update. September 26, 2000. <http://nhgri.nih.gov/Policy_and_public_affairs/Legislation/00upins1.htm>.

Hechtman, Peter and Feige Kaplan. "Tay-Sachs Disease Screening and Diagnosis: Evolving Technologies." *DNA and Cell Biology* 12, no. 8 (1993): 651-665.

Held, Virginia. *Feminist Morality: Transforming Culture, Society, and Politics*. Chicago: The University of Chicago Press, 1993.

Hill, Thomas E. Jr., "The Importance of Autonomy," in *Women and Moral Theory*, edited by Eva Feder Kittay and Diana T. Meyers. Savage, MD: Rowman and Littlefield Publishers, Inc., 1987: 129-138.

Hoagland, Sarah Lucia. *Lesbian Ethics*. Palo Alto: Institute of Lesbian Studies, 1988.

Holtzman, Samuel, Elissa Ozanne, Bill Carone, Mary Kane Goldstein, Gary Steinke, and John Timbs. "Decision Analysis and Alzheimer's Disease: Three Case Studies." *Genetic Testing* 3, no. 1 (1999): 71-83.

Jaggar, Allison M. "Caring as a Feminist Practice of Moral Reason." In *Justice and Care: Essential Readings in Feminist Ethics*. Edited by Virginia Held. Boulder: Westview Press, Inc., 1995: 179-202.

Jakobovits, Immanuel. *Jewish Medical Ethics*. New York: Bloch Publishing Company, 1959.

_____. *Jewish Medical Ethics*, enl. ed. New York: Bloch Publishing Company, 1975.

_____. "Judaism." *Encyclopedia of Bioethics*. Vol. 2. Edited by Warren T. Reich. New York: Macmillan and Free Press, 1978, pp. 791-802.

_____. "Jewish Medical Ethics--A Brief Overview." Journal of Medical Ethics 9, no. 2 (June 1983): 109-12.

_____. "Some Letters on Jewish Medical Ethics." *The Journal of Medicine and Philosophy* 8, no. 3 (August 1983): 217-224.

Jakobovits, Yoel. "Lord Immanuel Jakobovits." *Pioneers in Jewish Medical Ethics*, edited by Fred Rosner. Northvale: Jason Aronson Inc., 1997.

Jonsen, Albert R. and Stephen Toulmin. *The Abuse of Casuistry*. Berkeley: University of California Press, 1988.

Kaback, Michael M., Ted J. Nathan, and Susan Greenwald. "Tay-Sachs Disease: Prenatal Diagnosis – U.S. Experience and World Perspective." In *Progress in Clinical and Biological Research*. Edited by George J. Brewer, Vincent P. Eijsvoogel, Robert Grover, Kurt Hirschhorn, Seymour S. Kety, Sidney Udenfriend, and Jonathan W. Uhr. Vol. 18. *Tay-Sachs Disease: Screening and Prevention*, edited by Michael M. Kaback. New York: Alan R. Liss, 1977: 13-36.

Kaback, Michael, Joyce Lim-Steele, Deepti Dabholkar, David Brown, Nancy Levy, and Karen Zeiger. "Tay-Sachs Disease – Carrier Screening, Prenatal Diagnosis, and the Molecular Era." *Journal of the American Medical Association* 270, no. 19 (November 17, 1993): 2307-2315.

Kahneman, Daniel, Paul Slovic and Amos Tversky. *Judgment Under Uncertainty: Heuristics and Biases*. New York: Cambridge University Press, 1982.

Karfeld, Marilyn H. "Selecting a Baby's Gender Raises Ethical Questions: Scientists Develop Method So Parents Can Pick Their Child's Sex. Is It the Right Thing To Do?" *Cleveland Jewish News*. 25 September 1998.

Kellenberger, James. *Relationship Morality*. University Park, PA: The Pennsylvania State University Press, 1995.

Kellner, Menachem Marc, ed. *Contemporary Jewish Ethics*. New York: Sanhedrin Press, 1978.

Kerr, W. G. and J.J. Mule. "Gene Therapy: Current Status and Future Prospects." *Journal of Leukocyte Biology* 56, no. 2 (August 1994): 210-4.

Kevles, Daniel J. *In the Name of Eugenics* New York: Knopf, 1985.

_____. "Out of Eugenics: The Historical Politics of the Human Genome." In *The Code of Codes*, edited by Daniel J. Kevles and LeRoy Hood. Cambridge: Harvard University Press, 1992: 3-36.

Laken, Steven J., Gloria M. Petersen, Stephen B. Gruber, Carole Oddoux, Harry Ostrer, Francis M. Giardiello, Stanley R. Hamilton, Heather Hampel, Arnold Markowitz, David Klimstra, Suresh Jhanwar, Sidney Winawer, Kenneth Offit, Michael C. Luce, Kenneth W. Kinzler and Bert Vogelstein. "Familial Colorectal Cancer in Ashkenazim Due to a Hypermutable Tract in *APC*." *Nature Genetics* 17 (September 1997): 78-83.

Levy-Lahad, Ephrat, Raphael Catane, Shlomit Eisenberg, Bella Kaufman, Gila Hornreich, Ella Lishinsky, Mordechai Shohat, Barbara L. Weber, Uziel Beller, Amnon Lahad and David Halle. "Founder BRCA1 and BRCA2 Mutations in Ashkenazi Jews in Israel: Frequency and Differential Penetrance in Ovarian Cancer and in Breast-Ovarian Cancer Families." *American Journal of Human Genetics* 60 (1997): 1059-1067.

Lipschutz, Joshua H. "To clone or not to clone – a Jewish perspective." *Journal of Medical Ethics* 25, no. 2 (April 1999): 105 – 107.

Lowden, J. Alexander and John Davidson. "Tay-Sachs Screening and Prevention: The Canadian Experience." *Progress in Clinical and Biological Research*, eds. George J. Brewer, Vincent P. Eijsvoogel, Robert Grover, Kurt Hirschhorn, Seymour S. Kety, Sidney Udenfriend, and Jonathan W. Uhr. Vol. 18. *Tay-Sachs Disease: Screening and Prevention*. Ed. Michael M. Kaback (New York: Alan R. Liss, 1977): 37-46.

Mackler, Aaron L. "An expanded partnership with God? In Vitro Fertilization in Jewish Ethics." *Journal of Religious Ethics* 25 (1997): 277-304.

Mahowald, Mary Briody. *Genes, Women, Equality*. New York: Oxford University Press, 2000.

Manning, Rita. "Just Caring." In *Explorations in Feminist Ethics: Theory and Practice*, edited by Eve Browning Cole and Susan Coultrap-McQuinn. Bloomington: Indiana University Press, 1992: 45-54.

Maresco, Diane L., Patricia A. Arnold, Yukio Sonoda, Mark G. Federici, Faina Bogomolniy, Esther Rhei, and Jeff Boyd. "The *APC* I1307K Allele and *BRCA*-Associated Ovarian Cancer Risk." *American Journal of Human Genetics* 64 (April 1999): 1228 – 1230.

Marteau, Theresa M., Monica van Duijn, and Ian Ellis. "Effects of genetic screening on perceptions of health: a pilot study." *Journal of Medical Genetics* 29 (1992): 24-26.

McGowan, Ruth. "Beyond the disorder: one parent's reflection on genetic counselling [sic]." *Journal of Medical Ethics* 25, no. 2 (April 1999): 195-199.

Meirow, D. and J. G. Schenker. "Reproductive Health Care Policies Around the World: The Current Status of Sperm Donation in Assisted Reproduction Technology: Ethical and Legal Considerations." *Journal of Assisted Reproduction and Genetics* 14, no. 3 (1997): 133-138.

Merz, Beverly. "Matchmaking Scheme Solves Tay-Sachs Problem." *Journal of the American Medical Association* 258, no. 19 (November 20, 1987): 2636, 2639.

Munson, Ronald. *Intervention and Reflection: Basic Issues in Medical Ethics.* 6th ed. Belmont: Wadsworth, 2000.

Myrianthopoulous, Ntinos C. and Michael Melnick. "Tay-Sachs Disease: A Genetic-Historical View of Selective Advantage." In *Progress in Clinical and Biological Research*. Edited by George J. Brewer, Vincent P. Eijsvoogel, Robert Grover, Kurt Hirschhorn, Seymour S. Kety, Sidney Udenfriend, and Jonathan W. Uhr. Vol. 18, *Tay-Sachs Disease: Screening and Prevention*, edited by Michael M. Kaback. New York: Alan R. Liss, 1977: 95-106.

Navon, Ruth, Edwin H. Kolodny, Hiroshi Mitsumoto, George H. Thomas and Richard L. Proia. "Ashkenazi-Jewish and Non-Jewish Adult G_{M2} Gangliosidosis Patients Share a Common Genetic Defect," *American Journal of Human Genetics* 46 (1990): 817-821.

Navon, Ruth and Richard L. Proia. "The Mutations in Ashkenazi Jews with Adult G_{M2} Gangliosidosis, the Adult Form of Tay-Sachs Disease." *Science* 243 (March 17, 1989): 1471-1474.

Neuhausen, Susan, Teresa Gilewski, Larry Norton, Thao Tran, Peter McGuire, Jeff Swensen, Heather Hampel, Patrick Borgen, Karen Brown, Mark Skolnick, Donna Shattuck-Eidens, Suresh Jhanwar, David Goldgar and Kenneth Offit. "Recurrent BRCA2 617delT Mutations in Ashkenazi Jewish Women Affected by Breast Cancer." *Nature Genetics* 13 (May 1996): 126 – 128.

Noddings, Nel. *Caring: A Feminine Approach to Ethics and Moral Education*. Berkeley: University of California Press, 1984.

_____. "In Defense of Caring." *Journal of Clinical Ethics* 3, no. 1 (Spring 1992): 15-18.

Nozick, Robert. *Anarchy, State, and Utopia*. New York: Basic Books Inc., 1974.

Pence, Gregory E. *Who's Afraid of Human Cloning?* New York: Rowman and Littlefield Publishers, Inc., 1998.

Perlin, Elliott. "Jewish Bioethics and Medical Genetics." *Journal of Religion and Health* 33, no. 4 (Winter 1994): 333-340.

Peterson, Gloria M., Jerome I. Rotter, Rita M. Cantor, L. Leigh Field, Susan Greenwald, Joyce S. T. Lim, Chitra Roy, Victor Schoenfeld, J. Alexander Lowden, Michael M. Kaback. "The Tay-Sachs Disease Gene in North American Jewish Populations: Geographic Variations and Origin." *American Journal of Human Genetics* 35 (1983): 1258-1269.

Peto, Julian, Nadine Collins, Rita Barfoot, Sheila Seal, William Warren, Nazneen Rahman, Doublas F. Easton, Christopher Evans, Judith Deacon, and Michael R. Stratton. "Prevalence of BRCA1 and BRCA2 Gene Mutations in Patients with Early-Onset Breast Cancer." *Journal of the National Cancer Institute* 91, no. 11 (June 2, 1999): 943-949.

Petrukhin, Luba, JoEllen Dangel, Lisa Vanderveer, Josephine Costalas, Alfonso Bellacosa, Generosa Grana, Mary Daly and Andrew K. Godwin. "The I1307K APC Mutation Does Not Predispose to Colorectal Cancer in Jewish Ashkenazi Breast and Breast-Ovarian Cancer Kindreds." *Cancer Research* 57 (December 15, 1997): 5480-5484.

Plato. *Euthyphro*. Translated by Lane Cooper. In *Plato: The Complete Dialogues*, edited by Edith Hamilton and Huntington Cairns. Princeton: Princeton University Press, 1989.

Pollack, Robert. *Signs of Life.* New York: Houghton Mifflin Company, 1994.

Reilly, Philip. *Genetics, Law and Social Policy*. Cambridge: Harvard University Press, 1977.

Richards, C. Sue, Patricia A. Ward, Benjamin B. Roa, Lois C. Friedman, Alfred A. Boyd, Gretchen Kuenzli, J. Kay Dunn and Sharon E. Plon. "Screening for 185delAG in the Ashkenazim." *American Journal of Human Genetics* 60 (1997): 1085-1098.

Roa, Benjamin B., Alfred A. Boyd, Kelly Volcik and C. Sue Richards. "Ashkenazi Jewish Population Frequencies for Common Mutations in BRCA1 and BRCA2." *Nature Genetics* 14 (October 1996): 185-187.

Rosenfeld, Azriel. "Judaism and Gene Design." *Tradition* 13, no. 2 (Fall 1972): 71-80.

Rosner, Fred M. "Tay-Sachs Disease: To Screen or Not to Screen?" *Journal of Religion and Health* 15, no. 4 (1976): 271-281.

_____. "Recombinant DNA, Cloning, Genetic Engineering, and Judaism." *The New York State Journal of Medicine* (August 1979): 1439-1444.

_____. "The Biblical and Talmudic Secret of Choosing One's Baby's Sex." *Israel Journal of Medical Science* 15, no. 9 (September 1979): 784-787.

_____. "Test Tube Babies, Host Mothers and Genetic Engineering in Judaism." *Tradition* 19, no. 2 (Summer 1981): 141-148.

_____. "Medical Genetics: The Jewish View." *The New York State Journal of Medicine* (August 1982): 1367-1375.

_____, ed. *Medicine and Jewish Law*. Vol. 2. Northvale: Jason Aronson Inc., 1990.

_____. *Modern Medicine and Jewish Ethics*, 2d rev and aug. ed. New York: Yeshiva University Press, 1991.

_____. "Human experimentation and Clinical Trials." *Israel Journal of Medical Science* 31, no. 9 (September 1995): 580-2.

_____. *Pioneers in Jewish Medical Ethics*. Northvale: Jason Aronson, Inc., 1997.

Rosner, Fred and J. David Bleich. *Jewish Bioethics*. New York: Hebrew Publishing Company, 1979.

Rothman, Barbara Katz. *Genetic Maps and Human Imaginations*. New York: W.W. Norton and Company, 1998.

Rubin, Susan B. *When Doctors Say No: The Battleground of Medical Futility.* Bloomington: Indiana University Press, 1998.

Ruse, Michael. "Genetics and the Quality of Life." *Social Indicators Research* 7 (1980): 419-441.

Sagi, Michal. "Ethical Aspects of Genetic Screening in Israel." *Science in Context* 11, nos. 3-4: 419-429.

Saperstein, Judith."The National Tay-Sachs and Allied Diseases Association, Inc.," *Progress in Clinical and Biological Research*. Eds. George J. Brewer, Vincent P. Eijsvoogel, Robert Grover, Kurt Hirschhorn, Seymour S. Kety, Sidney Udenfriend, and Jonathan W. Uhr. Vol. 18. *Tay-Sachs Disease: Screening and Prevention*, edited by Michael M. Kaback (New York: Alan R. Liss, 1977): 9-10.

Scaltsas, Patricia Ward. "Do Feminist Ethics Counter Feminist Aims?" In *Explorations in Feminist Ethics: Theory and Practice*, edited by Eve Browning Cole and Susan Coultrap-McQuinn. Bloomington: Indiana University Press, 1992: 15-26.

Schenker, Joseph G. "Infertility evaluation and treatment according to Jewish law." *European Journal of Obstetrics & Gynecology and Reproductive Biology*. 71 (1997): 113-121.

Schonfeld, Toby. "The Afterlife in Judaism, Including Christian Influences." Working Paper, University of North Carolina at Chapel Hill, Chapel Hill, NC, May 1994.

Schorr, Melissa. "Scopes Trial." *abcnews.com*. July 19, 2000. April 22, 2001. <http://abcnews.go.com/sections/living/DailyNews/coloncancer000719.htm>.

"Selected Cancers." *American Cancer Society.* 2000 Facts and Figures. April 22, 2001. <http://www.cancer.org/statistics/cff2000/selectedcancers.html#colon>.

Shickle, Darren and Ian Harvey. "'Inside-Out,' Back-To-Front: A Model for Clinical Population Genetic Screening." *Journal of Medical Genetics* 30 (1993): 580-582.

Shulman, Nisson E. *Jewish Answers to Medical Ethics Questions*. Northvale: Jason Aronson Inc., 1998.

Siegel, Seymour. "Genetic Engineering." *Linacre Quarterly* (February 1983): 45-55.

Silver, Lee M. *Remaking Eden*. New York: Avon Books Inc., 1998.

Smith, Bradford R. 1998. Reestablishing Connections Between Bioethics and Christianity: Narratives and Virtues in Caring for a Christian Patient. PhD diss, University of Tennessee, Knoxville.

Sommerville, Ann and Veronica English. "Genetic Privacy: Orthodoxy or Oxymoron?" *Journal of Medical Ethics* 25, no. 2 (April 1999): 144-150.

Steiner-Grossman, Penny and Karen L. David. "Involvement of Rabbis in Counseling and Referral for Genetic Conditions: Results of a Survey." *The American Journal of Human Genetics* 53 (1993): 1359-1365.

Stoate, Howard G. "Can Health Screening Damage Your Health?" *Journal of the Royal College of General Practitioners* 39 (1989): 193-195.

Struewing, Jeffery P., Patricia Hartage, Sholom Wacholder, Sonya M. Baker, Martha Berlin, Mary McAdams, Michelle M. Timmerman, Lawrence C. Brody and Margaret A. Tucker. "The Risk of Cancer Associated with Specific Mutations of BRCA1 and BRCA2 among Ashkenazi Jews." *New England Journal of Medicine* 336 (May 15, 1997): 1401-1408.

Tendler, Moshe D. "Rabbinic Comment: In Vitro Fertiliation and Extrauterine Pregnancy ('Test-Tube' Baby)." *The Mount Sinai Journal of Medicine* 51, no.1 (January-February 1984): 7-11.

Terdiman, Jonathan P., Peggy G. Conrad, Marvin H. Sleisenger. "Genetic Testing in Hereditary Colorectal Cancer: Indications and Procedures." *The American Journal of Gastroenterology* 94, no. 9 (1999): 2344-2356.

Tong, Rosmarie. *Feminine and Feminist Ethics*. Belmont: Wadsworth Publishing Company, 1993.

_____. *Feminist Approaches to Bioethics*. Boulder, CO: Westview Press, 1997.

Toronto Sun, 23 July – 24 July 1996.

Triggs-Raine, Barbara L., Annette S. J. Feigenbaum, Marvin Natowicz, Marie-Anne Skomorowski, Sheldon M. Schuster, Joe T. R. Clarke, Don J. Mahuran, Edwin H. Kolodny, and Roy A. Gravel. "Screening for Carriers of Tay-Sachs Disease Among Ashkenazi Jews." *New England Journal of Medicine* 323, no. 1 (July 5, 1990): 6-12.

Tronto, Joan C. *Moral Boundaries: A Political Argument for an Ethic of Care.* New York: Routledge, 1993.

Troster, Lawrence. "Therapy or Engineering: Jewish Responses to Genetic Research." *Voice of Tradition* (April-May 1984): 21-25.

Tymstra, T. and B. Bielman. "The psychosocial impact of mass screening for cardiovascular risk factors." *Family Practice* 4 (1987): 287-90.

Veatch, Robert M. and Harley E. Flack. *Case Studies in Allied Health Ethics*. Upper Saddle River: Prentice Hall, 1997.

Verma, I. M. and R.K. Naviaux. "Human Gene Therapy." *Current Opinions in Genetic Development* 1, no. 1 (June 1991): 54-9.

Weinstein, Neil D. "Why It Won't Happen to Me: Perceptions of Risk Factors and Susceptibility." *Health Psychology* 3, no. 5 (1984): 430-457.

Weiss, Faedra Lazar. "Genetic Counseling in a Liberal Jewish Context." *Voice of Tradition* (April-May 1984): 26-32.

Wertheimer, Jack. *A People Divided*. New York: Basic Books, 1993.

Wilcox, Allen J., Jack A. Taylor, Richard R. Sharp, and Stephanie J. London. "Genetic Determinism and the Overprotection of Human Subjects." *Nature Genetics* 21 (April 1999): 362.

Wingerson, Lois. *Unnatural Selection: The Promise and the Power of Human Gene Research*. New York: Bantam Books, 1998.

Wolfe, J. H. "Recent Progress in Gene Therapy for Inherited Diseases." *Current Opinions in Pediatrics* 6, no. 2 (April 1994): 213-8.

Wolpe, Paul Root. "If I Am Only My Genes, What Am I? Genetic Essentialism and a Jewish Response." *Kennedy Institute of Ethics Journal* 7, no.3 (September 1997) 213-230.

"Women and Cardiovascular Disease." *American Heart Association*. Biostatistical Fact Sheet – Populations. May 16, 2000. <http://americanheart.org/statistics/biostats/biowo.htm>.

Woodage, Trevor, Sonya M. King, Sholom Wacholder, Patricia Hartage, Jeffery P. Struewing, Mary McAdams, Steven J. Laken, Margaret A. Tucker and Lawrence C. Brody. "The APC I1307K Allele and Cancer Risk in a Community-Based Study of Ashkenazi Jews." *Nature Genetics* 20 (September 1998): 62-65.

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