

Jewish Medical Culture:
Case Studies in End-of-Life Decision Making

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Every researcher comes to his or her work with a set of preconceptions and experiences that guide his or her thinking. These experiences are especially potent when the topic is as highly

charged as this one, dealing literally with matters of life and death. Given these circumstances, I consider my nine years as a pulpit rabbi to have been formative in my thinking about these topics. I was inspired to undertake this study by my pastoral role and responsibilities. Rabbi Haskel Lookstein, my mentor at Congregation Kehilath Jeshurun in New York, modeled the art of the rabbinate for me through his compassion and diligence. As I aided life-cycle events, including a number of wrenching end-of-life cases, with my congregants, I internalized the lifeworld as revealed through their *simchas* and struggles. I thank these congregants for allowing me to be a part of their lives, as a teacher and as someone they could trust.

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ABSTRACT

Jewish Medical Culture: Case Studies in End-of-Life Decision Making

A dissertation presented to the Faculty of the
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By Joshua N. Cypess

As the technology of medical care has advanced in recent years, the ethical, religious, and legal problems and questions surrounding it have multiplied. This principle is nowhere more true than in decision making in the care of patients at the end of life. Increasingly, scholars in the fields of ethics, sociology, and the sciences are beginning to recognize that the definitions of life and death and the necessary responses to various medical conditions at the end of life are often culturally contingent rather than strictly objective and verifiable. Within Jewish practice, end-of-life decision making takes on a singular character. Responses by Jewish patients, rabbinic authorities, and caregivers to issues as fundamental as the definition of death are inflected by the particular history of Judaism in the modern age. Taken together, those responses constitute what I call “Jewish Medical Culture,” the concept that lies at the heart of this work.

What is Jewish Medical Culture? It is a subset of Jewish culture that deals with health, the body, and issues of life and death. For Americans who associate with the constellation of symbols and definitions that come from a lived experience of the ethno-religious community of Judaism, behavior is often guided by principles that may be traced to that community. This is especially true in cases at the end of life, when the turn to religious principles may become most

pronounced. Thus analysis of particular cases in end-of-life decision making represents a means for elucidating this highly charged manifestation of Jewish Medical Culture. My aim is not to prescribe a Jewish bioethics or to determine the *halakhic* (Jewish legal) response to end-of-life cases. Instead, I study Jewish Medical Culture from a sociological perspective—how it manifests itself in actual practice.

Drawing on literature dealing with cultural differences toward American medical care, as well as the history and ethics of Jews and medicine, this study considers three significant cases related to end-of-life medical issues—two within Orthodox Judaism and one outside of it: the cases are those of Mordechai Dov Brody, the conjoined twins of 1977, and Terri Schiavo. These three cases in succession highlight complex medical issues around the end of life. Using a variety of source bases—including academic case reports, newspaper articles, websites, and *halakhic* writings—I propose to explicate the Jewish themes that are implicit in the American Jewish community's responses to major issues in medical decision-making. Although there is no single, unified Jewish American voice on medical care or ethics, I will argue that many of the responses to these cases from within the Jewish community—from patients, doctors, rabbinic leaders, and lay observers—had their underpinnings in Jewish tradition and Jewish concepts—that is, in Jewish Medical Culture. These manifestations of Jewish Medical Culture, I argue, reveal a great deal about contemporary Jewish ideas and practices, the extent to which Jewish identity is rooted in or distinct from the surrounding contemporary society, and the thumbprint of Jewish history in the present moment.

Table of Contents

Acknowledgements	iv
Abstract	x
Chapter One: A New Approach to Jewish Medical Culture	1
Introduction: Project Summary	1
Toward a Definition of Jewish Medical Culture	4
Secularization: Judaism between Modern and Pre-Modern Definitions	7
Studying Orthodox Jews as a Means of Exploring Jewish Medical Culture	11
Literature Review	14
Overview of the Fields	14
History of Jewish Medicine	16
Jewish Medical Law and Ethics	19
Academic Works on Jewish Medical Ethics	22
Academic Works on Secular Medical Ethics	23
Cultural Studies in Healthcare and Cultural Competency	24
End of Life: Basic Scientific Facts	26
Chapter Overview	27
Chapter Two: Religion, Politics, and PVS: The Case of Terri Schiavo and the Reaction of the American Orthodox Jewish Community	33
Underlying Concepts in Medical Ethics and Precedents in American Case Law	34
Euthanasia	37
The Facts of the Schiavo Case	38
Representative Jewish Responses to the Ethical Issues in the Schiavo Case	41

The Orthodox Response to the Schiavo Case in the Context of the Orthodox Reaction Against Enlightenment Ideals	47
Secularism: Further Definitions and Considerations	51
The Shift to Acceptance of Secular Power	55
Appeals to History	60
Understanding Jewish Memory	62
Conclusion	64
 Chapter Three: Brain Stem Death (BSD): Definitions and Conflicts	 66
The 1981 Presidential Commission's Report on the Definition of Death	67
Bleich's Opposition to BSD as a Definition of Death	75
The Position of Tendler	78
The Position of Breitowitz	81
The Commission Report: Acknowledgement of Nuances and Differences of Opinion	83
Conclusion	88
 Chapter Four: Brain Death, Paradigms of Thought, and Incommensurability	 90
The Facts of the Brody Case	92
Kuhn's Theory of Incommensurable Paradigms	93
Evidence of Kuhnian Paradigms: Rhetoric Surrounding the Brody Case in the Press and in the Language of Lawyers and the Hospital	99
Evidence of Kuhnian Paradigms: Rhetoric Surrounding the Brody Case in the Popular Orthodox Press	102
Whose Ethics? Evidence of Kuhnian Paradigms in the Smith–Flamm Case	104
Conclusion	112

Chapter Five: Taking One Life to Save Another: The Case of the 1977 Conjoined Twins	114
The 1967 Panel on Conjoined Twins	115
The 1977 Conjoined Twins Case	119
Facts of the Case	119
The Religious Context	123
The Jewish Family	124
Koop the Protestant	125
The Catholic Nurses	131
The Involvement of the State	135
The Jewish Process	138
Conclusion	143
Conclusion	147
Frameworks for Understanding Jewish Medical Culture	149
1. Interpretive Framework for Jewish Medical Culture: Ingrained Paradigms	149
2. Historical Framework for Jewish Medical Culture: Judaism as a System of Religion, Ethics, and Law	151
3. The Cultural Framework for Jewish Medical Culture: Katz's Notion of "Ritual Instinct"	156
4. The Philosophical Framework for Jewish Medical Culture: Maimonidean and Nachmanidean Modes of Thought	159
Avenues for Further Research	160
Application of Qualitative and Quantitative Methods to End-of-Life Issues	161
Gender and the Schiavo Case	161

Other Aspects of Jewish Medical Culture	163
Conclusion	164
Appendix A: Schiavo's Gravestone	166
Appendix B: Comments from <i>Vos Iz Naeis</i> about Motl Brody	167
Appendix C: The Duck-Rabbit Image	174
Bibliography	175

Chapter One

A New Approach to Jewish Medical Culture

Introduction: Project Summary

As the technology of medical care has advanced in recent years, the ethical, religious, and legal problems and questions surrounding it have multiplied. This principle is nowhere more true than in decision making in the care of patients at the end of life. What constitutes life and death? What sorts of interventions are desirable, what sorts are not, and why? What are the relative values of length of life and quality of life to an individual and to society? Who is to decide, and how? Increasingly, scholars in the fields of ethics, sociology, and the sciences are beginning to recognize that the answers to these questions are often culturally contingent rather than strictly objective and verifiable. Furthermore, since experts from different scientific, religious, and legal backgrounds cannot agree on the basic definition of death, it is imperative that we begin to question the assumptions that underlie their competing conceptions.

Within Jewish tradition the questions surrounding decisions concerning medical care at the end of life take on a singular character. As I will argue throughout this thesis, responses by Jewish patients, rabbinic authorities, and caregivers to issues as fundamental as the definition of death are inflected by the particular—indeed peculiar—history of Judaism in the modern age. Taken together, those responses constitute what I call “Jewish Medical Culture,” the concept that lies at the heart of this work.

What is Jewish Medical Culture? It is a subset of Jewish culture that deals with health, the body, and issues of life and death. I use the term “culture” in the manner employed by Clifford Geertz and the anthropologists and qualitative sociologists who follow him. In Geertz’s words, “culture is composed of psychological structures by means of which individuals or groups of individuals guide their behavior” (Geertz, 11). For Americans who associate with the constellation of symbols and definitions that come from a lived experience of the ethno-religious community of Judaism, behavior is often guided by principles that may be traced to that community. This is especially true in cases at the end of life, when the turn to religious principles may become most pronounced. Thus analysis of particular cases in end-of-life decision making represents a means for elucidating this highly charged manifestation of Jewish Medical Culture.

While most scholars today view Judaism strictly as a religion—a network of beliefs and rituals, divorced from systems of ethics and law—I follow Leora Batnitzky (2011) in arguing that the pre-Enlightenment identity of Judaism as encompassing all three of these dimensions—religion, ethics, and law—continues to inform Jewish cultural discourse surrounding medicine. Although a thorough history of the development of these dimensions since the Enlightenment is well beyond the scope of this study, I discern the existence of a characteristic “Jewish Medical Culture” encompassing aspects of all three. Indeed, I propose throughout this work that Jewish Medical Culture informs reactions on the part of Jewish patients, rabbinic authorities, and caregivers to such an extent that it can and regularly does come into sharp conflict with the mainstream, secular, and other religious conceptions of medicine today. These divergent medical conceptions sometimes cause confusion and contention between adherents to Jewish thought and those in the mainstream or in other traditions.

Despite the prominence of Jews in the field of medicine since at least the European Middle Ages (Berger 1997, Heynick 2002, Shatzmiller 1994), the complex constellation of Jewish attitudes toward medicine—at the end of life and at all stages of life—is very little understood.¹ This dissertation will explore historical and contemporary Jewish attitudes toward medical care as reflected in situations at the end of life. I apply a wide array of methodologies and principles to expound the cultural undercurrents that inform these attitudes. My approach is distinct from Jewish medical ethics: while ethicists attempt to spread normative standards of behavior, I wish to understand what is actually done. My interest lies not only in understanding Jewish law in the abstract, but also in understanding how Jews apply the principles they might have learned from religious authorities in their lives.

Drawing on literature dealing with cultural differences toward American medical care, as well as the history and ethics of Jews and medicine, this study considers three significant cases related to end-of-life medical issues—two within Orthodox Judaism and one outside of it: the cases are those of, Mordechai Dov Brody, the conjoined twins of 1977, and Terri Schiavo. These

¹ It is a commonplace perception that there is no distinctly “Jewish medicine” in the same manner as “Chinese medicine” (Nevins 2006). This claim is not entirely true; the Talmud and Rabbinic sources clearly prescribe remedies and procedures for medical ailments. The Talmud has so much text devoted to medicine and science that beyond the standard division of Talmudic literature into *Halakhah* (law) and *aggadah* (narrative), I would propose a third category: that of “Science/Medicine.” The medical knowledge on display in the Talmud, however, fell out of use over the centuries. This was not due to a lack of preservation but to a traditional Jewish law that requires the use of effective medical care, and the Jewish lawmakers recognized that Talmudic medicine was too dangerous to continue in practice (Jakobovits xxxi–23). This rejection of Jewish folk medicine has led to the perception that there is no “Jewish medicine.” In fact, there is an extant folk medicine still in use among the Jewish populations who adhere to mystical teachings (e.g. *Sefardim*, *Hasidim*) which can be considered a distinctly “Jewish medicine.”

However, this assumption does a disservice to the long inter-related history of Jews and medicine since the Rabbinic period. For example, Frank Heynick’s history of Jewish medicine argues that it is correct to identify medicine as integral to Jewish history: “one might almost say that for some 1,000 years and counting, medicine has been *the* Jewish profession” (7), and Jews as integral to the history of medicine. Considering that Jews made up half of the medical profession in Medieval Western Europe (Shatzmiller), and were instrumental in preservation of Greek medical tradition during that period, that one could posit that pre-scientific Western medicine was itself, at least in part, “Jewish” medicine.

Moreover, based on Sylvia Fishman’s concept of “coalescence,” I argue that for any subculture (e.g. medicine, entertainment) to which Jews are important contributors, those subcultures are infused with Jewish values (Fishman 2000, especially 9–13).

three cases in succession highlight complex medical issues around the end of life. Using a variety of source bases—including academic case reports, newspaper articles, websites, and Jewish legal (*halakhic*) writings—I propose to explicate the Jewish themes that are implicit in the American Jewish community’s responses to major issues in medical decision-making. Although there is no single, unified Jewish American voice on medical care or ethics, I will argue that many of the responses to these cases from within the Jewish community—from patients, doctors, rabbinic leaders, and lay observers—had their underpinnings in Jewish tradition and Jewish concepts—that is, in Jewish Medical Culture. These manifestations of Jewish Medical Culture, I argue, reveal a great deal about contemporary Jewish ideas and practices, the extent to which Jewish identity is rooted in or distinct from the surrounding contemporary society, and the thumbprint of Jewish history in the present moment.

Toward a Definition of Jewish Medical Culture

The foundational work of Peter L. Berger and Thomas Luckmann, in *The Social Construction of Reality*, demonstrated the extent to which human beings rely on the shared notions of their society to give meaning to and understand the signs, symbols, objects, and actions around them. Independently, Berger applied this theory of social construction to the subject of religion and religious meaning, emphasizing the essential interplay between the individual and the society; the two are constantly growing and changing as new members, new ideas, new symbols and new products come into play. As Berger writes in *The Sacred Canopy*, “Society is a dialectic phenomenon in that it is a human product, and nothing but a human product, that yet continuously acts back upon its producer” (3). In this view, the relationship

between individuals and the broader group is constantly in flux, as the individuals both contribute to and glean from the products of society—its culture. “Society,” Berger shows, “is not only an outcome of culture, but a necessary condition of the latter.” And, addressing religion in particular, Berger states, “Culture consists of the totality of man’s products. Some of these are material, others are not” (6). Religious culture can assume the form of material objects, but it also encompasses the shared ideas, beliefs, and symbolic meanings assumed by a given religious group.

It is in this sense that I approach the subject of Jewish Medical Culture. My aim is to understand how the influences of Judaism—whether latent or overt—appear in the conception of medical care and the definitions of life and death for those who associate with Judaism on some level. I follow Clifford Geertz in the belief that the study of human behavior—human practice—is as essential as the study of theory or systems of beliefs and ideas. As Geertz writes, “Behavior must be attended to, and with some exactness, because it is through the flow of behavior—or, more precisely, social action—that cultural forms find articulation” (17). For that reason, I seek articulations of Jewish Medical Culture on multiple levels and in the actions of multiple individuals and groups: it may present itself in the decisions of medical care providers to provide or withhold therapy from a patient, in the split-second determinations of one family member to resuscitate another, in the questions asked and answers given by a rabbinic authority (*posek*) asked to determine the proper course of action in a given case.

My thesis offers a new perspective on Jewish Medical Culture through consideration of a series of case studies in end-of-life issues, with a distinct case examined in each of Chapters Two, Four, and Five. I have addressed three extremely well-known end-of-life cases in part because of the extensive documentation of each—varying sources derive from patients, rabbinic

authorities, secular legal authorities, members of the press, and other eyewitness accounts. Throughout, my goal is to describe and explain Jewish Medical Culture as manifested in these case-studies. Ultimately, I hope this thesis will lay the groundwork for more comprehensive treatments of Jewish Medical Culture in cases outside of the realm of end-of-life care.

The case studies that I explore in Chapters Two, Four, and Five are based on the sociological analysis of written work. I use accounts of the medical cases and reactions to them as primary documents, contrasting them and analyzing them against the publicly available written record, including news accounts, academic publications, and on-line communications, to understand the mentalities of the populations under study through close reading. Although interviews and surveys may create new data, that data are by and large exclusive and available only in raw form. My method, by contrast, involves the use of material that is openly available, which enables an egalitarian transparency; in addition, I offer interpretations of the materials and the events they describe that go beyond the normal results of interviews and surveys. These interpretations thus assume the form of a “cultural reading” or interpretation in the sense described by Geertz: my goal has been, following Geertz, to “[sort] out the structures of signification...and determin[e] their social ground and import....Doing ethnography is like trying to read (in the sense of ‘construct a reading of’) a manuscript—foreign, faded, full of ellipses, incoherencies, suspicious emendations, and tendentious commentaries, but written not in conventionalized graphs of sound but in transient examples of shaped behavior” (9–10). I treat the behavior of the actors in these medical cases in this way, attempting to draw out the underlying beliefs, assumptions, and social conventions that shaped them.

The objection may be raised that the behavior of Jews who are actors in medical cases is not monolithic; how, therefore, can we speak of a Jewish Medical Culture? Yet culture as a

whole need not be monolithic in order to be conceived of and studied as a culture. Indeed, for Geertz, any description of social behavior that gives the impression of uniformity is actually untrustworthy. As he writes,

Coherence cannot be the major test of validity for a cultural description. Cultural systems must have a minimal degree of coherence, else we would not call them systems; and by observation, they normally have a great deal more. But there is nothing so coherent as a paranoid's delusion or a swindler's story. The force of our interpretations cannot rest, as they are now so often made to do, on the tightness with which they hold together, or the assurance with which they are argued. (17–18)

In the cases I will address in this thesis, I have observed a wide range of opinions, ideas, and deeds on the part of the Jewish actors; it is, indeed, a commonplace of Jewish culture as a whole that disagreement and argumentation abound. However, I will show that there are consistent systems of belief and assumptions made that underlie even these divergent opinions. It is these underlying themes that I will explicate over the course of this study.

Secularization: Judaism between Modern and Pre-Modern Definitions

Among the undercurrents of Jewish Medical Culture, perhaps none is as strong as the identity of Judaism as more than “just” a religion. Leora Batnitzky's recent work *How Judaism Became a Religion* (2011) traces the emergence of Judaism as a religion to the Enlightenment philosophy of Moses Mendelssohn, who sought to set Judaism on equal footing with Christianity, allowing the Jews to co-exist under the umbrella of a secular nation. Pre-modern Judaism viewed Jewish law and ethics as one and the same thing, in contrast to secularist philosophers of the Enlightenment, who introduced a theoretical framework that distinguished

among religion, morality, and law; each came to be thought of as a separate field. As Batnitzky explains:

in the case of Judaism, the category of religion, defined as a sphere of life separate from other spheres (such as politics, morality, and science, just to name a few), simply does not quite fit. Modern Jewish thought may be understood as the story of the attempt by Jewish thinkers to fit Judaism into this category and the rejection of this effort, which in turn inspires subsequent attempts to place Judaism into yet another category, such as culture or nationality, which as we have seen, does not quite fit either. (190)²

I will apply Batnitzky's framework to Jewish Medical Culture, using it to explain the distinctly legal aspects of Jewish methodology and thought on complex medical cases. The system of Jewish law (*Halakhah*) is primarily a legal system, in which a rabbinic authority (*posek*, pl. *poskim*) rules about case-law based on the legal precedents dating back to the time of the Talmud and indeed, to the Bible itself. Batnitzky is not alone in making this distinction explicit; her conclusion is strongly supported by Sullivan's (2005) general overview of the interplay of law and religion:

In the context of the modern West, however, law, religion, and ethics have been progressively differentiated, being understood, both socially and rhetorically, to inhabit different domains...Western observers may distinguish institutions and ideas that parallel modern secular legal ideas and institutions but, by and large, law in premodern societies was, to a greater or lesser degree, subsumed within and served what might be termed a religious worldview. (107)

² Batnitzky's work presents the clearest articulation of this concept. Many others have asserted similar points; see Blidstein 2009, Elon 1994, Jospe and Yahil 2007, Magid 2004, Moodie et al. 1993, Sarna 1986, for a historical perspective. For current expressions of the unity of *Halakhah* as a seamless combination of law, religion, and ethics/morality see Brand 2010, Breitowitz 1996, Broyde 2000, Crane 2012, 2013, Englard 1988, Falk 1994, Fishbane 1990, Glick 2008a, Goldsand et al. 2001, Green 2005, Jackson 1987, 2009, Lamm 2006, Lasker n.d., Levene 2005, Levin 1987, Lichtenstein 1975, Putnam 2005, Resnicoff 2006, Sagi 1994, Sinclair 1992, Teutsch 2005, Washofsky 2007 and 2012, Weingarten 2002, Wenger 1998, Woolf 2009.

Because law and morality are intertwined, *Halakhah* can refer to multiple domains within the Enlightenment system. Broyde, in an essay intended “to explain the works, process, and history of Jewish law (*Halakhah*) to the uninitiated [legal scholar],” emphasizes the amalgamated definition that, as we have seen, hearkens to the pre-modern religious system:

The term *halakhah* (in Hebrew, “the way” or “the path”) is usually interpreted to refer only to Jewish law as it relates to practical observance. However, it encompasses all of Judaism; law, theology, and ethics are all encapsulated in “the way” a Jew must observe. Thus, *halakhah* can be understood to refer to “law” in its largest definition: a structure in which internal faith as well as external conduct is measured and governed. (2000:25–26).

While there has long been a debate about whether *Halakhah* is or is not inherently moral,³ the debate, according to Batnitzky’s historical explanation, should be seen as a particularly modern invention because, before the Enlightenment, religion and morality were seen as one and the same.⁴

Indeed, some scholars of Jewish medicine and medical ethics have observed the effects of this pre-modern legal character of Judaism in contemporary Jewish practice. The distinction was made by Benjamin Freedman, a Canadian bioethicist, in his book *Duty and Healing: Foundations of a Jewish Bioethic*, which deals with the distinctions between “duty” (which he identifies as a Jewish concept) and “rights” (a post-Enlightenment and American concept), and the implications of this distinction in contemporary health care. Freedman cites the legal

³ As Yehudah Mirsky points out, Bahya ben Joseph ibn Pakuda, in his publication *Hobot ha-Lebabot*, endeavored to emphasize what would be considered moral laws and ideas that are distinct from ritual practices (see Kohler and Broydé 1906). For discussion of the question of *Halakhah* and morality, see Englard (1998), Fishbane (1990), Lamm (2006:321–357), Lichtenstein (1975), Magid (2004), Sinclair (1992), and Statman (2010).

⁴ In the field of “modern” ethics, this attitude about *Halakhah* and morality is characterized as deontological; see Solomon (1995:815–816).

historian Robert Cover (1987) as the primary source for this idea; Freedman applies Cover's idea to the formulation of a system of Jewish bioethics.

Cover notes that "the principal word in Jewish law, which occupies a place equivalent in evocative force to the American legal system's 'rights,' is the word 'mitzvah,' which literally means commandment but has a general meaning closer to 'incumbent obligation'" (65), analogous to the legal system identified by Batnitzky as a feature of pre-modern Judaism. Cover considers this difference to be fundamental to contemporary Jewish culture: "Indeed, to be one who acts out of obligation is the closest thing there is to a Jewish definition of completion as a person within the community" (Cover 67). The example he cites is that a bar mitzvah is not "free" when reaching maturity; rather, as the term literally means, the boy is now obligated to perform the work commanded of him.

Broyde (2001) accepts Cover's distinction between rights and duties and explains that the main practical difference is that duties are the responsibilities of the individual to him/herself and the community, while rights are what the community owes to the individual: "the notion of a duty to act to help others, rather than the notion that one in need has a right to be helped" (xxiv). Broyde illustrates this distinction by citing a series of examples: in Judaism, "there are no procreation rights, but rather the duty to procreate; there is no right due to mental incapacity, but rather a societal duty towards those who are incapacitated" (xxiii). A right can be waived by the individual more easily than a duty, and especially in the case of incapacitation. Duty-thought would claim that in the absence of information from the individual's desire, the duty to the individual still remains and does not change the presumption of action.

As Broyde notes, rights are passive, in that it is the responsibility of the individual to enforce them (or have them enforced). Broyde's illustration of this latter distinction is in the area

of child's education: if there exists a right to educate a child, the child could forgo that right; the government would have the responsibility to make sure that the right was made available, not necessarily to have the child educated. Duty-concept would determine that the individual has a duty to be educated and that society must enforce that duty, as Cover explains: "In Jewish law, an entitlement without an obligation is a sad, almost pathetic thing" (67). I would posit that the notion of duty leads to a legal model. Moreover, as in the case of the conjoined twins, the family was not consulting rabbis to discover the *ethics* of a given action, but rather to find direction about what they had to do: what were they **obligated** to do under these medical circumstances. The work of Cover and Broyde on this subject is significant in that it identifies a continuing influence of the pre-modern legal character of Jewish medical thought in the practices of contemporary America. This work forms an influential and essential precedent for my theory of Jewish Medical Culture, and I argue that it may be seen as a modern manifestation of the pre-modern character of Judaism highlighted by Batnitzky.

Studying Orthodox Jews as a Means of Exploring Jewish Medical Culture

The question "Who is a Jew?" is as fundamental as it is impossible to answer definitively. As Sarna (2004) explains at the beginning of his study of American Jewry:

The very term "American Judaism" defies meaningful definition, for Jews as a people cannot be disentangled from Judaism as a faith. Traditionally, Judaism constitutes what is known as an ethnic church: its members distinguish themselves as much by their common "tribal" ancestry (real or imagined) as by their doctrines and practices. (xvi)⁵

⁵ See also pp. xvii and 366–368.

Sarna is not alone in emphasizing the multi-categorical definition of Jews and Judaism, and it is this complexity that lies at the heart of any social-scientific study of this population.⁶ The field of Jewish sociology does acknowledge that Jews are at least definable in religious terms, as well as ethnic, cultural, and possibly even racial terms. Even limiting my field to contemporary American Jews does not define the group sufficiently; any serious attempt to encompass the culture of contemporary American Judaism, I argue, must accept that the subcultures are often incongruous. What the sociologists of Judaism recognize as the contemporary American Jewish community is a population that is so diverse in major cultural hallmarks that any claim of a single “Jewish Culture” (or Jewish Medical Culture) is potentially invalid from the start.

While this dissertation is about Jewish Medical Culture, all of the case studies that I discuss in subsequent chapters involve Orthodox Jews, either as commenters on medical cases in contemporary America, as the primary actors in the cases, or as representatives of and interlocutors with medical professionals. I base this methodology on Smith (2005), Director of the General Social Survey (GSS) at the National Opinion Research Center (NORC) of the University of Chicago; I take Smith’s general demographic findings as a starting point for my sociological evaluation of American Jewish attitudes toward medical care in America. Smith demonstrates the viability of the study of Orthodoxy in America as a means for understanding the nature of the entire Jewish population. Evaluating Jews along the matrices of both ethnicity and religion, Smith notes,

⁶ Studies of Judaism, especially from an “inside” perspective will need to explain the “more-than-a-religion” nature of Judaism. See the entire first chapter of Fishman (2000:1–13), Dashefsky et al. (2003), Goldstein (1993:89, “The Complexity of Jewish Identity”), and especially Smith (2005, see below).

1. “In over 80 percent of the comparisons, there are no statistically significant differences among Jews. Thus similarity among Jews rather than division is the most prominent feature.”
2. **“Second, when the subgroup differences do appear, one dominant pattern emerges. Jews tend to differ from non-Jews in the same direction that more secular Jews differ from more religious Jews....**That is, Jews with no denominational affiliation, those with low religious attendance, and those with no current religion tend to hold positions compared to more religious Jews that follow the differences between Jews and non-Jews.”
3. **“Likewise, when either measured by themselves or along with those with no denominational affiliation, Reform Jews differ from Conservative and Orthodox Jews in the same direction that Jews differ from non-Jews....**This suggests that nonreligious aspects of Jewish culture often do as much to distinguish them from non-Jews as do religious matters.” (50)⁷

Altogether, this means that even secular Jews are more alike in their behavior to Orthodox Jews—and therefore for the purposes of sociological evaluation—than they are to secular non-Jews; the more religious a Jew is, the more representative he or she is of Jewish distinctiveness. Smith’s conclusions demonstrate that researchers can study Orthodox Jewish practices, attitudes, and beliefs with a high degree of confidence that the conclusions of such

⁷ In addition to the GSS, the major projects that have attempted to capture a sociological picture of American Judaism include the National Jewish Population Study (NJPS, 2003) which essentially defines its subject, American Jews, according to the self-definition of its interviewed population, and the recent Pew study (2013). Complementing Smith’s work are the political theories of Elazar (1995) who puts the highly committed American Jews, Orthodox and traditional Conservative, as having a disproportionate effect on American Jewish culture.

studies correlate to overall Jewish culture. I emphasize that these practices do not necessarily correlate to the pronouncements of ethicists in *any* Jewish denomination. My purpose is not to understand the rationale of ethical norms as articulated by denominational leaders, but rather to evaluate how Jews of any denomination actually behave. (The potential clash between the opinions of the elite scholarly leadership on medical questions and the actual praxis of Jews in America who subscribe to these various denominations manifests itself in what Jacob Katz has called “ritual instinct”—a point to which I shall return in my conclusion.)

Smith recognized that to accurately study Jews in America, that population needed to be evaluated on two parallel matrices: first, in comparison to other religions, and second, in comparison to other ethnicities. In fact, Smith’s approach forms a close approximation of the broader conundrum within Jewish sociology as a whole: how is it possible to study an ethno-religious population that constitutively shares characteristics of both those models? As he explains,

As both an ethnicity and a religion, Jews occupy a special place in America’s ethnic/religious mosaic. Unlike groups that are only ethnic, Jews, as a religious group, are expected to maintain and pass on their Jewish identity. As an ethnic group, their religion is not only an attribute of individuals and families, but a trait of the collective Jewish community. Together, these joint aspects of Judaism make American Jewry distinctive and help to sustain that distinctiveness. (59)

Neither the religious nor the ethnic model alone succeeds in capturing the essence of Jewish identity, for even Jews with salient religious self-definition may also have a strong ethnic identity. Smith analyzes both of these aspects of identity quantitatively through the survey data of the GSS, elucidating further the importance of denomination as a hallmark of Jewish distinctiveness.

Literature Review

Overview of the Fields

The approach of this dissertation is broad and interdisciplinary, drawing on literature from a wide array of fields and methodologies. In this section I will present an overview of the literature that informs my thinking, while at the same time explaining how my approach differs from past writers. Above all, my methodology is distinct from that of most other writers in that I am attempting to describe cases from a social science perspective relating to American Judaism—not to prescribe the best practices from an ethical point of view. Such normative approaches have been adopted by scholars within Jewish Studies who have written on medical ethics, and also by scholars in the field of nursing who are attempting to render divergent religious and cultural norms more accessible to the nursing staff who provide care to patients.

The study of the relationship between Jews and medicine has often fallen into the categories of **the history of Jewish medicine** on the one hand and the practical philosophic endeavor of **Jewish medical ethics** on the other. Yet these two topics do not deal adequately with contemporary behavior of American Jews, and thus I have also explored the body of contemporary social scientific work on **cultural differences in health care**, which takes into account American Jews as a medical subculture, like any of the other ethnic and religious groups within the American health care system.⁸ Despite the comparatively small number of Jews in the United States, a handful of studies do attempt to understand the distinctiveness of American Jews

⁸ In general, these studies proceed from the view that as long as distinctions can be determined among different identity-groups, then those groups must have a distinguishing medical culture. While these studies do not use the term “medical culture,” I believe the term can easily be applied to them, as this is a basic sociological/anthropological application of “culture” and so it has been used in a number of other studies (see Lupton 2003, Sobo and Loustau 2010).

as patients, as well as Jews as medical experts. A major contribution to this area has been “**cultural competency**” studies, led by the field of nursing, and generally aimed at practical treatment of patients.

Within the vast fields of religious studies and healthcare studies, as well as the field of medical ethics, I have narrowed my work to address cases of **end-of-life decision making**. My reasoning is that this exceedingly complex area highlights the points of friction between divergent cultures—in particular, the relationship between Jewish Medical Culture and secular American society.⁹

History of Jewish Medicine

As stated above, most of the literature that attempts to understand a distinctively Jewish approach to medicine falls into either the historical or the philosophical realm—that is, either Jewish medical history or Jewish medical ethics. My approach, in contrast, is concerned with contemporary sociological and ethnographic aspects of the interaction between Judaism and modern medical culture.

Medical history and ethics provide a background to understand contemporary cultures, but in an indirect way. Studying changing beliefs toward medicine over the millennia of Jewish history helps us to understand better the continuities and discontinuities of the history of Jews and medicine and current Jewish medical ethics or medical practice. What these studies emphasize is the cultural and temporal contingency of Jewish conceptions of medicine.

Difficulties arise, however, both when contemporary Jewish ethics are imposed on

⁹ The same complexity exists at the beginning of life—e.g. in issues related to contraception and abortion—and that is why I choose as one of my test cases the interaction of the two—that is, the separation of conjoined twins (see Chapter Five).

historical circumstances and when Jewish history is read through the lens of present-day ethics. Examples of this may be seen in two recent scholarly debates: one over self-killing in the Talmudic era, and the other concerning the notion of disease in the Biblical period. I dwell on these two cases now to raise awareness of the pitfalls that may be introduced through the assumptions and anachronistic belief systems that the scholar may bring to the analysis of medical cases.

Droge and Tabor (1992) explore self-killing during the time of the Hebrew Bible, Second Temple, and Early Christian periods. As they explain, self-killing may be seen either in a positive light (as “martyrdom”), or a negative light (as “suicide”). Droge and Tabor show that despite post-Talmudic *halakhic* statements delegitimizing self-killing, there is ample Biblical proof allowing self-killing in a number of circumstances—for example, episodes relating to King Saul and Samson in the book of Judges. A shift in attitude seems to have occurred during the Hasmonean period, corresponding to the era of Socrates and Plato, during which the philosophic schools at the time were in favor of self-killing under many circumstances.

Modern rabbinic authorities, including Bleich (1998), dispute the existence of Jewish sources allowing or favoring self-killing, asserting that life has “infinite value,” and using as proof that martyrdom is only allowed by *Halakhah* in three extreme cases: to avoid being forced to commit murder, sexual perversion, or idolatry.¹⁰ In contrast, Droge & Tabor document the extensive practice of martyrdom described in the Talmud, and conclude that until the law was made explicit in those three extreme cases, Jews practiced self-killing extensively, often for violations of honor. I would take the argument of Droge and Tabor even further, suggesting that

¹⁰ Bleich’s ahistoric reading of Jewish law, as exemplified in this case, is a point of contention for many writers of *halakhic* history and Jewish bioethics.

the Talmudic rabbis enacted the rule of the three extreme cases—much like Matthias in the Book of Maccabees—to *curtail* the number of martyrdoms, not to increase them.¹¹

By contrast, some historical works appear to approach the study of Jewish medical history by applying contemporary ethics—sometimes with a bias against the Jewish past, and perhaps also with a latent intention to criticize Jewish practice in the present day. For example, the growing field of disability in religion sometimes takes an anachronistic and polemical tone. Avalos (1995)—a significant authority in this field—uses statements regarding the barring from the Temple of those with skin diseases (Leviticus 13–14), and blemished priests (Ibid., 21–22) to describe an antagonistic attitude toward the sick and disabled by the (Jewish) Biblical authors, specifically the P-author, reflecting the morality of the Priestly society.

Avalos’s reading of the Bible is contradicted point-by-point in the work of Jacob Milgrom (1991).¹² As Milgrom shows, it is not necessary to interpret the text in a manner that

¹¹ Another example of the contrast of modern ethical claims with the studies of Jewish history comes from Levenson’s (1993) work on the Biblical attitude toward child sacrifice. He cites ample evidence that the attitude toward child sacrifice went through three stages: (1) The first born, or beloved, child was commanded to be sacrificed, following the Ancient Near Eastern mythos of El sacrificing his beloved son Baal to the sea god Yamm. (2) An allowance was made to substitute an animal for the beloved child—and this is the import of the story of Abraham’s near-sacrifice of Isaac (Genesis 22). During this period, as shown in literary and historic evidence, children were still allowed to be sacrificed, but animals were allowed as well. (3) Lastly, as seen in the books of Prophets, human sacrifice was wholly rejected. Levenson’s thesis is corroborated by the echoes of the theme of “death and resurrection of the beloved son” in many Biblical stories, but ultimately in the lore of the early-Christian polemic against its “older brother” Israel. This is seen most clearly in the legend of the birth and death of Jesus, who, as in the ancient tale of El and Baal, was the “only begotten son” of god, and who was sacrificed to save the Universe but, following Baal’s path, was ultimately resurrected.

Other works in the field of Jewish medical history that demonstrate changing Jewish attitudes towards medicine and health are that of Boyarin (1993), concerning evolving attitudes toward the human body during the Talmudic era, and that of Rubin (2008) dealing with the Biblical and Talmudic periods. Others are the studies by Shatzmiller (1994) of the Medieval period, Ruderman (1987) for early modern Europe, and Hart (2007) for the nineteenth and twentieth centuries. Even those texts which do not discuss change over time are useful as reference works for their time periods; these include Preuss (1993) for the Bible and Talmud, as well as Rosner’s encyclopedic work (2000) and his focus on translation and commentary of the *oeuvre* of Maimonides (1997, 1998). Other perspectives about the history of Jews in medicine can be seen in Dubin (2012), Gilman (1991), Jacob and Jacob (1993), Leibowitz et. al. (1990), Praglin (2003), and Sperber (2008). For a specific look of the history of medicine for non-elite American Jews see Dwork (1981) and Lindenthal (1981).

History of medicine for non-elite American Jews: Dwork (1981) and Lindenthal (1981).

¹² Milgrom’s line of argumentation has been taken up by his students, including David Wright.

excoriates the ancient Israelites. One explanation for Avalos's apparent bias is revealed in the following excerpt, which betrays a possible Christian polemic underlying Avalos's description of the Priestly society:

The formation of large populations of "sick outcasts" may eventually constitute a political or social threat to the "normal community." The Hebrew Bible does not provide much indication of this potential threat. However, the New Testament indicates that it was these populations of outcasts that appear to have been the focus of Jesus and his disciples in the development of a dissident Jewish sect, which became known as Christianity. The healing activities of Jesus and his disciples may be viewed as a critique of the traditional Priestly health care system. In effect, the regulations in Leviticus promoted the development of a significant demographic group of which early Christianity took advantage. (393–4)

While it is not necessary to claim that Avalos is advocating a Christian reading of the Hebrew text, it seems possible that the centuries of polemical interpretation of Israelite society had an effect on his work, and it is this type of interplay of Jewish medical history and modern ethics that can be counterproductive. Nevertheless, it is essential that contemporary scholars become aware of the assumptions that they bring to the sources under consideration.¹³

Jewish Medical Law and Ethics

As noted above, the work of the ethicist Benjamin Freedman, and legal scholars Robert Cover and Michael Broyde, provides essential precedents for my theory of Jewish Medical Culture, in that it identifies the legal nature of Jewish medical ethics, which, I argue, has

¹³ This category also includes the biographical work and eclectic storytelling of physicians endeavoring to be amateur historians, such as Friedenwald (1946, 1967), Kagan (1934), Heynick (2002), Nevins (1996, 2006), and Savitz (1979).

significant implications for Jewish Medical Culture in contemporary America. However, beyond Freedman's identification with the legal aspect of Cover's work, his identification with the field of Jewish medical ethics is quite distinct from my own approach. The literature in Jewish medical ethics provides a valuable picture of the normative positions on the questions I seek to explore in this study. Whereas work in medical ethics seeks to impose a particular practice on a group of religious followers, or suggest authoritative guidelines for those interested in following them, my interest lies in understanding not ostensibly normative rules and principles but the actual, lived practice of Jewish Medical Culture as it is expressed in the decisions that are actually made by patients, doctors, and families in consultation with their religious leaders. Yet, in contrast to the study of Jewish medical history, the field of Jewish medical ethics has a direct impact on American Jewish Medical Culture, because goals and ideals comprise a key component of culture. However, the map is not the territory: what the elites require or demand may not, in fact, appear in the behavior of the masses.

Jewish medical ethics can be divided into the work of the institutions of the major American Jewish denominations: Orthodox, Conservative, Reform, and Reconstructionist (NJPS 2003). While the polity of American Jews does not generally fall among clear denominations, this division is useful for understanding the ideologies of the cultural elite.¹⁴

Orthodox Judaism in America is not governed by a single specific institution, yet participants in the lawmaking process can be divided into three groups: (a) Rabbinic authorities

¹⁴ For authoritative writing on from Conservative Judaism see Dorff (2005, 2004, 2002, 1998, 1990), Dorff in Moodie et. al. (1993), Feldman (1986, 1995, 2006), Mackler ed. (2000), Nevins (2004), and Reisner (1991). For Reform, see Cahana (2005), CCAR (2002, 1994, 1991, 1990, 1989a, 1989b, 1986, 1985, 1984, 1980, 1975, 1969, 1968a, 1968b, 1953, 1950), Cohen (2005), Cohn-Sherbok (1987), Crane (2013, 2012), and the essays in Jacob and Zemer (1995). For Reconstructionist see Fenner (2005), Teutsch (2005), and Teutsch and Waxman (2002)

who are favored as singularly authoritative,¹⁵ (b) popular disseminators of the opinions of others,¹⁶ and (c) a combination of the two—rabbinic authorities who are not accorded universal acceptance within Orthodoxy, but whose opinions are considered possible authoritative interpretations in Orthodox law.¹⁷ The non-Orthodox denominations have more centralized institutions, and the publications of their seminaries are important for defining the baseline ideology for the leaders of the movements. However, there are also specific figures in Conservative Judaism who rise above the institutions in terms of their authority.¹⁸

Interestingly, there is much more consonance among the denominations in their attitudes toward medical care than one might anticipate, and I believe this can be attributed to a common reliance on most of the same sources from the Bible and Talmud. As anticipated, the greatest differences lie at the ends of the conservative–liberal spectrum, but based on the range of legal sources, a generally accepted set of shared assumptions guiding Jewish medical ethics can be delineated. These shared assumptions can be contrasted with the actual practice of American Jewry as found in the social scientific work.

Another category of Jewish medical ethics exists which is denomination-neutral. These are works that fall into three categories:

1. Those that attempt to describe attitudes across the religious denominations,¹⁹
2. General readers of Jewish sources chosen without ideological discrimination,²⁰ and

¹⁵ These include Abraham (2000, 2004), Feinstein and Tendler (1996), HaLevi (1987), Friedman (1993), Herring (1984), Isaacson (1991), Schostak (2003), Shulman (1998), Shabtai (2008), Steinberg and Waldenberg (1980), and Tatz (2010).

¹⁶ Examples include Rosner (2001, 1993), Rosner and Tendler (1997), Rosner and Schulman (2005), Halperin, et al. (2004, 2006), Steinberg (2003), and Wiesen ed. (2009).

¹⁷ These include Bleich (1979, 1991, 1998, 2006), Bleich and Rosner (1979), Breitowitz (2008, 1996), Jakobovits (1959, 1986, 2007) and Tendler (1990).

¹⁸ See Crane (2013, 2009) for a study of specific denominational representatives on the topic of medical ethics. Examples of these figures include Dorff (1998, 2002, 2005), Feldman (1986, 1995, 2006), and Reisner (1991).

¹⁹ Dorff and Newman (1995), Falk (2001), Flancbaum (2001), Meier (1986, 1991)

²⁰ Cutter (2007, 2011), Freeman & Abrams (1999), Person (2003);

3. Those that try to describe a Jewish tradition that combines religious and cultural components.²¹

Academic Works on Jewish Medical Ethics

While the works listed above deal with Jewish ethics from a prescriptive (ethical) perspective, there are also academic works that take a descriptive approach to American Jewish practice. Most of these works are not ethnographic; rather, they describe the position of the religious elite, but are published in academic journals and are intended to educate scholars, as opposed to the descriptive works in the previous section which are directed at lay readers.²² Another set of literature aspires to use academic, usually philosophic, rigor to analyze the “official” positions in Jewish ethics so to speak from the outside.²³ In addition, there are many works which provide important ethnographic data concerning the behavior and ideology of the contemporary American Jewish public.²⁴ Other valuable work concentrates on the interplay between the rabbinic leadership and the lay public.²⁵ Most important for my work are those who apply direct social science methods to the study of American Jewish health (Levin 2011).²⁶

²¹ Freedman (1999), Glick (2008a, 2008b, 1994), Goldstein (2008), Pollack (2000).

²² This category of academic Jewish medical ethics is exemplified in Baeke et al. (2011a, 2011b, 2011c), Blachar (2008), Dorff (2004), Falk (1998), Gesundheit and Shaham (2008), Gesundheit et. al. (2006), Goldsand, Rosenberg, and Gordon (2001), Gordon (2006), Glassner, Lachoff, and Lichtenstein (2003), Grodin (1994), Kinzbrunner (2004), Loike (et al. 2010), Ravitsky (2005, 2009), Resnicoff (1998), Schostak (1994), and Weiss (2007).

²³ Bodell and Weng (2000), Cohen (1997), Cohen-Almagor and Shmueli (2000), Crane (2009), Davis (1994), Eisenberg (2007), Ellenson (1991), Gillick (2001), Gray (2009), Greenberg (2009), Jotkowitz (2010, 2008), Kunin (2003), Levin and Prince (2010), Rosin and Sonnenblick (1998), Rosner (1991, 2005), Sokol (1988), and Zohar (2006). Some works in this category seem intended to establish a secular Jewish medical ethic, e.g. Newman (1990, 1998), Novak (2007), Zohar (1997).

²⁴ Borovoy and Hine (2008), Grazi and Wolowelsky (2006), and Jacobs and Giarelli (2001)

²⁵ Coleman-Brueckheimer, Spitzer, Koffman (2009), Flannelly et al. (2006)

²⁶ My research on secular legal theory and its comparison to what would be an American Jewish Legal Culture – a parallel to Jewish Medical Culture, involved a number of areas. For general literature on legal theory see Alexander (2008), Coleman (2005), Golding (2005), Holmes (2009), Jones (1974), Kippenberg (2005), LaFond (2012), and Orth (2012). For secular academic works on the sociology of law as it relates to religious or cultural law, see Langlois (2001), Skene and Parker (2002). For works that aim to interpret American Jewish Legal Culture to a secular academic audience, see Baruch and Lokken (2000), Berger (1998), Broyde (2001, 2000, 1991), Broyde and Weiner (2012), Davis (1994, 1992), Dow (2008), Faur (1970), Fishbane (1990), Friedell (1992), Goodrich (2001),

Academic Works on Secular Medical Ethics

The works of and about Jewish medical ethics in the previous section can be used to describe a Jewish Medical Culture if contrasted with the general secular ethics of the surrounding American culture. Most of the works in this latter category attempt to describe a non-religious—and non-culturally contingent—set of principles that would speak to Americans at large irrespective of their religious affiliations or lack thereof. The works on general ethics are important to set the overarching principles of American secular ethics.²⁷ This category also includes publications by major institutions, including the American Medical Association (1992).

Other works in this category include inquiries that do not advocate a position about end-of-life issues; they approach the topic either from a philosophical perspective²⁸ or a legal one.²⁹ This literature stands in contrast to the ethical works that advocate for a specific secular set of principles from the perspective of individual thinkers.³⁰

Most valuable for my project are the descriptive works of end-of-life in practice, whether in general social science terms³¹; or more importantly as it relates to decision-making and/or

Kaplan (1992), Magid (2004), Malina (2008-2009), Meislin (1980), Mittleman (2005), Newman (1990), Novak (1998), Roth (1986), Stone (2007), Weisbard (1979), and Wixen (1992). Jewish law is considered a casuistic system (see Sarna 1986, 158-189, 237-240) but this term was created to explain Roman Catholic canon law and carries with it implications particular to the history of Christian law, in addition to pejorative connotation that could even be seen as anti-Jewish (see Wieseltier 2011). Moreover, the Roman Catholic notion of casuistry has been appropriated by secular bioethicists as a possible method, which has, in turn, changed the meaning even further; see Brody (2010a), Davis (1992), Jonsen (2011, 2013), Mertes and Pennings (2011), and Tomlinson (1994).

²⁷ These include Beauchamp (2003), Beauchamp and Childress (1994), Coughlin (2008), Forbes (1935), Holmes and Purdy (1992), McDougall and Gorman (2008), McKeown (1979), Murphy, Butzow, and Suarez-Murias (1997), Thompson (2010), Thiroux (1998), and Wenger et. al. (2008).

²⁸ Brody (2010a, 2010b, 1990, 1988), Curlin et. al. (2007, 2005), Daaleman and VandeCreek (2000), Dieterle (2007), Hackler (2001), and Macklin (1991).

²⁹ AMA (1992), Battro et. al. (2007), Beecher (1984), Cantor (2001), Fleck (1992), Youngner et al. (1999)

³⁰ Angell (1993), Cantor (2010), Conard (1992), Kaufman (2000), Singer (1988), Wolf (1990, 1992, 1996, 2004, 2008), Wolpe (1998).

³¹ Cook et al. (2003), Moulton, Hill, and Burdette (2006), Verbakel and Jaspers (2010)

conflict among the stakeholders (physicians, nurses, family).³² It is within this area that I situate much of my intellectual background. In addition, I employ Starr (1982) and Tesh (1998) as works that provide a necessary social history of American medicine.

Only one study produced thus far employs the term “medical culture”: Collins et al. (2009), which applies the term in the context of physicians and their training.

Cultural Studies in Healthcare and Cultural Competency

In the contemporary era medicine has been closely associated with science (Starr 354) which provides a presumed objectivity and universality. However, numerous studies show that certain medical concepts are culturally and socially determined, and this is especially true for end-of-life issues.³³ Wijdsicks (2002) surveys the criteria for determining brain death in 80 countries, including the United States and Israel, and found that while there is general agreement on the types of examination to determine brain death, there is wide divergence in actual practice. Some countries set the bar high, requiring multiple tests as well as the agreement of a number of physicians; others countries have more lax standards for determination of brain death, relying on the opinion of only one physician. Remarkably, Wijdsicks found a similar range of differences among the states in the U.S.A. The author suggests that “it can be argued that these differences

³² Anspach (1997), Appel (2005), Baumrin (1991), Bosek and Sue (2007), Christakis and Asch (1995), Kellehear (2008), van Laarhoven et al. (2009).

³³ For the impact of race/ethnicity/culture on end-of-life decision making, see Callender et. al. (2006), Demons and Velez (2006), Gamble (2006, 1997), Siegel and Prigerson (2010), Smith et al (2009, 2006), Williams et. al. (2006); for Muslim attitudes see Burazeri et. al. (2008), Clarfield et. al. (2003), Moodie et. al. (1993), Sachedina (2005); for Roman Catholic. see Clarfield et. al. (2003), Mackler (2003), Markwell (2005), McGovern (2008), Moodie et. al. (1993), Pellegrino and Faden (1999), Shannon and Walter (2005); for Protestant, see Engelhardt Jr. and Iltis (2005), Hauerwas (1995), Marty (1991), Pauls (2002); for Christian Science, see May (1995), for India and/or Hindu, see Firth (2005), Gupta (2010), Mani (2006), and Whitman (2007); for generalized Asian (and/or Buddhist and/or Taoist) see Ihara (2009), Izumi (2010), and Tai (2008, 2009a, 2009b).

could have resulted from dissatisfaction with the original concept of brain death and could reflect cultural attitudes” (24).³⁴

Ultimately, the body of work I hope to expand and contribute towards are social scientific studies about religious and ethnic differences in the American health care system. There are basic works that establish the conceptual and methodological possibility of this type of study.³⁵ Many studies have found significant differences among ethnic subgroups—a fact that underscores the cultural contingency of medical definitions and ideas.³⁶ There are, similarly, studies for different religions in the American landscape and those in other countries³⁷—with some specifically about the American Jews.³⁸

Within the field of nursing, the cultural differences of diverse populations within hospital settings have been elucidated in the field of “cultural competency.”³⁹ Nursing researchers have found that acknowledgement of the different assumptions and practices of various social, religious, and cultural groups can lead to more effective treatment and communication, thus improving the delivery of medical care. In this field, the determination of validity is based on whether or not the work helps the caregiver in dealing with Jewish patients. Ethnographic accuracy is thus *not* the primary goal. The “cultural competency” approach deals in generalizations: for example, the authors may emphasize that Jews have a special calendar with

³⁴ Wijdicks’s work is confirmed by many other studies, and others have expanded the work to capture specific processes within the determination of brain death. For example, Yaguchi et al. (2005) found that crucial factors are whether nurses are involved and whether the healthcare providers require an oral or written DNR order.

³⁵ Bhui & Dinos (2008), Blank (2011), Cohen-Mansfield (et. al 1992), Crawley (2002), Deep (et al. 2008), Irish, Lundquist & Nelsen (1993), Jenks (2011), Julia (1996), Kagawa-Singer & Blackhall (2001), Kahana (et al 2004), Koenig, McCullough & Larson (2001), Lupton (2003), Oguamanam (2006), Pochard & Abroug (2005), Satcher, Pamies & Woelfl (2006), Shaw & Armin (2011), Sobo & Lousaunau (2010), Stein (1985).

³⁶ Armstrong et al. (2007), Braun et al. (2008), Gamble (1997), Gray (2013), Heyman and Gutheil (2010), Ihara (2009), Johnson, Kuchibhatla, and Tulsky (2008), Keown (1998, 2005), Kwak and Haley (2005), Leslie and Young (1992), McKinley, Garrett, and Evans (1996), Smith, Sudore, and Pérez-Stable (2011).

³⁷ Benjamins (2006), Bülow et al. (2008), Curlin et al. (2007), Gielen (2009), Levin (2009), Park et al. (2008), Röcklinsberg (2009), Sprung et al. (2007), Tench (2006).

³⁸ Bonura et al. (2001), Spitzer (2003), Shafran and Wolowelsky (2012).

³⁹ Kukoyi et al. (2006), Nunez and Robertson (2006).

religious restrictions on their Sabbath, which falls on Saturdays, but that knowledge would be useful and true only for those Jewish patients who observe the Sabbath. If a nurse mentions the Sabbath to a Jewish patient, the metric of cultural competency has been satisfied.

In this respect, cultural competency stands in contrast to ethnography, the aim of which is the accurate representation of a given population, which in turn often requires recognition of considerable variation within that population. Generalizations of the sort advocated by the literature in cultural competency are highly suspect: ethnographic studies that generalize to the point of assuming strict commonality within a population could reach the level of stereotype—a circumstance that would render the ethnographic work a failure. In addition, the practical ends of cultural competency—the delivery of medical care—do not harmonize with the ends of social-scientific work, in which practical outcomes and the imposition of normative standards are considered outside the purpose of academic study. In sum, and despite some initial, superficial resemblances, my methods diverge from the field of cultural competency first because the full diversity of the Jewish population resists generalization, and second because the fieldwork it would require would be extensive and would have questionable goals.

End of Life: Basic Scientific Facts

Finally, my work relies upon the scientific literature for its understanding of the complex issues involved in the end of life. The definition of that term only began in the 20th century; meanings of the various conditions will be explored in Chapter Three. The key distinction between cardiac death and brain death was initiated by the Ad Hoc Committee of the Harvard Medical School (1968), and codified by the Presidential Commission of 1981; the Commission's acceptance of brain stem death as the definition of death was accepted by the United States

government in that year, as well as by the AMA (1989) and ABA (Shapiro 2008). Joynt (1984:5) explains the historical background for the Harvard committee: there were two growing issues in the medical sciences and practice: (a) a recognition that while “death” had been understood as the total cessation of a biological system, scientific observation had shown that the human nervous system could stop functioning—could “die,” as it were—before the rest of the body did; and (b) there was increasing success in organ donation: “the acquisition of living organs from dead patients [in 1968 had] become an accepted part of medical practice.”⁴⁰ Thus the ethical questions around the definition of death emerged in tandem with ethical questions related to medical breakthroughs in the preservation of life.

Chapter Overview

General Overview

The literal life-or-death consequences of end-of-life decisions create an even greater need than usual for clarity as well as reasonableness. Unlike theological or legal questions, issues of life-support and initiating or withholding care at the end of life touch nearly every family. They bear the gravest of consequences, also influencing issues such as family dynamics and long-term relationships.

The Jewish community is faced with these issues more and more, both because of lengthening life-spans, and no less significantly, a changing cultural and moral climate. Confronted with phrases such as “right to live” and “right to die,” “prolongation of life” and “prolongation of death,” and a generalized social conflict between science and religion, Jews—like all Americans—are increasingly aware of the need to become educated about these topics.

⁴⁰ Shemie (2007) argues that organ donation was a major driving force for the bifurcation of the death definition.

The extent to which they identify as Jews may affect their decisions in these extreme circumstances.

I have chosen the three cases with a recognition that the end of life, because of its gravity, creates a stark contrast about views and values and the methods employed to achieve those values. The issues that emerge from my discussions are touchstones for the major issues in medical sociology as a whole in the 21st century.

Chapter Two: Religion, Politics, and PVS: The Case of Terri Schiavo and the Reaction of the American Orthodox Jewish Community

Theresa “Terri” Schiavo, a non-Jew, entered a Persistent Vegetative State (PVS) with no hope of regaining consciousness. Nevertheless, she was still alive according to both American law and Jewish law. Yet it is not my purpose to address the legal context of this case: instead, I address the discourse that grew around it within the American Orthodox community. There were a variety of Jewish responses to the wish of her husband to remove nutrition. In addition, because the government ultimately intervened in the Schiavo case, it also provoked heated debate within the American Jewish community over the issues of patient or family autonomy, relationships with interventionist political stances, and relationships with religious leaders outside the Jewish community. At issue in the Schiavo case are the conflict between state laws and the religious systems, secularization, and the conflicting values of “quality of life” and “right to life.”

Chapter Three: Brain Stem Death (BSD): Definitions and Conflicts

In 1981 a Presidential Commission was convened to create a uniform definition of death in light of new medical technologies that, in effect, extend the process of dying. While the

Commission's report explains its reasoning for adopting Brain Stem Death (BSD) as the standard uniform definition in United States law, this definition was not adopted by the majority of Orthodox Jewish authorities. As a result, Orthodox Jews whose family members experience this condition come into sharp conflict with medical practitioners following U.S. law. While the Commission's report reflects an understanding of the nuances involved in perceptions of BSD, and recommends that treatment of BSD patients recognize cultural differences in the understanding of death, more recent applications of the Commission's definition appear not to reflect this understanding. Case studies in BSD explored in Chapter Four detail the results of this conflict.

Chapter Four: Brain-Death, Paradigms of Thought, and Incommensurability

Mordechai "Motl" Brody was a *Hassidic* boy who, in 2008, became brain-dead after an unsuccessful treatment for brain cancer. The hospital sought to remove medical care, but the family, which believed that only cardiac arrest could define death, fought to continue medical care until the boy experienced cardiac arrest naturally. Although the distinction between cardiac and brain death is relatively straightforward, the case nevertheless highlighted the tensions between divergent *halakhic* opinions on that distinction. In addition, it brings to the fore the conflict between an increasingly paternalistic system of medical care, and religious Jews who sought to retain autonomy, which they believed to be a American right that would allow them to observe their religious requirements.

Ultimately, the Brody case was about the definition of death. As I will show, throughout the writings on this case it is clear that the parties involved were "talking past" one another. This phenomenon is also seen in a case described in the academic literature concerning an anonymous

Orthodox patient (Smith and Flamm 2011); in this case, even the academic observers abandon their objective stance, expressing sympathy with the view of the medical practitioners and exasperation with the Orthodox family. Although in both these cases the two sides were using the same terminology, their understandings of that terminology were so sharply divergent as to be entirely incompatible.

In order to explain this phenomenon, I call upon the theory of “paradigms” of thought and “incommensurability” outlined in Thomas Kuhn’s monumental work *The Structures of Scientific Revolution* (1962; repr. 1970). Although Kuhn’s notion of paradigm was first formulated to explain scientific revolutions historically, it is, more broadly, a theory of the development of ideas—of shifts in the ways that groups of people share and spread ideas, and the ways in which they see those ideas fitting together; it has been applied fruitfully in the social sciences in the past, especially in the sociological field of Science and Technology Studies (STS).⁴¹

A key aspect of Kuhn’s theory is the notion of “incommensurability.” In this notion, the same terms or symbols can be used by various groups to mean entirely different things. As a result, the assumptions that underlie these paradigms come into sharp conflict. This concept has been the most controversial in the philosophy of science and its reaction to Kuhn. I posit, however, that the case of brain-stem death presents an apt illustration of Kuhn’s assertion of incommensurability. The Orthodox Jewish families in these cases who consider a BSD patient to be alive, and therefore in need of medical care, think within a paradigm that is incommensurable with that of the medical professionals, who consider a BSD patient to be dead, and therefore no longer of medical concern. The two sides, as I will show, fail to understand on a basic,

⁴¹ See Aronova (2009) for the history of Kuhn in STS and Urry (1973) who substantiates—at an early date—Kuhn’s contribution to the sociology of knowledge.

fundamental level how the other side perceives the issue, in this case, the very meanings of ‘life’ and ‘death’. The Kuhnian concept of incommensurability helps to explain why the various parties in the Brody case were so incapable of communicating with one another. Their cultural associations and basic ethical understandings were so much in conflict that they led to tremendous strife.

Chapter Five: Taking One Life to Save Another: The Case of the 1977 Conjoined Twins

The third case is that of conjoined twins born to an Orthodox Jewish family from Lakewood, New Jersey, whose name has been kept private. Here the issues were most complicated and distressing. Because the infant twins had only one heart, surgical separation mandated the choice of one life over the other; the only alternative would have been to allow them both to live briefly and die naturally. Leaders and laypeople in the Jewish community voiced their opinions, and remarkably, there was widespread agreement that the family would be justified in moving forward with the surgery.

My discussion of the twins case will show that the methods of Orthodox Judaism in approaching the ethical question of what to do—to separate conjoined twins with the possibility that one would survive, or to decline intervention and allow them both to die—are highly legal. The similarity between the determination of a Jewish ethics case to a legal process is shown (1) through the comparisons of the Jewish process with the secular legal process in that very case; (2) through similar legal processes in other related cases of conjoined twins; (3) through the use of the 1977 case as part of the legal arguments in a 2000 British case of conjoined twin.

What this demonstrates is that the presumption that Judaism can be understood within the modern definitions of religion, as opposed to an ethical or legal system, is a fallacy. Rather,

Judaism as practiced by the Orthodox Jews in these examples, follows an integrated model that encompasses all three of these components as essential. I demonstrate that Jewish Medical Culture is highly legal; as noted above, in this respect, it builds on the framework established in Batnitzky 2011.

Taken together, my approach to the cases in this study sheds new light on contemporary Jewish Medical Culture in the United States. Each case illuminates a particular aspect of this culture. Through application of a wide array of theories and methodologies, and above all through attention to the special concerns of the parties involved, I attempt to contribute to the overall discourse about the religious, ethical, and legal concerns that inform the Jewish experience of end-of-life issues. Ultimately, I offer what I hope will be a first step toward a more complete understanding of Jewish Medical Culture.

Chapter Two

Religion, Politics, and PVS:

The Case of Terri Schiavo and the Reaction of the American Orthodox Jewish Community

Terri Schiavo was not Jewish—she was Roman Catholic—but the public debate over her end-of-life saga became a point of focus within the American Jewish community as well. Questions of medical ethics are a significant site of communal self-definition among rabbinic leaders and thinkers of the Orthodox Jewish community in particular. The prominence of medical ethics may be attributable to the weight of the issues—these are questions that are ultimate, final, and literally life-or-death. The debates over the Schiavo case within the Orthodox Jewish community, however, assume another valence; they reveal areas of anxiety concerning the surrounding American culture more generally. Many Orthodox Jewish thinkers frame the Schiavo case in terms of the value of human life, a fear of Nazi-style inhumanity and a culture of death pervading the secular society, and apprehension over the possibility of a “slippery slope,” leading to social brutality.

At the heart of the Jewish response to the Schiavo case lie two important issues in understanding Jewish Medical Culture: first is the issue of individual autonomy in medical decision-making. Patient autonomy has a solid basis in American law, and it carries significant implications for religious freedom. However, many Orthodox Jewish thinkers rejected the notion

of patient autonomy, supporting the secular government's intervention in her family's end-of-life decision-making process.

This encouragement of intervention by the government is significant, and it points to the second underlying issue in this case—that of secularization. As evidence from statements by members of the Orthodox community show, the calls for government intervention reveal a continued ambiguity toward the separation of church and state. Drawing upon the work of Jacob Katz and others, this chapter argues that this ambiguity is a manifestation of the tendency among many right-leaning Orthodox Jews to resist the influences of secularism and post-Enlightenment thought.

Underlying Concepts in Medical Ethics and Precedents in American Case Law

Although the primary focus of this discussion is on the reception and responses to the Schiavo case within the American Orthodox Jewish community, and not on the approaches of American case law, it is nevertheless important to understand the case law as a contextual factor in the behavior of American Jews. In the United States patient autonomy is the law of the land. This principle was established by the Jewish American Supreme Court Justice Benjamin Cardozo (1914): “Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages.”⁴² Wolpe (1998) offers an explanation of how this principle became the dominant medical ethic in America: “The use of autonomy as a panacea for ethical problems in medicine is a very recent, and particularly

⁴² *Schloendorff v. Society of New York Hospital*, 211 N. Y. 125, 129–130, 105 N. E. 92, 93

American, solution to the problems of modern, technological biomedicine” (38). Wolpe continues by explaining the significance of World War II and the Holocaust in the shaping of modern bioethics, and patient autonomy in particular. In contrast to the Nazi regime, in which the government assumed the power to make medical decisions for its subjects (and victims), American law espouses individual autonomy: “The historical roots of modern bioethics were conceived in Nuremberg and its aftermath” (39). The patient’s right to make choices is of the utmost importance in modern biomedical ethics: “Where ‘organic’ trust is scarce, rituals of trust emerge (50) and one of those rituals is the patient’s authority over his medical fate through ‘informed consent.’” Generalizing these principles, Wolpe writes, “One could easily write a modern history of America by tracing the theme of individual liberty, especially as it’s been translated into ‘rights’” (53–54).⁴³

The American laws pertaining to the Schiavo case were previously established through two major precedent-forming cases: that of Karen Ann Quinlan (March 29, 1954–June 11, 1985) and that of Nancy Cruzan (July 20, 1957–December 26, 1990).⁴⁴ The case of Quinlan established the right to remove care: Quinlan was assumed to be brain-dead following a collapse from a drug overdose; her breathing assistance (ventilator) was removed after the 1976 court battle that established the right for Americans to withdraw care. Ironically, after the ventilator was removed she was seen to breathe on her own, a fact that established her status as a Persistent Vegetative State (PVS).⁴⁵ Her family kept her on nutrition until she died of pneumonia, after nine years.

⁴³ Starr (1982:31) connects this to observations on American society by Tocqueville.

⁴⁴ For the legal case of Quinlan, see *In re Quinlan* (1976); for Cruzan, see Supreme Court of the United States (1990).

⁴⁵ AMA (1989) presents definitions of various medical conditions that will be useful in understanding the Schiavo case.

1. Coma: “Abrupt loss of consciousness usually consists of an acute sleep-like state of unarousability called coma that may be followed either by varying degrees of recovery or severe, chronic neurologic impairment. The stage of coma itself, however, is invariably temporary and in progressive disease is often absent altogether.” (1)

The case of Cruzan, who was in a PVS following a car accident, created the law that in the absence of stated wishes, the patient's family may make decisions about the patient's medical care. The Cruzan decision cemented a position already stated by the American Medical Association: "If patients have not expressed their wishes clearly and convincingly, it is important to determine what standards of decision making apply. In general, family members or other guardians are permitted to make treatment decisions on behalf of the patient on the basis of what they believe the patient would have chosen if competent to decide. This is known as 'substituted judgment'" (AMA 1989:5). The AMA report also explained the logic behind the position: "Patients have a legally enforceable right to decline life-prolonging treatments and that their caretakers have no legal duty to prolong life when treatment will not restore consciousness or produce other medically definable benefits" (AMA 1989:1).

Basing itself on the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1983), the Council on Ethical and Judicial

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2. Vegetative State: "Persons with overwhelming damage to the cerebral hemispheres commonly pass into a chronic state of unconsciousness called the vegetative state in which the body cyclically awakens and sleeps but expresses no behavioral or cerebral metabolic evidence of possessing cognitive function or of being able to respond in a learned manner to external events or stimuli" (1).
 3. PVS: "When such cognitive loss lasts for more than a few weeks, the condition has been termed a persistent vegetative state (PVS) because the body retains the functions necessary to sustain vegetative survival. Some have applied the term 'cognitive death' as a synonym for the state. Recovery from the vegetative state is possible, especially during the first few days or weeks after onset, but the tragedy is that many persons in PVS live for many months or years if provided with nutritional and other supportive measures" (1–2). Adding further: "The distinguishing feature of PVS is chronic wakefulness without awareness." Furthermore, "Once qualified clinicians have determined that a person is awake but unaware, the permanence of the vegetative state depends on the nature of the brain injury.... the chances of regaining independence after being vegetative for three months are vanishingly small. Rare exceptions are claimed, but some of these may have represented patients who entered an unrecognized locked-in state shortly after reawakening from a coma-causing injury. Ultimately, all have been severely disabled."

It is imperative to note that PVS is not the same as brain death, which occurs when the entire brain has been rendered inoperable, including the brain stem, which controls (among other things) breathing. PVS is a state that occurs when the entire brain *except* the brain stem has been destroyed ("liquefied"). Another step up is severe mental retardation. The status of 'coma' is parallel to these statuses, but a prolonged coma is not the equivalent to PVS. Patients may emerge from a coma; but PVS and other forms of brain damage are irreversible because the brain has been physically destroyed.

Affairs of the American Medical Association (1986), and the report of the Hastings Center (1987), the AMA presented its conclusion:

Physicians should honor the patient's previously expressed desires regarding the use of life support. Thus, if the patient has chosen to forego life-sustaining measures, they should be withheld or withdrawn. However, in many cases, the patient will not have indicated his or her desires before becoming permanently unconscious. In such cases, the decision whether to use life support should be based on the patient's perceived preferences and values, and the decision should be made by the family or legal representative. If the patient's preferences or values are not ascertainable, the family or legal representative should decide on the basis of the patient's best interests.

Euthanasia

Physicians in the Western world have been socialized to accept a duty to heal as a long-standing ethical and professional principle. That principle is strikingly evident in the active model of medicine, epitomized by the notion of "heroic measures."⁴⁶ Euthanasia presents a threat to that principle. Within the concept of euthanasia is an implicit allowance of doctors to decide whether they will treat a patient at all.⁴⁷ Killing a patient goes even further. A refusal of care to a patient, and euthanasia even more so, go against decades, even centuries, of traditional medical culture.

⁴⁶ This "allopathic" form of medicine (Starr 100) may be contrasted with, for example, that of osteopaths, who have a more holistic and passive view of medical care (see Raffel and Barsukiewicz: 61–62). For more about minority American secular medical cultures, see Bates (2002), Floyd (2006), Gevitz ed. (1988), and Raffel and Barsukiewicz (2002).

⁴⁷ See Anspach (ch. 2, pp. 25–54) for an overview of the medical ethics positions about euthanasia, especially for infants.

Contemporary rhetoric surrounding euthanasia often refers directly to the Holocaust. While this may be expected in Jewish discussions of euthanasia, references to the Holocaust may be seen even in secular journals (see *Gesundheit* 2006).⁴⁸

Opponents of legal euthanasia also argue that euthanasia is a type of execution. They frequently distort the liberal position (i.e. the position allowing euthanasia) by imputing that euthanasia constitutes an execution of an undesired person, whose only sin is physical or mental unfitness. This objection would make sense if the euthanasia were determined and enforced by the government or society as a whole as was the case with the Nazis; yet where euthanasia is allowed it is only as a measure of individual autonomy. This necessary nuance, between state and individual actions, looms large in the debate between the liberal and conservative positions in the Schiavo case, as shown below.⁴⁹

The Facts of the Schiavo Case

Terri Schiavo, suffered a cardiac arrest on February 25, 1990 and entered a Persistent Vegetative State (PVS) from which she never recovered.⁵⁰ While initially her husband, Michael,

⁴⁸ In addition to Nazism, the other frequent “warning model” used to deter the legalization of euthanasia—this one contemporary rather than historical—relates to decisions in the Netherlands. Yet Nazi Germany and the modern Netherlands are quite opposite, the former a racist totalitarian state and the latter largely a liberal-libertarian one. This liberalism was quite helpful for the 17th-century Jewish population fleeing the expulsion from Spain and Portugal—especially as seen with the re-conquest of Recife in 1635 and the need for the Jews to escape the Catholic Inquisition and find refuge among the Protestants of either England or Holland (Sarna: 6)

⁴⁹ With regard to death sentences sanctioned by the state, Foucault (1977) highlights doctors’ involvement in the execution process, noting that “today a doctor must watch over those condemned to death, right up to the last moment—thus juxtaposing himself as the agent of welfare, as the alleviator of pain, with the official whose task it is to end life” (11). Foucault points out the paradox of medicine that the figure of the doctor can be associated with official procedures that may lead to death as well as to health. As will be seen in the Schiavo case, doctors and religious thinkers placed themselves on both sides of the life/death conundrum. Furthermore, euthanasia has a curious connection to two other moral issues: the death penalty and abortion. Partisans fall according to typical lines on euthanasia based on those other two: liberals oppose the death penalty and support abortion, while conservatives do the opposite.

⁵⁰ The facts of the case come from the official court records (Greer 2000) as well as Wolfson 2005 and Thogmartin 2005.

agreed with Terri's parents, the Schindlers, to pursue every avenue to restore Terri to consciousness, after three years Michael believed that Terri was not going to recover. In the meantime, in 1992 Michael successfully sued Terri's doctors for malpractice and the \$700,000 settlement was applied to Terri's care.

Since PVS was understood as a permanent destruction of the brain (see footnote 3 above), Michael believed that his wife's unwritten but verbally-expressed wishes would be to have her care removed. A picture (see Appendix A) of Schiavo's tombstone, erected by Michael, engraves in stone his interpretation of the key aspects of the case: (1) that Terri "departed the earth" as a result of the PVS following her heart attack and (2) in 2005 she was finally "at peace"; furthermore, he declares on the bottom of the stone, (3) "I kept my promise."

Terri's parents, the Schindlers, refused to believe that their daughter would have wanted to have care removed and they launched a number of efforts to have the power to make medical decisions removed from Michael and given to themselves. Multiple court cases were brought, based on allegations that were all ultimately dismissed, including an imputation of spousal abuse. The "Schindler Position," which term I will use to describe the position not to remove care from Terri Schiavo, succeeded in delaying the removal of care by more than a decade and eventually resulted in a special law enacted by the U.S. Congress to have Terri's feeding tube reinstated.

Unlike in the Quinlan and Cruzan cases, no new salient case law has been established through the Schiavo case.⁵¹ Those two earlier cases prompted the Supreme Court to rule first that a person has a right to die or to withdraw care, and second, that in the absence of a written directive, the relatives of the patient are empowered to make decisions. These principles were established and working properly in the Schiavo case, and Schiavo did not prompt the creation of

⁵¹ A search in the *findlaw* database yields information on much of the latter stage of the Schiavo legal battle. See <http://news.findlaw.com/legalnews/lit/schiavo/>

new law. However, Schiavo is an important case on other levels, including American religious history. Indeed, it is remarkable because of the extent to which religious conservatives were able to blur the line between church and state. (This point is emphasized in Broyde and in Adlerstein 2005b.)

The Schiavo case also highlights the importance of States'-rights issues with regard to medical decisions. Wolfson (2005) points out that the state of Florida already had laws in place establishing which party was entitled to make medical decisions in this case. In Florida the closest living relative is the spouse, in this case Michael Schiavo. In fact, Michael Schiavo claimed that he remained married to Terri (even when cohabiting with a different woman) in order that he could maintain his authority to make medical decisions on her behalf, and to see that her wishes were carried out.⁵² Wolfson further notes that the AMA, ABA, and the Florida laws had already declared that PVS was a medical condition in which the patient's relative would be allowed to withdraw nutrition and hydration.⁵³

In view of this medical and legal context, the remaining questions were as follows: First, was Michael Schiavo fit to make decisions for Theresa? Legally, yes. His antagonists, however, attempted to undermine the perception of his fitness by claiming that he abused Terri, that he was committing adultery, and that he wanted to kill her in order to inherit her estate.

Second, did Terri really claim she wanted to have care withdrawn? This was the weakest part of Michael's case in terms of empirical evidence, but even then the law was clear (based on Cruzan) that the husband was empowered to make the decision in the absence of an advance

⁵² The Schiavo case exemplifies another important aspect of medical culture in America broadly: the role of gender in determining the behavior of the parties in such cases. This is a topic that I address in the conclusion to this thesis.

⁵³ Wolf (2004) describes the effect that the Schiavo case had on the medical-ethical establishment. Prior to Schiavo, it was thought that medical, ethical, and legal professionals had arrived at a consensus regarding the fixedness of the law in these cases. However, Schiavo revealed ruptures in that system.

medical directive from Terri. Only if she had left a directive to the opposite effect, or if it could be established that she was against euthanasia, would Michael have been blocked from terminating care. This was the area where the legal cases were most fraught.

Third, was Terri really in a PVS, or was she in a different medical condition—for example, a reversal coma—that would not meet the threshold established in Cruzan to allow the removal of care? Partisans opposed to the removal of care emphasized this point enough to distort much of the news coverage (see Racine 2008). This explains, for example, why Senator Dr. Bill Frist (R-TN) would analyze a video tape of Terri to determine if she followed sights, trying to argue that she was merely brain-damaged, and not in a PVS.

Representative Jewish Responses to the Ethical Issues in the Schiavo Case⁵⁴

There is universal acceptance within the Orthodox Jewish community that it is *halakhically* impermissible for a third-person to remove nutrition and hydration from a PVS patient. There is some disagreement among Orthodox authorities about the permissibility of refusal of treatment for oneself. Schostak states that the noted authority Rabbi Hershel Schachter, *Rosh Kollel* (head of the assembly of learners, analogous to a Society of Fellows) of Yeshiva University, rules that a patient with capacity may withhold any treatment, even refusing being placed on a ventilator, because the patient may claim that this treatment is not beneficial for him [51]). Schostak further notes that “Rabbi [Zalman Nechemia] Goldberg – a highly-regarded authority, and son-in-law and disciple of the outstanding halakhist and medical ethicist Shlomo Zalman Auerbach, maintains that depriving a dying patient access to resources such as food or

⁵⁴ Non-Jewish scholars and ethicists were of course also involved in the debate over the ethics of the Schiavo case, but their work lies outside the scope of this essay.

oxygen does not constitute homicide, but is considered removing the means of ‘saving’ or prolonging his life,” and is therefore prohibited (53).⁵⁵ If Schiavo were an Orthodox Jew, and her husband had approached an Orthodox rabbi to ask whether it would be permissible to remove care from her, that rabbi would undoubtedly have said no. Most voices from the Orthodox community who spoke out on the Schiavo case came from the *haredi* (right-leaning)⁵⁶ world, and their response was overwhelmingly to support Terri’s parents in their efforts to stop Michael from removing care. In this position they were merely following the dictates of their own religion, without bearing in mind the larger legal and cultural principle involved—namely, that of patient autonomy. Only Rabbi Michael Broyde (a Modern Orthodox authority) calls attention to the value of individual autonomy, even if it meant allowing Schiavo’s medical proxy (Michael) to make a decision that went against Jewish law.

Broyde’s statements, to be quoted below, were prompted by a post on the web log *Cross Currents* by the *haredi* rabbi Yitzchok Adlerstein. In this exchange, Adlerstein first expresses his dissatisfaction with the “culture of death” prevalent in American society. He writes (2005a Silence):

Terry [sic] Schiavo left no written instructions regarding treatment in extremis. While Western systems of law generally provide layers of protection before taking a life (think of the mandatory appeals in capital punishment cases), Schiavo’s right to life is forfeited to the judgment call of individual judges, who have decided what she would have really wanted. They have ruled in favor of a husband who stands to gain financially by her death, and who admits he wishes to be free to remarry. (Or as Mark Steyn put it, wants to be rid of her because she is no longer convenient.) All these issues run against the opposing claims by a loving family, and a tradition of religious belief she herself subscribed to, which would mandate continuing to give her food and water. (Schiavo, it should be remembered, was breathing on her own, without the aid of a respirator.) Can

⁵⁵ For the Conservative Jewish opinions on these subjects, see Reisner 1991 and Dorff 1990. The Conservative opinions were also taken up by Reform and Reconstructionist writers and thinkers.

⁵⁶ For more about this group, and the distinctions within the Orthodox Jewish community, see Gurock (2009), Lazerwitz et. al. (1998), and Skolnik and Heilman (2007).

the competing narrative of Terri's parents be summarily dismissed? Shouldn't a "beyond a reasonable doubt" standard prevail, similar to the one we use before we convict an accused party? It is not hard to figure out what the judges are thinking. Terri has no "quality of life." She will never regain higher cortical function. Her life, therefore, has already been extinguished and has no real legal gravitas.

In contrast to secular attitudes towards "life" and "quality of life" issues are the *haredi* views espoused by Rabbi Adlerstein. Justifying his own involvement in the Schiavo case, Adlerstein (2005a Silence) continues:

Every religious community that sees life as G-d given should be up in arms. The Christian Right in particular should be rallying the troops. The media is putting all the blame upon them for Congressional interference; they should at least take the moral credit for taking a strong stand. They should be organizing shows of support for Schiavo's parents in every major city, with traditional Jews, Catholics, and Moslems at their side.

This column by Adlerstein prompted a response by Rabbi Michael Broyde. Five days later, Adlerstein cited the long email response by Broyde⁵⁷ which Adlerstein followed with a further rejoinder. First, I will quote Broyde (Adlerstein 2005b Dispute):

I do not think that the Schiavo case is an important one at all in terms of legal precedent and it is for that reason that thoughtful commentators both on the left and the right are not really involved (something which Rabbi Adlerstein bemoans, but which I think is obvious, for reasons I will explain).

In America we have adopted a basic view of health care in the last 30 years in which adults get whatever medical care they want (and can pay for, which is a different topic). Thus, almost all advanced directives a person provides for will be honored. That political compromise maximized medical freedom and allows a complex society—with very diverse attitudes towards death—to live in peace. In a situation in which a person does not leave a directive (a living will, for example) a person may also leave a durable power of attorney, which says "should I be incapable of making decisions, so-and-so... shall make them for me." That is fine also.

⁵⁷ The original is not online, so Adlerstein's reprinting is the only text available.

In situations where no durable power of attorney is left and no living will is left, the courts appoint a guardian, who by tradition is one's closest living relative (which is a spouse, if one has a spouse). That person makes all decisions for you and can only be removed in cases of clear error.

Every day hundreds of people are taken off life support, deprived of water or food or other medical decisions based on these choices and NO ONE CARES A WIT—so long as this is what one wants, or what one's guardian wants without contest. We are already a culture (not of death, as Rabbi Adlerstein writes) but of choice, which we—as Orthodox Jews—like.⁵⁸

Broyde's points about the Schiavo case are as follows: (1) it is not important or novel in terms of legal precedent,⁵⁹ (2) the removal of hydration and nutrition, what Michael Schiavo did to his wife, happens every day in America—further reducing this case's novelty (3) the status quo of American medical ethics is a preservation of the right of patient autonomy, (4) and Broyde believes this status-quo is in the best interest of the American Orthodox Jewish community.

In the Schiavo debate, Broyde seems to have been a lone voice from the Orthodox community to speak out against (a) lobbying for government interference in the Schiavo case and (b) against an application of the principles of *Halakhah* in a case where the American legal precedent dictated otherwise. However, outside this particular case, there are other statements from Orthodox Jewish authorities on medical ethics that emphasize the value of individual autonomy, a value that Broyde relates to the culture of choice in the United States.⁶⁰

In contrast, the voices from Orthodox Judaism that resonated with Adlerstein were plentiful during the Schiavo turmoil. In all cases, these voices emphasized their moral outrage, without acknowledging either the law of the land or the issue of individual autonomy. For example, the noted celebrity Rabbi Shmuley Boteach (2005) wrote:

⁵⁸ Parenthetical comments, capitals, etc. are in the original.

⁵⁹ As opposed to the Cruzan and Quinlan cases; see above.

⁶⁰ See Broyde (2001), Zweibel (2001), Ifrah (1992) Falk (1998:382), Sinclair (1998) and especially Sinclar (2009:301)

I never believed I would live in a country that would, in effect, execute a brain-damaged woman, who never hurt anyone in her life.... an American woman who suffered severe brain damage 15 years ago after a heart attack is subjected to death by dehydration and starvation by order of a judge.

Boteach's statement attacks the husband, stating that Michael's actions "sound a lot to me like wanting to inherit her estate." He uses extensive Nazi imagery, even quoting Hitler, who disgustingly associated the opposition of euthanasia with Judaism. Boteach's article also brings together the two issues of the "slippery slope" and the potential for descent into Nazism, even citing the well-known passage by the Pastor Martin Niemöller: "First they came for the Communists, but I was not a Communist..."

Boteach was not alone in these types of statements and use of rhetoric, but he does have all the contestable elements in one place. A similar attitude to that of Boteach and Adlerstein is seen in the words of another official contributor to *Cross-Currents*, Toby Katz, who starts her column (2005) by declaring: "Remember how the feminists crowed when they won—in *Roe vs Wade*—the right to kill unwanted babies? Little did they suspect that the same logic would produce a right to kill unwanted wives!" Using (anti-)feminist rhetoric in a drive to establish conservative religious principles,⁶¹ she also advocates an attachment to conservative politics: "The genuine liberals, the classical 19th century liberals, are all in the Republican Party now." Her comment is similar to the citation, employed by Adlerstein and other *Cross-Currents* writers, of a *Wall Street Journal* op-ed by conservative political partisan Peggy Noonan. In a twist, while Katz (2005) invokes Nazi imagery, it was in reaction to a comment by a liberal columnist (Frank Rich, then of the *New York Times*): "People who want to save Terri's life are

⁶¹ The fourth form of secularism, which is found in Katz, as noted below .

like Father Coughlin—the famous radio anti-Semite of the '30's. The thing that pro-lifers and Father Coughlin have in common is—drum roll, please!—religious faith! Which everyone knows is horribly dangerous for civilization.” Rich’s original statement (cited by Katz 2005) employs Coughlin not as an example of Nazism *per se*, but as an example of intolerance from religious leaders: “While sometimes God racketeers are guilty of the relatively minor sin of bad taste...sometimes we get the demagoguery of Father Coughlin or the big-time cons of Jimmy Swaggart and Jim Bakker.” The essence of this contretemps is not about religion as much as using religion as a mask for political aims. Katz (2005) wanted her readers to believe that those who wished to deprive Terri Schiavo of her feeding tube are anti-religious liberals, and her essay ignores any subtleties attendant to the case that Broyde put forward.

Support for the “Schindler Position” was publically given by a number of Orthodox organizations, especially from the leading *haredi* rabbinical institution, the Agudath Israel of America. This support was similar to their position on the earlier cases of Quinlan and Cruzan. In a similar case, Agudath Israel submitted an *amicus curiae* brief to the New York State legislature claiming:

Agudath Israel is troubled by the message this notion of unlimited personal autonomy delivers. It embodies a value judgment that society’s interest in the preservation of human life must bow before an individual’s decision that his life is no longer worth living. The implications of this message run directly counter to prohibitions against suicide and euthanasia that have long been accepted among civilized societies, and portend ominous changes in these social norms.

I understand the position of Agudath Israel, and the above *haredi* authors, as exhibiting three strains of anxiety: (1) overt physical coercion by the government (hence the use of Nazi

imagery), (2) overt cultural coercion, (3) implicit cultural coercion—the dissolution of “Judeo-Christian” ethics to allow euthanasia. But as we will presently see, there was something more.

The Orthodox Response to the Schiavo Case in the Context of the Orthodox Reaction Against Enlightenment Ideals

Three significant trends emerge from the Orthodox reaction to the Schiavo case. First is an alliance with those in conservative politics and other conservative religious traditions.⁶² Second is the appropriation (or misappropriation) of Holocaust imagery. Third, and most significantly, is the display of a fearful attitude toward the separation of church and state—that is, a fear of secularism that is stronger than a fear of intervention by other religious movements. The remainder of this chapter will situate these three interrelated tendencies within precedents in Jewish history and thought. Indeed, the statements of Adlerstein, Boteach, and others may be viewed as an extension of the anti-Enlightenment tendencies that shaped the inception of what would later be labeled Orthodox Judaism in the nineteenth century, described by Jacob Katz and expanded upon in the more recent work of Leora Batnitzky.⁶³

According to Smith,

secular and less observant Jews generally hold more liberal positions than do more traditional and religiously active Jews This result is usually seen as weakening support for accepting traditional religious beliefs such as *tzedaka* (charity or, more loosely, social justice) as an explanation for Jewish distinctiveness in general and liberalism in particular, since one would assume that more observant Jews would be the

⁶² In this context it is significant that Adlerstein as well as Toby Katz cite Peggy Noonan in the *Wall Street Journal*, whose headline reads, “Don’t Kick It: If Terri Schiavo Is Killed, Republicans Will Pay a Political Price” (see also Geller (2005)). The connection of Orthodox Jews to conservative political groups is the subject of studies by Stanislawski (2003)

⁶³ See also Wurzbarger et al. (2007) for more about the formation of Orthodox Judaism.

most likely to hold such values. However, it might be argued that these are the values of Judaism that the more secular Jews keep with them and perhaps emphasize as they discard other values and practices (e.g., patriarchalism and keeping kosher).

The Orthodox reactions to the Schiavo case—especially those of *haredi* Orthodox Jews—are very much in keeping with this tendency to be conservative in a normative sense, that is, as a dictionary defines it: “disposed to preserve existing conditions, institutions, etc., or to restore traditional ones, and to limit change” (Collins 50–51).

As noted with regard to the exchange between Broyde and Adlerstein, a distinction must be made between the Modern Orthodox and *haredi* viewpoints. The *haredim* who wrote and spoke out about the Schiavo case—Adlerstein, Boteach, representatives of the *Agudah*, and others—expressed little concern about—even an opposition to—patient autonomy. In expressing this viewpoint, those *haredi* writers demonstrated a disdain for the concept of church–state separation, which is a fundamental value of Enlightenment philosophies, as Katz and Batnitzky have shown, and as I discuss below. This standpoint also aligns these *haredi* voices with other right-leaning religious groups in America and with their Haredi counterparts in Israel. The same *haredim* joined calls for the Florida and U.S. governments to intervene in the Schiavo case—and framed their arguments in religious terms—further eschewing the boundary between church and state, and also aligning themselves with the right-leaning political trends exemplified by the administration of then-president George W. Bush (see, for example, comments in Menken 2005a, 2005b).

According to Katz (2001), the Enlightenment ideal of a division between church and state was opposed by traditional Jews in Europe from the very beginning of modernity, because they feared that it would result in a loss of rabbinic power within the medieval *kehillah* (community). The religious Jewish population (then as now) considered the need for Jewish leaders to maintain

religious order to be a necessary religious directive. The major difference between pre-modern and modern religious movements, at least as seen in Judaism, is the acceptance of binding and universal religious norms. Orthodox Jews believe that *Halakhah* is created by God and preserved by Man, and that it applies universally. The modern movements (including Jewish Conservatism and Reform, as well as Modern Orthodoxy) understand and value the primacy of individual autonomy and choice, even without adhering to moral relativism. If the *haredi* community views the choice to break with tradition as a sin, Reform Jews and other Enlightenment-influenced voices view a break with tradition as a redefinition of virtue.⁶⁴

As Katz explains, before the Jewish Emancipation following the Enlightenment and the French Revolution, Jewish communal leaders were able to use coercion and their total communal control to enforce Jewish law. The secular governments of Europe generally allowed the Jews this communal autonomy. After the Enlightenment, secular governments stripped Orthodox leaders of their ability to govern over their communities, and allowed the Reformers, or freethinkers, to modify the definition of Judaism. The Orthodox sought to use government power to maintain Orthodox law in the Jewish community to whatever extent the secular government would allow; Katz notes that this power was maintained only in the case of circumcision (equated by the government with baptism—an essential rite). In this case, Katz suggests, the Reformers were also reluctant to go too far in modifying the definitions of Jewish practice, because the Jewish right of residence was predicated on the ancient lineage. Adherence to some measure of tradition offered proof of this lineage.

It is useful at this juncture to review the concept of secularism as defined by Katz (1986):

⁶⁴ It is worth noting that overall, the Jewish community (dominated in numbers by Conservative and Reform Jews), does support the separation of church and state. This is manifestation of the variation in Jewish Medical Culture as discussed in the introduction.

The comprehensive concept of secularization refers to the fact that in the course of the transition from medieval to modern society many aspects of human life that had formerly had been conducted under the auspices of religion—and perhaps even controlled by its institutions—now extricated themselves from its sphere and began to lead an independent secular existence. (21)

I would claim that the traditional religious communities and leadership have not given up the fight to reverse this trend—to reinstate as many “aspects of human life” as possible within a religious framework.⁶⁵ Many of the paradoxical positions or relationships taken by conservative religious leadership can be understood under this rubric—as a part of the continued battle to reverse time and reverse the effects of the Enlightenment.⁶⁶

Katz describes the inherent threat of secularism to religion: “Philosophy, science and art as well as the economy and the control of the state and society, proclaimed their independence and asserted their right to follow their intrinsic trends without any concern for what religious doctrine and authority would permit or recommend” (34). This is only one definition of the process of secularism, and while it is the most well-known within the sociology of religion, Katz describes a second form as well:

The second, more specific, application of the term *secularization* is also our clue to an important limitation of true neutrality [of the European Enlightenment societies]. This application follows more closely the original meaning of the term.... Concepts, symbols, and all kinds of stylistic elements originating in the realm of religion had been translated into a purely profane context.⁶⁷ (22)

⁶⁵ There is a good deal of evidence that Orthodox religious philosophies retain aspects of medieval thought. This is not only seen in the appeal to earlier over later religious authorities, but in the popularity of neo-Platonic ideas and mysticism in the Orthodox community. Even rationalism is described by the (Modern) Orthodox proponents in medieval terms, as appeals to Maimonidean and neo-Aristotelian philosophies.

⁶⁶ While this statement could be considered polemical, my intention is analytical.

⁶⁷ One contemporary example is the American concept of Christmas as a secular holiday; see Sarna 1990.

While the first definition relates to applications in which topics of religion become the domain of a “rational” secular world, the second definition specifies instances in which religious concepts are considered to be the equivalent of universal principles.

Secularism: Further Definitions and Considerations

In addition to Katz’s two definitions of secularism, I posit two more definitions that can be derived from Katz by reversing the direction of the actors. The third definition is the **overt use of secular principles within religion** and the fourth is the **covert use of secular principles within religion**. There is support for these additional definitions from Katz’s own work, as I will show below.⁶⁸

The third form of secularism, the overt use of secular principles within religion, came about in 19th-century Europe when both Christianity and Judaism were subject to the same critical rejection by rationalism. The proponents of each religion consequently changed their public tone to substantiate their continued relevance and legitimacy in a secular world:

While the old areas of conflict receded, new issues now came to the fore. Which of the two religions conformed more closely to rational criteria? Which was burdened more heavily by mysteries? Such were the questions posed during the Age of Enlightenment. With the rise of Romanticism, the question assumed something of this nature: Which of the two religions is more capable of satisfying the urge for religious emotion? When positivism became dominant, religion appeared almost entirely discredited. Only the moral issue remained as the deciding factor in assessing the relative merits of the two traditions. (Katz 1986:35)

⁶⁸ I would argue that Katz’s definition of nationalism (1986:89)—“the transforming of ethnical facts into ultimate values”—resonates strongly with the idea of secularization. Traditional definitions that formed ethnic categories through secularism were transformed into a religion-like ideology. For views from one of the originators of the field, see Luckmann (1990); and for a recent, enriching, work that expands on the work begun by Katz on secularization see Ben-Porat (2013).

Katz's description points to a need for religious organizations and thinkers to constantly conform to the *weltanschauung* of the day, whether it be rationalism or romanticism.⁶⁹ The dynamic described by Katz leads to an ironic result, namely that religious leaders are forced to adopt secular language and ideas in order to maintain their religious populations. I define this dynamic as a third form of secularization.

In Katz's description, the leadership of the religious communities of Christians and Jews found that they had much in common in their resistance to secular principles, even while they still maintained, according to Katz (1986:44), their historical confrontations. However, while their doctrinal differences were significant to the adherents, the Jewish and Christian appeals to the enlightened masses were the same. This pattern of thought helps to explain the popular idea in the United States that there exists a "Judeo-Christian" ethical system.⁷⁰

It is possible, given the nature of American disestablishment and foundational freedom,⁷¹ conservative religious groups perceive a need to ally together in the pursuit of a common political agenda. In the sociology of religion, there is a growing recognition that membership in a denomination may not be as relevant for behavior, thought, or even identity, as placement on the conservative or liberal socio-political continuum (Wuthnow 1988, Roof and Greer 1993, Smith 2005). This trend has been observed in the connection between Orthodox Jews and conservative Christians.⁷²

⁶⁹ See Besecke (2005:179) concerning "the 'invisible' nature of religion in modern societies," Billings and Scott (1994) about the mechanisms and tools of religious political activism, and Sharot (1991) for alternative views.

⁷⁰ See Herberg 1960.

⁷¹ "Citizenship rights had implicitly been guaranteed to Jews in the United States by the American Constitution (1790)" (Katz 1986:6).

⁷² There is even some evidence of a consanguinity between conservative Jews and Muslims, as noted by events in the Second World Congress of Imams and Rabbis for Peace that met in Seville in 2006—which included non-Orthodox rabbis but no female rabbis.

(<http://www.worldjewishcongress.org/publications/wjcreport/06summer/irr.html>)

Stanislawski (2007), in his study of the assassination of the Reform rabbi Abraham Kohn in Lemberg in 1848, identifies as a key historical question the alliance of Orthodox Jews and the political conservatives in the secular government. His first piece of evidence is based on the traditional Jewish support for the Austrian state against the Polish Revolution in 1846, but is further substantiated by the perceived collusion between the Austrian authorities and the Orthodox community to cover up Kohn's assassination:

The Kohn assassination reveals a fundamental aspect of modern Jewish history that has heretofore remained all but unstudied: the alliance in many times and places between Orthodox...and conservative and even reactionary political forces and states—even in unexpected places like late tsarist Russia, where we have just begun to understand the growing coalition that emerged between the government and the leadership of Orthodox Judaism. More well known is the alliance between the Agudath Israel party and the increasingly anti-Semitic government of late-interwar Poland, and we are just now beginning to have studies on such alliances in contemporary Israel, and even, most recently, in the United States as well. (119)

For further support Stanislawski cites his own 2004 study, along with that of Bacon (2004); to these we may add the work of Levin (2007).

As defined above, the third definition of secularism is an overt, self-conscious attempt to inject religious principles and ideas into secular language. The fourth definition of secularization involves the same dynamic, but as part of a covert process. The American religious community response to the Terri Schiavo case illustrates this covert process of secularization and can be elicited through discourse analysis. The terminology of “culture of life” vs. “culture of death” is seen by many as this type of covert process. Annas (2005) quotes then President George W. Bush about the rhetoric of the culture of life:

The case of Terri Schiavo raises complex issues. . . . Those who live at the mercy of others deserve our special care and concern. It should be our goal as a nation to build a culture of life, where all Americans are valued, welcomed, and protected—and that culture of life must extend to individuals with disabilities.

The phrase “culture of life” employs secular terms and imagery but may also be understood as a translation of the speaker’s religious principles. As Annas comments (1): “For the first time in the history of the United States, Congress met in a special emergency session (on Palm Sunday, March 20, 2005) to pass legislation aimed at the medical care of one patient” (Annas 2007:1710). This unprecedented federal law to reinstate Schiavo’s feeding tube was later rejected by federal courts. The Schindlers and their allies were not only denying the established law of patient autonomy; in addition, they were able to enlist first the governor of Florida and then the U.S. Congress to join in this opposition. According to Nelson’s (2004:545) description of the case: “In the original proceedings before the trial court, a priest testified about Catholic teaching [about removing care].” Moreover, as Nelson describes, the case involved the courts judging the individual *religious* status of a U.S. citizen:

The parents also attempted to convince the trial court that Terri was a practicing Catholic who was serious about her faith, but her husband testified that Terri was a lapsed Catholic. The appellate court, in a rather off-handed manner, sided with the husband on the question of Teresa’s [sic] religiosity and affirmed the trial court order permitting the husband to order the withdrawal of treatment.

The attempt by the Schindlers to overturn established law constituted a mechanism of replacing the secular law in favor of another, religious legal system.

The Shift to Acceptance of Secular Power

The four mechanisms of secularization outlined above help to explain why the *haredi* Orthodox community as a whole was led to align itself with conservative political forces within the secular government as a way to maintain its religious authority. The third definition of secularization noted above—the substantiation of religion using secular terms—is especially applicable here. Katz (1990:104) describes the situation in 19th-century central Europe:

The resignation of Orthodoxy to its status as a minority also led to an important shift in its ideological presentation. Having lost the ability to enforce the law, the rabbis could no longer simply state their halakhic views. They had to defend them ideologically, underpinning the whole edifice of the Orthodox tradition on its dogmatic and practical details.

This formulation corresponds to what I defined as a third apparatus of secularization—the overt adoption of secular language to define and justify religious values.⁷³

Katz (1990) describes further how the transition from the medieval *kehillah*, which afforded the traditional leadership authority to enforce religious principles in their community, was eroded by the Enlightenment: “The growing intervention of the respective governments in the affairs of the Jewish communities, undermin[ed] the autonomy upon which the authority of the rabbis depended.” Katz believes that this liminal period changed the Orthodox attitude to the

⁷³ Ferziger (2005) sees Orthodox response to modernity in a constant state of boundary maintenance (10), which often was expressed in defining itself against an “other.” He also deals with the paradoxical desire on the part of the Orthodox community to create religious boundaries while maintaining ethnic ones—that is, to reject Reform Judaism while accepting the Reform Jews. With the Schiavo case I am exploring another paradox: how Orthodoxy rejects the dominant culture of secularism while using the tools of the state. The adherence to conservative political and religious forces is similar as stated by Katz to the differences between the challenges of Sabbateanism and the challenge of reform. Shabbatai Zevi was a challenge within the traditional framework while Reform, and Enlightenment, constituted a paradigm shift that rejected the nature of religious authority. (24–25)

non-Jewish authorities. As described in *halakhic* terms by Schachter (1984), “in the centuries of our Diaspora, one of the most difficult areas of adjustment has been in finding the proper mode of accommodating the rules of a secular or Christian society to a Torah *weltanschauung*” (85).⁷⁴ Schachter describes a type of continuum of relationship: on one end is “*dinah de’malchuta dinah*” (lit. “the law of the kingdom is *halakhic* law,” henceforth DDMD)⁷⁵ which rules that secular law is binding for Jews; at the other end is the prohibition against *mesirah*—handing over a Jew to gentile authorities for punishment.⁷⁶ The distinction in *Halakhah* is that DDMD applies to only financial matters while *mesirah* is over criminal matters,⁷⁷ but the distinction is at times hard to make and the underlying concepts—a key component in secularized discourse—are even harder, if not impossible, to distinguish.

The prohibition on *mesirah* should encourage a separation of church and state, yet Katz describes how at the beginning of the modern era, there was an appeal by the Orthodox to use government coercion to regain a semblance of the lost power of *herem* (a sentence akin to excommunication). For example, in 1819 Rabbi Raphael Cohen of Hamburg, as part of his tactics to prevent the establishment of a Reform temple, sent a letter to other rabbis in Europe: “The purpose of the letter was to evoke replies of condemnation which would force the [gentile] town senate to support the rabbinical court in its endeavor to forbid the functioning of the newly built temple” (1990:95). This might have been considered a form of the forbidden *mesirah*, but

⁷⁴ It is fascinating to connect this quote with the assertion of Katz that the third definition of secularism is marked by the fact that “the exponents of religion preferred to speak the language of *Weltanschauung* rather than of religion” (36). While Schachter’s selection of words could be serendipitous, I believe that the very randomness of the selection lends support to Katz’s assertion.

⁷⁵ See Shilo and Elon (2007) for more about this principle.

⁷⁶ See Broyde (2002) for a full treatment of the topic of *mesirah*, also available online: <http://www.jlaw.com/Articles/mesiralaw2.html>

⁷⁷ It is ironic that in the contemporary Orthodox community in the United States, there is a reversal of the prohibitions, with *haredi* support for the gentile government’s intrusion into personal matters in the moral realm, but a concomitant evasion of financial responsibilities, especially regarding tax payment.

instead it was perceived as a method to regain a lost—and legitimate—power of the Orthodox leadership.

A similar attempt of intervention in 1844 by Zvi Hirsch Lehren of Amsterdam, a call to traditional rabbis across Europe to oppose a Reform conference, was marked by a recognition that an appeal to the gentile authorities was at that point too dangerous: “[Lehren in his letter] did refer to the non-Jewish authorities, but not as a possible source of protection for Orthodoxy” (Katz 1990:102). Only in very specific areas—for example, circumcision—could the Orthodox hope for gentile intervention in intra-Jewish battles, and mainly because, as noted above, circumcision was considered the equivalent to Christian baptism (96).⁷⁸ While the gentile government allowed Jewish reform based on Enlightenment principles, they also recognized the need to maintain religious integrity: “Religious education and affiliation were still regarded as the only guarantee of political loyalty as well as juridical reliability” (Ibid.). The Orthodox rabbinate attempted to balance these two forces—their *halakhic* strength and the gentile laws—sometimes using the gentile power to uphold their own power and ideas, in whatever way they deemed viable. This appeal to secular gentile power described by Katz in the anecdotes recounted above was motivated, I believe, by the same impulse that motivates the contemporary American Orthodox community to blur the lines of church and state in the Schiavo case.

The association of the Orthodox, and principally the *haredi*, community with conservative political and religious groups could be an implicit “wag the dog” process related to what Tesh (1988) calls the “hidden arguments” of ideology behind policy. Tesh’s description of the underlying beliefs behind health policy brings to light the view that a policy can be held

⁷⁸ Katz describes how a Jew, resisting the demand to circumcise his son, avoided the punishment of the rabbis by choosing Baptism.

because of its incremental support for an ultimate goal, the philosophy of the end justifying the means writ large.

Tesh points out that in 19th-century America a debate raged about what caused disease and how to deal with medical issues. Many clergymen still preached that disease was caused by sin, which allowed religious condemnation of victims (17) and that epidemics could be countered by prayer along with “church attendance and pious thoughts” (20). On the other side, “anticlerical radicals” and other liberal groups called for “political democracy, universal education and the rights of the common man” (20), calls that stemmed from the belief that poverty and illness “sprang not from personal inadequacies but from economic conditions” (20). Not only did the clergy’s ideas of medical theory align them with conservative forces and against the radical groups focusing on economic conditions, but another faction arose regarding disease and health that Tesh calls “the personal behavior theory” (24). They advocated “the central political idea of modern times: the belief in individual freedom and autonomy.” As we see, this same 19th-century debate characterized the various positions in the Schiavo case: the religious right believed that one should not interfere in medical issues because to do so would go against God’s will, while the more liberal idea countered that individuals should have the power to control their own lives (25).

Because these ideas about God’s role in medical issues of disease and dying are similar among conservative religious groups of many denominations, we see in the United States that the *haredi* community becomes more vocal about their support of other religious groups that oppose euthanasia and abortion, or support “intelligent design” and the addition of the phrase “under God” to the Pledge of Allegiance—all issues commonly associated with the Christian right.

Schechter (2003), in his study of Jews in 18th-century France, sees the Jews as “an example of a marginal or peripheral group contesting, negotiating, and otherwise adjusting familiar descriptions of itself and in the process co-authoring, as it were, its own cultural text” (248). Today, the *haredi* position is to understand themselves, and the rest of the religious factions in America, as a persecuted group—possibly a minority, possibly the Nixon-esque “silent majority,” or at least a disempowered group vis-à-vis the liberal/secular medical culture. As a result, the discourse is oppositional, confrontational, and desperate. See as proof Toby Katz’s (2005) presumption of the “religious” as a group mocked by the majority culture.⁷⁹

Schechter uses Foucault, who in turn uses Nietzsche, to assert that (disempowered) minority groups can gain power through assimilation. On one side assimilation is overtly resisted by *haredi* rhetoric; on the other, it seems, the association with the powerful Christian conservative groups can actually confirm the powerful pull of assimilation even upon the *haredim*. The difference is to see political power not in the numeric terms of majority and minority, but in qualitative terms: who actually wields the power in society? So while *haredim* may resist church-state separation, which has been a hallmark of the Constitution and American culture for centuries, the resistance to this separation has inherent value for religious groups. The assimilation frequently leads to friendly relationships among incongruous individuals or groups, including historical enemies such as the hard-line Catholic church, or with the anti-Semitic Tzar, as shown above.

⁷⁹ Possibly this sense of desperation is forcing the *haredi* to become bedfellows with the Christian right and other conservative religious groups; it may also be why the legal overreach of the Schiavo took place during the most hegemonic years of 2004–2006, when Bush had won a second term (erasing the asterisk of the 2000 election), when the Republicans controlled both houses of Congress, the White House, and a majority on the Supreme Court. The two Supreme Court judges appointed by Bush were confirmed during that period, and they shifted the court even more to the religious (Catholic) right (especially through the replacement of the pro-choice Sandra Day O’Connor with the pro-life Samuel Alito).

Appeals to History

Katz recognizes that because of secularism, religion needed to rely more and more on the legitimacy afforded by history, which is implied by his use of the term “traditional.” However, this appears to also lead to the need to be *creative* with religion as well. As he writes, “If religion is no longer the mainspring or inspiration [for members of secular society] it is still part of the life of individuals and certainly of the group. But it has to rely, instead of on the vital impulse and creative impetus, on notions and symbols inherited from the past” (Katz 1986:47). This point is echoed by Ferziger’s understanding that the classic perspective of the Orthodox community. Only Orthodox adherents, he explains,

were the exclusive bearers of authentic Judaism as it had been lived in premodern, traditional society...[and] while external social and political realities had changed dramatically, and many alternative forms of Judaism had begun to be expressed, only the Orthodox had succeeded in insulating the true Judaism from these powerful influences.
(1)

Even though the current consensus in Jewish studies is to perceive Orthodox Judaism as itself a product of the Enlightenment, what is relevant for this discussion is the self-identity of the Orthodox community, as Ferziger describes:

Recent study of [Orthodox Judaism]...has focused on the ability to choose one’s form of religious expression, or the lack thereof, as a fundamental characteristic that distinguishes modern Jewish life from the “taken for grantedness” of traditional society. (Ibid.)

This use of a legitimizing past to provide the weight of tradition has been associated in recent Orthodox thought with the experience of the Holocaust, and it can explain the pervasive use of

Holocaust imagery in Orthodox discussions of the Schiavo case. Heilman's (2006) sociological study of contemporary Orthodoxy, with a special emphasis on *haredi* ideology, highlights the centrality of the Holocaust to *haredi* thought. First, one should consider the demographic point that there was a significant influx of Orthodox Jews into America as Holocaust survivors (Waxman 2007) and that a high percentage of these immigrants maintained their Orthodox denomination (Heilman 2006:16).

Second, and most salient for this paper, is the use of the Holocaust as a symbol of secular brutality. Rabbi Yitzak Hutner, "the postwar head of the major Orthodox Chaim Berlin Yeshiva in America" claimed that one lesson of the Holocaust was that "Jews were deluded into trust in the Gentiles by a series of laws and regulations in their behalf, only to have that trust shattered by the rescission of those very laws" (Heilman 2006:25). This reaction to the Holocaust is prevalent in memory and discourse: appeals to secularism could be repudiated by waving the bloody shirt of the destruction.

Heilman also demonstrates that the Holocaust was used as support for the increasing insistence on religious restrictions as a sign of the resistance of secular society:

"As surviving witnesses we are charged with an awesome responsibility" one Orthodox writer stated in the *Jewish Observer*. . . . That responsibility was not only to hold onto traditional beliefs and maintain an uncompromising ideological commitment to an invigorated Orthodoxy as part of the consciousness of the *churban* [lit. "destruction," meaning the Holocaust]. For many Orthodox Jews, it meant also joining an ideological battle, which was best won by becoming *even more* punctilious in religious and ritual practices to slow down the inevitable decline and corrosion of Judaism that modern life had wrought. (30)

This insight of Heilman not only explains what he calls the "sliding to the right" of Orthodox society, but the centrality of the Holocaust to the rationale for the outlook of stringency and, by

extension, the resistance to secular brutality as the ultimate goal. While Ferziger and Katz understand Orthodoxy as a modern movement similar to the Reform movement, I would claim, using Heilman's analysis, that while the formation was modern, the ideas and impulse constitute an appeal to a pre-modern state, in which denominations did not exist, and in which the religious government ruled over the *kehillah*. By chronological fact, Orthodoxy is modern—but its idea system maintains the hallmarks of the earlier paradigm—a circumstance widely recognized within the Orthodox community itself.

Understanding Jewish Memory

The Orthodox use of Nazi imagery in the Schiavo case fits Yerushalmi's (1996) notion of traditional Jewish memory as cyclical; current events are identified and defined by the categories of the past, in what Bahloul (1996) understands as the "social production" of memory (125). Bahloul explicitly states that "The relation of the vast majority of contemporary Jews to their past is marked by the experiences of genocide or emigration or both" (125). I would argue then that the discursive process described by Bahloul as pertaining to memory is actually a process of active living, as the Schiavo case shows.⁸⁰

Bahloul writes that "memory is a narrative art" (127), an idea that can explain the distortions of the facts of the Schiavo case among Orthodox critics as seen in the above examples. The narrative they needed to construct suggested that what they saw as state-mandated euthanasia would lead to Nazism. This narrative is part of the "social dimension of memory"

⁸⁰ This perpetual anxiety of the Jewish community as eternal victims, seen as a hallmark of Orthodox Judaism by Heilman, also supports the anti-Zionist trend in *haredi* philosophy which is an argument against self-determination as well as against autonomy.

(127), since the same facts can be used by either side of the partisan divide. For example, Michael Schiavo, in allowing Terri to be euthanized, was depicted as a shallow eugenicist using secular ethics, which Boteach (among others) identified as the source of Nazism; its instrumental, utilitarian view of life apparently denied holiness in favor of usefulness. In the other view, the established law of Florida, and ethics codified by the AMA and ABA, stated that personal autonomy allowed the removal of care.

The linchpin of the religious opposition to Michael Schiavo was to reinterpret his behavior as hating Terri—and life—so much that he was willing to stay married to her (despite having children with another woman with whom he continued to cohabit) in order to maintain the ability to kill her. Michael's financial benefit was widely evoked as well, but it did not seem enough. The idea that a person would hate life so much is seen as plausible by the secular rejectionists only in relation to the image of Nazism.

Furthermore, the very notion of a “slippery slope” (in which the ethics of the United States lead inevitably in the direction of the Nazis, the Netherlands, or as part of opposition to the erosion of church and state) constitutes an appeal to historical precedent. It is ironic that Schindler supporters would use Nazi imagery as evidence of the slippery slope, since the unprecedented intervention of the federal government in the individual medical case is an imposition of religious law onto secular law—more of a hallmark of totalitarianism than the reverse.

In the Schiavo case the *haredi* community, in allying itself with the government and with other right-leaning religious groups, found itself in strange company indeed. It is worth noting that the parents of Terri Schiavo were represented by a notoriously anti-Semitic lawyer. According to the Southern Poverty Law Center (Potok 2006),

The [radical traditionalist Catholic] movement also may be gaining influence on the larger political scene. A case in point is that of Christopher Ferrara, leader of the American Catholic Lawyers Association. Ferrara, who writes for the anti-Semitic, radical traditionalist journal *The Remnant*, was the lawyer for the family of Terri Schiavo and a key player, along with Republican and Christian Right leaders, in getting Congress to pass a law to keep the severely brain-damaged woman alive. It was later overturned.

Indeed, at least one Orthodox family found itself in trouble following the Schiavo case, precisely because the family's individual autonomy was not respected. This was the case of Motl Brody, which I address in Chapter Four.⁸¹

Conclusion

The case of Terri Schiavo, while widely remembered as a case involving medical ethics, was actually unremarkable in that arena. Rather, the most notable aspect of the case was the intervention of the American government into a private family case and the imposition of religious principles under the guise of secular Enlightenment-based ideals. This attempted dissolution of the line between church and state was supported by voices within the American Orthodox Jewish community, primarily from the *haredi* community. The reason for their support for the dissolution of church and state separation, as well as their alliance with political and

⁸¹ In the case of Motl Brody, a young boy who became brain-dead, the hospital came into conflict with the boy's Orthodox parents, who adhered to the Orthodox view that brain-death does not constitute *halakhic* death, and therefore wanted to maintain their son's care. As reported on MSNBC, "The hospital said it would help the family move what [the hospital] called the boy's 'earthly remains' to another medical facility, but has found none willing to accept a brain-dead child" (MSNBC 2008). In this case, the parents weren't necessarily expecting a miracle cure, but were restricted by religious beliefs from removing care. Yet, "Arthur Caplan, a professor of bioethics at the University of Pennsylvania, said physicians aren't obligated to provide care that can't possibly be medically helpful. 'Doctors are well within their rights to say, 'We are stopping,'" he said. 'I don't think medicine can become subservient to religious, spiritual or mystical hopes and beliefs concerning how to manage death'" (MSNBC 2008).

religious conservatives and their use of Nazi imagery, as I have argued, is part of the mission of Orthodox Jewish ideology to reverse the secularization of the Enlightenment and regain the ability to create a religious environment more in line with the pre-modern *kehillah*. The actions and attitudes demonstrated in the Schiavo case by the American Orthodox and *haredi* communities are consistent with their struggle over the past few hundred years in the Western World.

Chapter Three

Brain Stem Death (BSD): Definitions and Conflicts

As a case involving a patient in a Persistent Vegetative State (PVS), the case of Terri Schiavo presented little ambiguity in the medical status of the patient. Notwithstanding the controversy surrounding the case described in Chapter Two, both medical and *halakhic* authorities agreed that she was alive; the ambiguity in the case involved the authority of her husband, acting, as he said, on her behalf, to remove her care.

Compared to PVS cases, those involving Brain Stem Death (BSD) are considerably more complex. Whereas laws in all 50 states define BSD as death, and most medical practitioners in the United States today likewise follow this definition, most Orthodox *poskim* adhere to the definition of death as stoppage of the heart. Therefore, BSD cases find Orthodox authorities and many laypeople who identify as Orthodox in conflict with the prevailing scientific and legal definition of death.

In Chapter Four I will present cases involving BSD—most important among these being those of Mordechai Brody and the anonymous case described by Smith and Flamm—and offer an explanation of the fraught discourse around them. First, however, it will be helpful to consider in detail the complex issues that attend the definition of death in these contexts. To this end, the present chapter offers a close analysis of the report of a presidential commission tasked with addressing the definition of death, entitled *Defining Death: A Report on the Medical, Legal and*

Ethical Issues in the Determination of Death, written in 1981, and referred to hereafter as the “1981 Presidential Commission’s Report” or the “Commission Report.” Subsequently, I present the views of Orthodox rabbinic authorities that stand in contrast to the Commission. My discussion of Mordechai Brody and related cases in Chapter Four will draw on these definitions, explaining how the principles of each side were applied by the patients’ families, the medical practitioners in the hospital, and numerous factions within the Orthodox Jewish community, who expressed themselves in both formal and informal written forums.

The 1981 Presidential Commission’s Report on the Definition of Death

Advances in medical technology over the past century have had the benefit of prolonging life for many individuals suffering from conditions that, in former eras, would have caused an early and immediate death. But just as medical technology has extended life, it has also extended the process of dying. The moment of death can be difficult to determine precisely, and it may depend on socially constructed ideas of death even more than any objectively measurable, biological consideration.⁸² Because of this extension of the process of dying, medical advances have raised issues concerning the definition of death from religious standpoints. Indeed, the issue of the prolongation of dying is treated seriously in both secular and Jewish ethics.⁸³

⁸² See James L. Bernat, Charles M. Culver, and Bernard Gert, the authors of “Defining Death in Theory and Practice”

(http://www2.sunysuffolk.edu/pecorip/SCCCWEB/ETEXTS/DeathandDying_TEXT/Bernat_Culver_Gert.htm)

⁸³ This question of the prolongation of dying has been a subject of concern for *halakhic* thinkers going as far back as the time of the Talmud. The Talmudic concept that serves as one basis for the modern understanding of prolongation of dying is the category of *goses* (“a halakhic term that describes the terminal patient in the last stages of life” [Steinberg 2003:1046]). In its simple Talmudic form the *goses* is not a practical concept in the 21st century. However, since the *halakhic* process is constitutionally dependent on precedent and citation of the earliest possible sources, the current ambiguity of the definition of *goses* in modern medicine leads to fundamental disagreement among modern *poskim*.

Within American law and medical practice, the standard of BSD as death was established by the 1981 Presidential Commission's Report. Since this document is so important to the definitions of death, I believe it is essential to understand not only its conclusions, but also the concerns that the authors expressed regarding their attempt to deal with the way new technology impacted on the idea of death.

The Commission's Report was produced by a group appointed to study the topic. The commission was chaired by Morris B. Abram, a lawyer who had been at the International Military Tribunal at Nuremberg and went on to a distinguished career as civil rights advocate and Jewish communal leader.⁸⁴ As stated on page 1 of the report,

In performing its mandate, the Commission has reached conclusions on a series of questions which are the subject of this Report. In summary, the central conclusions are:

1. That recent developments in medical treatment necessitate a restatement of the standards traditionally recognized for determining that death has occurred....

The question of prolonging death in Orthodox Judaism is a *halakhic* question based on a metaphysical notion that the soul of a moribund patient—generally interpreted as a *goses*—is in pain, being suspended between the physical world and the afterlife. The longer the process of dying occurs, the greater the spiritual pain. Certainly the question of whether a person needs to live in pain is an important one. Are Jews required to do everything to maintain a life despite suffering? Although this question intersects with some of the issues in this dissertation, it lies beyond the scope of the present study. However, a brief overview is possible here:

The category of *goses*, obvious to previous generations, is under debate in contemporary *Halakhah* due to the radically different medical and scientific landscape. The most explicit type of description of *gesisa* is still an aggadic type of analogy to a flickering candle, with which Jewish tradition associates the human soul, and the state of the *goses* was equated with the sputtering candle.

There is a Jewish law against murder; there is also a law against “standing idly by” while a person is in danger. The case of the *goses* is the fulcrum where the balance between these two principles comes into play. Onlookers recognize that a *goses* is suffering, and thus, deserves to not have his suffering prolonged. However, as certain types of intervention are deemed equivalent to the snuffing out of the candle, and thus, tantamount to murder. For that reason, a delicate evaluation of the serious competing principles is necessary.

A *goses* can be placed into the larger category of the conflict between preserving life in suffering vs. allowing a suffering person to die. Active euthanasia is a possibility under certain circumstances in Jewish tradition, but has generally not been an accepted virtue in recent centuries (see Chapter One). All accepted measures for treating a *goses* are passive and indirect.

⁸⁴ According to his obituary in the *New York Times* (Honan 2000) among his other accomplishments, Abram had also served as the national president of the American Jewish Committee from 1963 to 1968 and chairman of the National Conference on Soviet Jewry. He was President of Brandeis University, 1968–70.

6. That death is a unitary phenomenon which can be accurately demonstrated either on the traditional grounds of irreversible cessation of heart and lung functions or on the basis of irreversible loss of all functions of the entire brain.

7. That any statutory “definition” should be kept separate and distinct from provisions governing the donation of cadaver organs and from any legal rules on decisions to terminate life-sustaining treatment. (p. 1)

Point 1 makes clear that the need for this definition of death derives from medical advances—later specifically identified as the effectiveness of ventilators—and not from a desire to increase organ donation, as emphasized as well in point 7.

Point 6 is even more important: the Commission recognized death as a single (“unitary”) phenomenon, which can be demonstrated in a variety of biologic ways. Brain stem death (BSD) is in reality no different from cardiac death—cardiac criteria and brain-based criteria are, according to the Commission, simply two means of measuring the same phenomenon of death. As the report explains, the respirator (ventilator) *masks* the death of a patient that would, without the respirator, be apparent through the cessation of the heart. The report states,

Prior to the advent of current technology, breathing ceased and death was obvious. Now, however, certain organic processes in these bodies can be maintained through artificial means, although they will never recover the capacity for spontaneous breathing or sustained integration of bodily functions, for consciousness, or for other human experiences. (3)

This statement might be read as suggesting that the definition of death is being qualified, especially through the introduction of the notion of “human experience”; however, I believe these are mere elaborations of the definition of “death.” It is significant that in modern medical circumstances, death is so ambiguous as to require social definition.

The Commission Report expands on this notion further in its elucidation of the relationship among the heart, lungs, and brain. In the authors' view, these three components are essentially interrelated, and in past medical eras the stoppage of one would have led nearly immediately to the stoppage of the other two. This circumstance has changed, however, due to the changes in medical technology. I quote at length:

Three organs—the heart, lungs and brain—assume special significance, however, because their interrelationship is very close and the irreversible cessation of any one very quickly stops the other two and consequently halts the integrated functioning of the organism as a whole. Because they were easily measured, circulation and respiration were traditionally the basic “vital signs.” But breathing and heartbeat are not life itself. They are simply used as signs—as one window for viewing a deeper and more complex reality: a triangle of interrelated systems with the brain at its apex. As the biomedical scientists who appeared before the Commission made clear, **the traditional means of diagnosing death actually detected an irreversible cessation of integrated functioning among the interdependent bodily systems. When artificial means of support mask this loss of integration as measured by the old methods, brain-oriented criteria and tests provide a new window on the same phenomenon.**

In this view, **death is that moment at which the body's physiological system ceases to constitute an integrated whole. Even if life continues in individual cells or organs, life of the organism as a whole requires complex integration, and without the latter, a person cannot properly be regarded as alive.**

This distinction between systemic, integrated functioning and physiological activity in cells or individual organs is important for two reasons. First, a person is considered dead under this concept even if oxygenation and metabolism persist in some cells or organs. There would be no need to wait until all metabolism had ceased in every body part before recognizing that death has occurred.

More importantly, this concept would reduce the significance of continued respiration and heartbeat for the definition of death. This view holds that continued breathing and circulation are not in themselves tantamount to life. Since life is a matter of integrating the functioning of major organ systems, breathing and circulation are necessary but not sufficient to establish that an individual is alive. **When an individual's breathing and circulation lack neurologic integration, he or she is dead. (33)**

Human death has ramifications for society that rise beyond mere biology. From the standpoint of objective biology, without human input, death does not require precise definition any more than a marriage certificate is needed for mating. Without the anthropic principle, defining the world through the values of humanity, the scientific facts that regularly enjoy a patina of objectivity, become social constructs along with every aspect of human culture. Indeed, as the Commission Report notes, a distinction must be made—to some extent a subjective one—between the absence of brain activity and death:

Death has been established when “all functions of the brain have permanently and irreversibly ceased.” In measuring *functions*, physicians are not concerned with mere *activity* in cells or groups of cells if such activity (metabolic, electrical, etc.) is not manifested in some way that has significance for the organism as a whole. The same is true of the cells of the heart and lungs; they too may continue to have metabolic and electrical activity after death has been diagnosed by cardiopulmonary standards. [emphasis in original] (28–29)

The Commission Report points out some of the illogicality involved in a definition of death based on cardiac arrest given modern medical circumstances—here the medical circumstance alluded to is heart transplant:

Furthermore, other changes in medical abilities have contributed to the concern about the “definition” of death. For example, the importance customarily accorded to a person’s beating heart in differentiating the living from the dead is challenged when a “dead” person’s heart can beat in the chest of a “living” person whose own heart has not merely stopped but has been removed from his or her body.” (4)

The Commission Report offers us a key description of the science involved in these cases:

Unlike the respiratory system, which depends on the neural impulses from the brain, the heart can pump blood without external control. Impulses from brain centers modulate the inherent rate and force of the heartbeat but are not required for the heart to contract at a level of function that is ordinarily adequate. Thus, when artificial respiration provides adequate oxygenation and associated medical treatments regulate essential plasma components and blood pressure, an intact heart will continue to beat, despite loss of brain functions” (16).

The Commission notes that “Traditionally, the cessation of heartbeat and of breathing were regarded by the lay and medical communities alike as the definitive signs of death” (5). It is also noted that “the brain cannot regenerate neural cells to replace ones that have permanently stopped metabolizing. Hence, longer periods without blood flow (ischemia) or oxygen (anoxia) may cause complete and irreversible loss of all brain functions” (5).

These observations form part of a larger point: despite all the advances in medical technology, brain replacement and even some neural replacement are still impossible. Modern medicine cannot yet repair the spinal cord or transplant a brain, as it can a heart or other organs. This singularity of the brain has been used by a number of advocates to emphasize the unique importance of the brain for personhood. What a ventilator *can* do is keep the brain oxygenated during a cardiac arrest or a heart transplant. Thus even when the heart stops, modern medicine may still see the patient as alive, as long as the brain continues to function. The reverse is not true. From this perspective, the heart works for the brain, which in turn works for the “person.” Without a ventilator, the brain’s destruction would result in a cessation of regulation of the heart

and lungs—and indeed, this was the universal understanding of human death prior to the invention of the ventilator.

In cases where the ventilator keeps the brain oxygenated during cardiac arrest, the ventilator acts as the brain stem. Moreover, from the perspective of the Commission, BSD constitutes death because the body is designed to keep the brain alive. This is because modern medicine does not consider living cells to be the full definition of a living person. The intention of the body's system, the authors of the Commission Report argue, is to enable the brain to control that body's functions – so that taken together they constitute an organic living whole. When that ability is lost through the destruction of the brain stem, death has occurred, despite the enduring presence of living cells within the body and even within the brain.

All 50 of the United States apply this definition of BSD as death, and the only opposition comes from the belief that the brain does not matter, as life is determined by heartbeat alone. This opposition is thus not scientific, but cultural. For those who do not adhere to a tradition of heartbeat equaling life, there would be no reason to dispute the brain death definition.⁸⁵

Given the sensationalism over BSD cases, it is important to know that ventilators were invented only for genuine medical need: “Medical interventions can often provide great benefit in avoiding irreversible harm to a patient’s injured heart, lungs, or brain by carrying a patient through a period of acute need” (18). Many ethicists advocate careful, measured application of the ventilator, such that it not be applied without a plan of medical care that sees the ventilator being eventually removed as part of the treatment.

⁸⁵ The only other rationales for disputing the definition of BSD as death would derive from (1) concern about the reliability of testing for BSD, and (2) the popular mistranslation of irreversible coma or PVS as “brain dead.” PVS is a form of brain death, but not *brain stem death*, or as it is also called, “whole-brain death.”

To summarize, the Commission Report acknowledges that the determination of death is a subjective and culturally contingent phenomenon. However, given modern science, the necessity arose for new criteria in the determination of death. As the report states,

Thus, brain-based criteria do not introduce a new “kind of death,” but rather reinforce the concept of death as a single phenomenon—the collapse of psycho-physical integrity. The statute merely allows new ways to recognize that this phenomenon has occurred....The death of a human being—not the ‘death’ of cells, tissues or organs—is the matter at issue. The cessation of vital bodily systems provides the basis for broad standards by which death can be judged to have occurred....What was formerly a person is now a dead body and can be socially and legally treated as such. (58)

Is death a biological concept, as averred by Bernat et al⁸⁶? Although it has a basis in biology, the marking of the moment of death is a social concept. As the Commission repeatedly states, there is a distinction between the death of cells and the death of an organism. A living person can have dead portions (as in a case of gangrene), while a corpse can have some living portions—but all of this occurs at the cellular level. To paraphrase Socrates, a human being is a political animal, and when society determines the life and/or death of an individual, the definition rests on the importance of the individual in society. This may sound like philosophy, and it is; as stated above, even aspects of science are socially constructed.

⁸⁶ James L. Bernat, Charles M. Culver, and Bernard Gert, the authors of “Defining Death in Theory and Practice” (http://www2.sunysuffolk.edu/pecorip/SCCCWEB/ETEXTS/DeathandDying_TEXT/Bernat_Culver_Gert.htm)

Bleich's Opposition to BSD as a Definition of Death

With near complete unanimity, Orthodox *poskim* define death as occurring at cardiac arrest exclusively, and *not* with Brain Stem Death.⁸⁷ The one dissenting opinion is that of Rabbi Moshe Dovid Tendler, who along with his mentor and father-in-law, Rabbi Moshe Feinstein, accepted BSD as death. However, Tendler's position has not gained widespread acceptance. The position of Tendler contrasts with that held by Rabbi J. David Bleich, and, more recently, Rabbi Yitzchok Breitowitz, exhibiting differences that bring out some of the key issues in the most widely accepted Orthodox Jewish position. It is worth noting that both Tendler and Bleich were members of the 1981 Presidential Commission. Their understanding of death is rooted not in a commonsensical 'intuition' or in objective observation of biological phenomena, but in the *halakhic* tradition. Their lay followers, who, as I will show in Chapter Four, do not always grasp the full complexities of the science involved, therefore approach the idea of death from a different standpoint from that of the authors of the Commission Report. This difference in approach helps to explain why their position is so irreconcilable with the position of the 1981 Presidential Commission.

⁸⁷ For example, in 2010 many prominent members of the Rabbinical Council of America attempted to overturn that organization's long standing, yet minority, decision to accept BDS as death. The acceptance came through the efforts of Moshe D. Tendler via his father-in-law, Moshe Feinstein. This act of resistance exposed the deep rift in Modern Orthodoxy over the issue of brain-death, and the extent of the majority-minority split (see Ain (2010) and RCA (2010)). For more about the rest of the Orthodox world, aside from the cases in the next two chapters, see Abraham (2004a, 200b), Ain (2010), Baeke et. al. (2011a, 2011b), Bard (2007), Bleich (2006, 1998, 1991), Bosek (2007a, 2007b), Breitowitz (2008a, 2008b, 1992), Clarfield et. al. (2003), Dorff (2005, 1998), Falk (1998, 1994-5), Feldman (2006), Flancbaum (2001), Gesundheit et. al. (2006), Gray (2009), Grodin (1994), Halperin et. al. (2004), Hurwitz et. al. (2006), Ifrah (1992), Kunin (2004), Meier (1991, 1980), Moses (2011), Nevins (2004), Rastogi (2008), Ravitsky (2009, 2005), Reichman (2004), Resnicoff (2006), Rosner (2006, 2005, 2001, 1993), Rosner and Schulman (2005), Schostak (2003, 1991), Shabtai (2008), Shulman (1998), Sinclair (2009, 1994, 1992, 1989), Sokol (1988), Steinberg ed. (2003), Steinberg and Waldenberg (1980), Tatz (2010), Weiner (1995), Weisen ed. (2009), and Zweibel (1991).

Bleich has become the chief rabbinic spokesperson for the perspective that BSD does not constitute death. The basis for his position may be summarized as follows:

- 1) In Bleich's view, every second of human life must be preserved, since it is of infinite value. In this view, such a position is divine law and is not subject to change through logical argumentation. Factors such as quality of life or the desire of the patient to continue living are not considered.
- 2) The heart is the seat of life as defined by divine rule, and the brain is irrelevant except in cases of decapitation (though that, too, is a result of a divine rule).
- 3) Resuscitation is necessary, for to refuse resuscitation is tantamount to suicide/homicide. (Bleich 1998:72)

When applied to cases of BSD, these three rules result in the extreme situation that requires a BSD patient on a ventilator to be given CPR in the case of cardiac arrest.

Noam Stadlan (2011) has critiqued Bleich's position that only cardiac death constitutes death. Stadlan notes that if a patient receives a new heart, the new heart does not form a new person. Moreover, Stadlan employs Bleich's position on conjoined twins against him, for Bleich claims, for example in the 1977 case (to be discussed below in Chapter Five), that two brains connected to one heart nevertheless indicate the presence of two separate individuals. In this case, clearly, Bleich views the brain as the seat of the identity: it is the nervous system, not the circulatory system, that he sees as the definition of personhood.

Indeed, the objections that Stadlan raises to Bleich's understanding are similar to those that sparked the formation of the Presidential Commission in the first place. The ability of modern medicine to perform heart transplants, keeping the brain alive by means of artificial respirators, prompted the need for a redefinition of death according to brain-based criteria.

However, for those who maintain that Jewish tradition unequivocally asserts that the heartbeat is the sole criterion of the definition of human life, denying the patient access to the respirator or other artificial means of stimulating the heart would constitute an unacceptable act of withholding care.⁸⁸ There are *poskim* who suggest that care can be withheld in certain cases—for example, if the ventilator is connected to a timer that requires it to be reactivated at certain intervals. Ventilators with timers would be acceptable to almost all Orthodox authorities.⁸⁹

The Commission cites Bleich’s writings on the subject of cardiac death as its source for the position of cardiac death exclusively as death. Yet the Commission’s description is different from the traditional way in which the Orthodox Jewish literature has described cardiac death.

Bleich describes his own conception of death as a continuation of the western world’s conception of death; he holds that his view preserves the cultural accepted and authoritative definition of death as contingent on cardiac arrest. His understanding is thus in direct competition with that of the Commission, which for its part considers *brain death* to be a faithful continuation of the same cultural tradition that Bleich makes claim to. As a result, the Commission depicts Bleich as upholding a strange, unrecognizable, and inconsistent position. As the report states,

⁸⁸ This extreme position on the value of human life resonates with the Babylonian Talmud, Tractate Yoma 85a, which explains that if a person is buried in rubble, others must rescue him or her even doing so would violate the rules of the Sabbath. This situation is akin to the paradox of Schrödinger’s cat: the rescuers do not know if the person is alive under the rubble, but they are permitted to violate the Sabbath even for the potential of saving a human life. The Talmud emphasizes that even if some bodies are found dead, the rescuers must continue digging rather than assume that others buried under the rubble are also dead. Upon discovering a body, the Gemara commands that the person be examined for signs of life, and much of the modern debate is over how these signs should be interpreted in contemporary medicine. For our purposes it is enough to know that the Talmud understands the ambiguity related to this enterprise of rescue.

To build on the analogy of the Commission, the ventilator may be seen as a pile of rubble that is covering the body and obscuring its status as alive or dead. The Commission recognized this ambiguity and created in effect a new way to determine life when the status of the body is being obscured.

⁸⁹ It would be acceptable to all authorities except those who similarly reject “do-not-resuscitate” (DNR) directives.

The various physiological concepts of death so far discussed rely in some fashion on brain functioning. By contrast, a literal reading of the traditional cardiopulmonary criteria would require **cessation of the flow of bodily ‘fluids,’ including air and blood**, for death to be declared. This standard is meant to apply **whether or not these flows coincide with any other bodily processes, neurological or otherwise**. Its support derives from interpretations of religious literature and cultural practices of certain religious and ethnic groups, including some Orthodox Jews and Native Americans. (41) (Emphasis mine)

According to the Commission, Bleich believes in a fluids-based definition of death—that death occurs only when the fluids stop in the body. Yet this is not the way Bleich describes his own position. In fact, the fluids are not the focus—the heart is. Why this inconsistency? Without brain stem function, the Commission holds that the only function of a heart is to circulate fluid. Indeed, as the report grimly notes, “The flow of bodily fluids could **conceivably** be maintained by machines in the absence of almost all other life processes; the result would be viewed by most as a **perfused corpse**, totally unresponsive to its environment” (p. 42, emphasis mine). As I will show in the following chapter, this image of the corpse perfused with fluids is precisely how the caregiving hospital viewed the request of the family of Mordechai Brody that their son be kept on the ventilator despite the onset of BSD.

The Position of Tendler

Moshe Dovid Tendler, who accepts BSD as death and is himself a trained biologist, follows his father-in-law, Moshe Feinstein, in describing brain death as a form of decapitation, and this too, conforms to ancient understandings that a decapitation will result in instant death despite the heart continuing to beat and, in some cases, the body moving. Brain death can thus be

seen as a form of “intact” decapitation. The Commission does use the concept of decapitation, citing Tendler (11), but also in their own words, seeing this as an explanatory model: “hypothetical of a decapitated body treated so as to prevent the outpouring of blood and to generate respiration: continuation of bodily functions in that case would not have restored the requisites of human life.” (36)

Although Tendler’s analogy to decapitation was at first seen as useful by some authorities, recent scientific data on brain-dead bodies shows that decapitation does not constitute an apt model (Kunin 2004). As explained in a response to Kunin, Reichman (2004) asserts that Feinstein’s acceptance of BSD was never meant to rely on decapitation for its model; rather, it relies on the absence of the brain’s ability to induce spontaneous respiration. Reichman shows that this was the original reasoning of Feinstein, so his position on BSD is not affected by the new data.

Interestingly, like the Commission and like Bleich, Tendler justifies his position on BSD by claiming adherence to an older tradition on the understanding of death: “A consensus is emerging among most rabbanim who are able to comprehend both the physiological facts and the halakhic analysis, that **brain death has always been accepted as halakhic death by Torah authorities**” (1990, p. 6, col. 1).⁹⁰

Tendler’s description of BSD closely echoes that of the 1981 Commission which in a *halakhic* sense renders that scientific text into a *halakhic* one. He writes,

⁹⁰ In this context, Tendler explains why, in 1968, he had opposed organ donation: “From the bio-medical point of view, the most important distinction that must be made when considering the entire issue of death is the distinction between ‘brain death’ and ‘cerebral death.’ I wrote the first article in 1968 (*Tradition*, Vol. 9, No. 4), accusing Dr. Christian Barnard of committing double murder, and the reason I did so was *at that time* Barnard was not only performing an experimental operation which hastened the death of his recipients, but also because he was dealing with donors who were cerebrally dead as opposed to brain dead. Cerebral death is not death according to Jewish law” (p. 6, col. 1–2). Cerebral death is what we now call PVS.

Organismic death refers to the breakdown of the two systems that are integral to a human being; the neural system and the hormonal or endocrine system. When these systems break down, one part of the body doesn't know what the other parts of the body are doing. In addition, there is no ability to breathe autonomically. This is organismic/brain death. I could take such an organismically dead or "brain" dead body, remove the heart and keep it alive for years, or take out the lungs or kidneys and keep them alive in a perfusion system for days, and have each of these organs separated in different rooms in the hospital. This would be no different than a brain dead patient except for the fact that in the latter case the skin would be connecting all of the organs together. Once an individual is brain dead, we have an "organ system," not a living organism. Our language is confusing here because sometimes physicians speak loosely of having a brain dead person on a "life support" system. But this, of course, is a misnomer: the patient is *dead*, and what we have him on is an organ perfusion system. **When the body loses its integrative capacity, the patient has died.** (p.6, col. 2; bold mine)

Tendler is adamant in his opposition to the method and thinking of Bleich, who was also on the 1981 Presidential Commission:

Rabbi J. David Bleich (*The Jewish Review*, Vol. 3, No. 2) accuses the Israeli Rabbinate of relying on respiration as the sole criterion of death, and he argues on this basis that it would be consistent for them to declare a polio victim dead. Such an individual cannot, and will never, Rabbi Bleich points out, breathe on his own. But for that matter, a person who has a pacemaker could be declared dead by cardiac criteria. All this proves is that death is never determined by breathing or heart-beat. The fact that a polio patient cannot breathe, but is yet alive, is based precisely on the fact that he is an organized system. Indeed it is based on the fact that he has a functioning brain. The question isn't whether a person can or cannot breathe, but only *why* he can't breathe. Why can a fellow who is under debris and not breathing be declared dead? Because the brain died. Otherwise we would have an obligation to try to revive him using C.P.R. And what does C.P.R. do? Bring a person back to life? No! C.P.R. is effective only when the brain has not died; it is only when C.P.R. does not work that the patient is, indeed, dead. In such an instance, the individual suffers from an irreversible respiratory failure which stems from an irreversible cause, the death of the brain. Brain death is the finest criterion of death, according to halakha, precisely because the classic criteria of irreversible respiratory and cardiac arrest are dependent upon the death of the brain. (p.7, col. 1)

The Position of Breitowitz

Breitowitz (1992a) claims, “The purpose of this article is not to take sides nor in any way resolve the halachic debate” (p. 61 col 2). Yet despite his protestations of objectivity, Breitowitz demonstrates that he is firmly against acceptance of BSD as death. This is seen through his description of the cases—an endeavor which requires acceptance of one or the other position. Those who oppose the BSD definition are either dominated by the frightening nature of error in these situations, or by the cognizance of the difficulty in the clarity of the sources for cardiac death, or by the newness and counter-intuitive nature of determination of BSD.

Breitowitz’s mistrust of the medical system is exemplified in his rhetoric. Fearful, apparently, that patients will be killed prematurely in order that their organs may be harvested, he writes, “First, moving the time of death to an earlier point facilitates organ transplants, and indeed makes such transplants possible” (1992a, 61 col3). In the eyes of the Commission, it is unintelligible to use the term “moving the time of death to an earlier point.” There is no “earlier point” to their understanding: this is the same time as death would be without a ventilator. In this sentence Breitowitz demonstrates his acceptance of the Bleichian formula that sees Brain Death as a premature declaration. He emphasizes organ donation as a sign of what he sees as the mercenary goals of the medical establishment.

Even if the Commission is disingenuous in its adamant disavowal of organ donation as an impetus in the recognition of BSD, the emphasis of this ulterior motive as the first reason for BSD tips Breitowitz’s hand. This reading of Breitowitz is confirmed by what he perceives as suspicious motivations from the medical establishment: “Given the increasing success of these

operations and the relative uselessness (from a secular standpoint!) of sustaining ‘brain dead’ patients on respirators, there is a natural temptation to redefine death so that organs become available to serve higher ends” (1992a, 61, col. 3–63, col. 1). Putting “brain death” in quotation marks, as he does, also contributes to the conclusion of bias on the part of the author.

The other two reasons Breitowitz gives for the introduction of BSD as a definition of death are “triage and allocation of scarce medical resources” (1992a, 63, col. 1) and “an understandable desire to spare families the agony and anguish of watching a loved one experience a protracted death.” Like organ harvesting, these other two reasons would seem to constitute ulterior motives on the part of the Commission and the general medical community. Breitowitz cannot see the acceptance of BSD as anything but a ploy.

In his interpretation of the writings of Feinstein (which he treats separately from those of Tendler), Breitowitz again interprets sources to reject BSD as the definition of death. Feinstein’s 1976 letter to the New York State Assembly about a “time of death” law states, “The sole criterion of death is the total cessation of spontaneous respiration.” This statement seems like a clear statement in support of BSD as death. However, the next paragraph in Feinstein’s letter states: “In a patient presenting the clinical picture of death, i.e., no signs of life such as movement or response to stimuli, the total cessation of independent respiration is an absolute proof that death has occurred.” This sentence seems necessary to clarify that first stage: before applying the tests for BSD, the patient must actually appear as a candidate for death—she or he must be unresponsive, for example. However, this is not how Breitowitz reads that sentence: “In other words, absence of respiration is a necessary confirmation of death only when coupled with absence of other vital signs. **Arguably**, heartbeat and circulation may be precisely the type of vital sign that prevents absence of breathing from being determinative.” (1992b, p.79, col. 2,

emphasis mine). This, however, is not the most straightforward reading of Feinstein's words. It seems likely that, consciously or not, Breitowitz expected to find this prefigured meaning in the letter.⁹¹

The Commission Report: Acknowledgement of Nuances and Differences of Opinion

The difficulties of interpretation of BSD are acknowledged in the 1981 Commission Report. The authors of the report took pains to explain the complexities of BSD; the members of that commission acknowledged the difficulty of accepting brain death, and they took pains to respect that difficulty and educate their readers. This effort at accommodation, as I will show in Chapter Four, is largely absent in more recent literature; it deserves comment because there is a need for the two sides to understand one another. Both sides, as the Commission acknowledged, see their position as a continuation of earlier understandings of the nature of death.

Popular terminology confuses the categories of "brain death" "brain stem death," "higher brain death," "PVS," and "coma," melding all of these categories. This circumstance, I believe, has produced a great deal of controversy among laypeople. Anecdotes about brain-dead patients regaining consciousness and full health are likely the result of bad definitions, which contribute

⁹¹ Breitowitz describes the experiment done at the request of Shlomo Zalman Auerbach: "The Talmud in *Archin* posits that a fetus cannot survive its mother's death. Since BSD patients can carry babies to term, **it was thought that this alone was conclusive proof** that BSD patients were *halachically alive*. To test this hypothesis, an experiment was performed at R. Auerbach's request, whereby a pregnant sheep was decapitated and hooked up to a respirator. Heartbeat and blood pressure were maintained and a live lamb was successfully delivered by caesarean section. Since it is undisputed that under these circumstances, the mother sheep was dead, (decapitation results in death according to all authorities), the Talmud's ruling that the life of the fetus establishes vitality of the mother does not apply when the mother's vital functions can be mechanically maintained." (1992b, p. 79, col. 3, emphasis mine) To those who did not know about the "conclusive proof" from the Talmud in *Archin*, the sheep experiment seemed to be as strong as possible to show that decapitation and BSD were functionally equivalent. However, as stated above, the firm belief in cardiac death comes from an interpretation of sources and not from science. The best science could do, according to Breitowitz, was put the Talmud in *Archin* in context, and not to contradict it. In opposition to this type of mentality, logic and science have not much power, as would even be admitted by Bleich and Breitowitz.

to conspiracy theories and antagonism to the medical community (see Chapter Four, especially the section analyzing comments from the popular Orthodox web site *Vos iz Neias*).

The Commission recognized that this mistrust of the medical establishment was not new. The report describes the situation in the eighteenth century, when doctors were not trusted to declare death; coffins were designed with speaking tubes to avoid cases of accidental burial (13–14). As the report notes, “The debate dissipated in the nineteenth century because of the gradual improvement in the competence of physicians and a concomitant increase in the public's confidence in them” (14). Advances in technology, including the invention of the stethoscope, helped as well.

The Commission Report appeared at the beginning of a new period of mistrust, brought on, as the report acknowledges, by new developments in medical technology. The same fears which demanded speaking tubes in coffins can be seen at play in current rejections of BSD as death.

It is understandable that laypeople who consider BSD patients to be alive would interpret doctors' actions as an abandonment of a living patient. The medical practitioners, on the other hand, see themselves as acting ethically, because they want to bury a dead person. Medical practitioners who are forced to sustain a BSD patient on a ventilator may see *that* action as unethical; furthermore, the care of what they see as a corpse may, understandably, have a traumatic effect. In other words, and crucially, the disagreement over BSD is not one between science and ethics but over two different ethical positions as each community – rabbis and doctors – understands them.

The Commission notes, “With the aid of modern medicine, some comatose patients can be kept from a rapid death. Many, however, become permanently and totally unresponsive. In

other words, their appearance resembles that of the dead as traditionally perceived: they no longer respond to their environment by sensate and intellectual activity. But their appearance also differs from that traditionally associated with the dead because mechanical support generates breathing, heartbeat, and the associated physical characteristics (e.g., warm, moist skin) of life” (21). In other words, the authors of the Commission knew how difficult it would be to make distinctions between comatose and BSD patients based on appearances. The Commission’s sympathy for the layperson’s confusion appears to have been lost today by many medical professionals; this circumstance may be seen in the way that medical professionals are described in published descriptions of the cases.

The Commission Report stresses the mandate of the medical community to maintain the trust of the public:

The social and legal as well as medical consequences attached to a determination of death make it imperative that the diagnosis be incontrovertible. One must be certain that the functions of the entire brain are irreversibly lost and that respiration and circulation are, therefore, solely artifacts of mechanical intervention. Indeed, though suspicious that their interventions may be doing nothing more than masking what would otherwise manifestly be death by the traditional measures, physicians are concerned about doing anything—such as removing a respirator—that would hinder the recovery of a patient whose loss of brain functioning might be only partial or reversible (22).

The ambiguity in the appearances of patients with different conditions is underscored on page 4 of the Commission Report, which notes that the same technology that is used to keep a brain dead body with a heartbeat as that used in therapies to restore a patient in extreme circumstances to health. The authors acknowledge the confusion that might come from the use of these overlapping treatments.

The Commission's approach, contrary to what some may have thought, opted for a conservative approach to BSD, as is evident through contrast with their approach to "higher-brain death" (a category that includes PVS). As the report states,

"Personhood" consists of the complex of activities (or of capacities to engage in them) such as thinking, reasoning, feeling, human intercourse which make the human different from, or superior to, animals or things. One higher brain formulation would define death as the loss of what is essential to a person. (38)

The Commission argues against equation of higher-brain death with death for two reasons: (1) The loss of higher consciousness that the higher-brain death definition asserts is not clinically measurable: "In order to be incorporated in public policy, a conceptual formulation of death has to be amenable to clear articulation. At present, neither basic neurophysiology nor medical technique suffices to translate the 'higher brain' formulation into policy" (40). (2) The Commission believes "whole brain death" (BSD) is the functional equivalent of the previous definition of death as understood in Western society while "higher brain death" would constitute a break in that tradition. One reason that a break with this tradition is undesirable, as the report suggests, is that a radical change in the definition of death would inhibit the lay public from accepting the plausibility/comprehensibility/authority of any new definition. Furthermore, it would also imply that the older definition of death was wrong:

The adoption of a higher brain 'definition' would **depart radically from the traditional standards**. As already observed, the new standard would assign no significance to spontaneous breathing and heartbeat. **Indeed, it would imply that the existing cardiopulmonary definition had been in error all along, even before the advent of respirators and other life-sustaining technology.** (40-41, emphasis added)

The Commission recognizes that brain death is hard to understand. As shown in the following chapter, this sympathy for the layman is absent from the hospital in many BSD cases.

The Commission Report states,

Most Americans still feel they recognize the manifest signs of death, at least through the arts and the communications media, if not first-hand. The “whole brain” signs of life and death are less well comprehended by nonspecialists, and they measure functions that are less clearly manifest. The heart and the lungs move when they work; the brain does not. (58–59)

The Commission Report justifies its conservative approach to the modification of the definition of death, again citing the difficulty that society will have in changing its view of the subject:

Conservatism seems justified in articulating a rule that will not only be applied within the legal system but will also guide the beliefs and behavior of physicians and the public. People's attitudes toward death evolve....Change does not occur overnight, however, and there seems to be no reason to force it by statute when wrenching change is not necessary....The conservative nature of the reform here proposed will be more apparent if the statute refers explicitly to the existing cardiopulmonary standard for determination of death. The brain-based standard is, after all, merely supplementary to the older standard, which will continue to be adequate in the overwhelming majority of cases in the foreseeable future.” (59)

The Commission made clear its hope for accommodation of conscientious resistance to the idea of BSD as death on religious or other grounds:

The statute specifies that death has occurred if either cardiopulmonary or brain criteria are met. Although, as a legal matter, there is no personal discretion as to the *fact* of death when either criteria is met, **room remains for reasonable accommodation of personal**

beliefs regarding the actions to be taken once a determination of death has been made. Such actions, whether medical (*e.g.*, maintaining a dead body on a respirator until organs are removed for transplantation) or **religious (*e.g.*, withholding religious pronouncement of death until the blood has ceased flowing)**, can vary with the circumstances. Some subjects in the Commission's hospital survey, for example, were maintained on ventilators for several hours after they were dead, in deference to family wishes or in order for the family to decide whether to donate the deceased's organs. (81, emphasis mine)

Furthermore, the Commission recognized the fears of the public. "Part of the public concern over employing a brain-based standard to determine death seems to arise from fear that this may cause medical treatment to be withdrawn from some patients who might have 'recovered,' that is, regained consciousness or at least the ability to breathe without the aid of a respirator. This fear is expressed in anecdotes about patients who have resumed normal lives after long periods of coma or even after having been pronounced dead" (81–82). Although this point speaks to the confusion among laypeople about the nature of BSD, the Commission evidently felt that fears and mistrust of the medical community were factors that warranted accommodation.

Conclusion

Consideration of the 1981 Commission Report alongside documents on BSD from Orthodox Jewish authorities reveals the source of the divide that exists between American law and medicine on one side and the predominant Jewish Medical Culture on the other. American law considers a BSD patient to be dead, and the majority of Orthodox Jews – lay and elite – consider a BSD patient to be fully alive. The consequences of this divide are manifested in the

cases discussed in Chapter Four of this dissertation; I will explicate those cases through the lens of the notion of “incommensurable paradigms” expounded by Thomas Kuhn. As I will show, adherents to the two disparate positions on BSD face stark differences in their approaches to these cases. Adoption of the attitudes originally expressed in the 1981 Commission Report—attitudes of understanding, sympathy, and an openness to accommodate religious and ethical differences in the treatment of BSD patients—would aid the parties in such cases in communicating with one another. In the absence of this communication, the two positions appear irreconcilable.

Chapter Four

Brain Death, Paradigms of Thought, and Incommensurability

As outlined in Chapter Three, the mainstream American position concerning Brain Stem Death (BSD)—namely that it constitutes a medical and legal definition of death—comes into sharp conflict with the position of the majority of Orthodox Jewish *poskim*, most prominent among them J. David Bleich, who view life and death only in terms of cardiac activity and cardiac arrest. These definitions occur at the level of the elite: intellectuals in American medical and ethical thought on one side, and widely respected rabbinic authorities on the other.

The ways in which these divergent opinions manifest themselves in the medical cases and in discussions between the mainstream American medical community and Orthodox Jews—manifestations of what I call the Jewish Medical Culture—are also important for understanding how a religious sub-group with contrasting views on life and death can struggle within a secular majority system. In this chapter I will consider the ideas of BSD held by medical practitioners and caregivers, laypeople, family members, and medical decision-makers, as well as the application of the cardiac-death position by *poskim*, in significant BSD cases: the Motl Brody case and the Smith-Flamm case, both described below.

At a fundamental level, as I will show, the interaction among these various stakeholders in BSD cases demonstrates a striking lack of understanding of the concerns of opposing groups. Although the intellectual elites may comprehend one another's position, at the level of the

medical practitioners and family members in the cases, such an understanding does not exist. Instead, adherents to each view the position of the other side as illogical, nonsensical—and, as a result, the cases are highly charged and extremely contentious.

I seek an understanding of the conflicts in these cases through consideration of the concept of intellectual “paradigms” and “paradigm shifts” as outlined in Thomas Kuhn’s work *The Structures of Scientific Revolution* (1962; repr. 1970). Although Kuhn first formulated his theory as a means of explaining intellectual history, it is at its essence a theory of the spread of ideas within a society. Furthermore, while Kuhn’s conception has been criticized as a form of eschatological history, in which “bad” ideas are replaced by successively newer, better ideas—and thus forms part of the story of humanity perfecting itself, this was never his intention. Indeed, in its application to the social sciences (Aronova 2009), the pattern of paradigms takes on a cyclical form, with older paradigms of thought being applied anew in lieu of paradigms that may be losing their usefulness. In BSD cases involving the Orthodox Jewish community, the paradigm of thought that views BSD as death (held by most medical practitioners and the laws of all 50 states) comes into conflict with the paradigm that sees BSD patients as alive.

This is not just a simple conflict over the meaning of the term: the definition of BSD patients as alive or dead determines the entire course of the ethical, legal, and religious interaction of the patients’ families with the hospitals and medical practitioners. The two sides are so deeply entrenched in their positions, with their entire view of the case colored by the unstated assumptions of their communities or authority figures, that they cannot communicate effectively with those on the other side. The paradigms of thought that underlie Orthodox Jewish Medical Culture come into conflict with those of secular paradigms and paradigms of other religions. Thus while the parties involved in a given medical case might be using the identical

vocabulary, their patterns of thought—their assumptions and preconceptions—mean that they are “talking past one another” rather than communicating effectively or meaningfully.

The Facts of the Brody Case

The facts of the Brody case may be gleaned from newspaper articles and other news sources that appeared at the time. Motl Brody was the nickname of twelve-year-old Mordechai Dov Brody of Brooklyn. Suffering from brain cancer, he was treated at Northwest Washington Hospital in Washington, D.C. (Wilber 2008). He was declared “brain dead” on Tuesday November 4, 2008. His parents, Eluzer and Miriam Brody, members of the Bobover branch of *Chassidim*, tried to prevent the hospital from removing life support. The hospital responded by suing in D.C. Superior Court to remove the boy from life-support equipment.

As accounts in the *Washington Post* make clear, the family’s rabbi, whom the *Washington Post* identified as “Chaim Jacob Tauber, chief rabbinical judge of the Bobov Hasidic community in Brooklyn” (Labbé-DeBose et al. 2008) gave his opinion that BSD does not constitute death. The argument of the parents was that in Jewish law “there is no such thing as brain death” and “their religious beliefs are entitled to respect.” The hospital claimed as a basis for its suit that “scarce resources are being used for the preservation of a deceased body” (Wilber 2008). Sophia Smith, a doctor who had been providing care, was quoted as saying, “This child has ceased to exist by every medical definition” and moreover, she and the medical group were “distraught at what is providing futile care to the earthly remains of a former life....Ethically, there is no appropriate treatment except removal of the ventilator and of the drugs.” The *Post* stated that the hospital had “no choice but to stop life support or risk fines and other sanctions”

(Wilber 2008). The attorney for the hospital wrote “Continuing any support to this child eliminates any dignity this child has left....There is **no religious principle at issue in this case**, but a clash of the definition of death” (Wilber 2008; emphasis added). From the hospital’s perspective, the medical professionals are being sympathetic because they want to bury a child who has died. In their minds they are being forced to see the body of a dead child constantly, which is understandably a traumatic affront.

Ironically, had they stayed in New York, the Brody family could have make use of a religious accommodation built into the state health law. Among all 50 states, only New Jersey and New York acknowledge this possibility of exemption from the mandate to withdraw medical care in BSD cases for religious reasons.

In the Brody case, as in many such cases, before the court could determine the outcome of the case, the patient's heart stopped beating of its own accord; this cardiac arrest occurred on November 15, 2008, a Saturday, eleven days after he was pronounced brain dead. The case was therefore never decided.⁹²

Kuhn’s Theory of Incommensurable Paradigms

Discussions of the Brody case by lawyers, ethicists, and medical professionals aligned with the side of the hospital reveal a sharp divide between the secular and Jewish perspectives. In some cases, it seems that these secular thinkers and professionals claimed to “respect” the rights

⁹² Benjamin Schuman-Stoler, writing for the blog of *Moment* magazine, dubbed the Brody Case a “Jewish Schiavo.”⁹² (Benjamin Schuman-Stoler, “Jewish Schiavo” Motl Brody Passes Away,” November 17, 2008. <http://momentmagazine.wordpress.com/2008/11/page/2>). The author equates Brody’s circumstances to those of Schiavo without any reasoning, even though Brody had suffered BSD and Schiavo did not. The medical conditions were thus not the same, yet very often lay people do not understand the medical distinctions between PVS and BSD. See also Aizenman and Chandler (2008),

and beliefs of the patient's family, but they nevertheless did not feel bound to allow the family to observe its religious mandates; they may even have had pressure to withdraw medical care by the laws of their states. Medical professionals and ethicists raise a number of questions, including quality of life and the use of resources, to justify adherence to the definition of BSD as death.

As suggested above, I attribute these deeply entrenched positions—and the often inflammatory language that emerges from each of them—to adherence to an underlying paradigm of thought. It is impossible for most Orthodox *poskim* and their followers to speak of BSD as death; at the same time, the rhetoric of lawyers and secular medical professionals reveals an unwillingness to adapt to religious differences. In this sense the case is reminiscent of the abortion debate. The Pro-Choice side may consider the fetus a potential human life, but not one on the same level as a functioning, independent life. In the case of BSD, even that level of recognition is lost. In claiming that their son was still alive, Brody's family was perceived as causing an affront to the hospital, and as being unethical. The Orthodox Jewish position on BSD—based on a long tradition of interpretation of Jewish textual sources—was viewed as idiosyncratic to a small religious community, rather than as a more widespread view of, for example, a fetus as a human being. The hospital and its lawyers could not understand the Brody family's attempts to adhere to their rabbinic authorities and tradition as a moral or religious imperative, because they were operating from a different—indeed, completely opposed—paradigm.

Before turning to an analysis of the rhetoric concerning the Brody case, it is necessary to expand upon the idea of a “paradigm” as put forth by Thomas Kuhn, and to explain its applicability to the understanding and spread of ideas in society.

Of all the social theories that describe patterns of thought—including social constructionism, modern anthropology, non-Western sociologists of religion, and indeed the core thinkers of social science—I consider Kuhn’s concept of the “paradigm” most useful. Kuhn’s theory explains how ideas change over time through conflict between adherents of opposing paradigms. Paradigms elucidate how two people who appear to exist within the same “culture” can in fact retain conflicting views that yield dramatically different ways of perceiving even the same objects.⁹³

Kaiser (2012) offers a compelling summary of Kuhn’s key ideas as applied to the history of science:

A field of [scientific] study matures by forming a paradigm—a set of guiding concepts, theories and methods on which most members of the relevant community agree. There follows a period of “normal science,” during which researchers further articulate what the paradigm might imply for specific situations.

In the course of that work, anomalies necessarily arise—findings that differ from expectations.... Often, Kuhn argued, the anomalies are brushed aside or left as problems for future research. But once enough anomalies have accumulated, and all efforts to assimilate them to the paradigm have met with frustration, the field enters a state of crisis. Resolution comes only with a revolution, and the inauguration of a new paradigm that can address the anomalies. Then the whole process repeats with a new phase of normal science. Kuhn was especially struck by the **cyclic nature of the process**, which ran counter to the then-conventional ideas about scientific progress....

Kuhn himself came to realize that he had saddled the word [paradigm] with too much baggage: in later essays, he separated his intended meanings into two clusters. One sense referred to a scientific community’s reigning theories and methods. The second meaning, which Kuhn argued was both more original and more important, referred to exemplars or model problems, the worked examples on which students and young scientists cut their teeth.... Scientists learned by immersive apprenticeship; they had to hone what Hungarian chemist and philosopher of science Michael Polanyi had called “tacit knowledge” by working through large collections of exemplars rather than by memorizing explicit rules

⁹³ Many of the notions inherent in Kuhn’s theory of paradigm have their foundation in the views of these other great thinkers; however they do not concentrate as much on the moments of idea change, or the conflict, in the way Kuhn does. My work here is about those conflicts, especially as it relates to the very definition of a religion, and the definition of death.

or theorems. More than most scholars of his era, Kuhn taught historians and philosophers to view science as practice rather than syllogism.

Most controversial was Kuhn's claim that scientists have no way to compare concepts on either side of a scientific revolution. For example, the idea of "mass" in the Newtonian paradigm is not the same as in the Einsteinian one, Kuhn argued; each concept draws meaning from separate webs of ideas, practices and results. If scientific concepts are bound up in specific ways of viewing the world, like a person who sees only one aspect of a Gestalt psychologist's duck-rabbit figure, then how is it possible to compare one concept to another? To Kuhn, the concepts were **incommensurable**: no common measure could be found with which to relate them, because scientists, he argued, always interrogate nature through a given paradigm.

Perhaps the most radical thrust of Kuhn's analysis, then, was that science might not be progressing toward a truer representation of the world, but might simply be moving away from previous representations. Knowledge need not be cumulative: when paradigms change, whole sets of questions and answers get dropped as irrelevant, rather than incorporated into the new era of normal science. In the closing pages of his original edition, Kuhn adopted the metaphor of Darwinian natural selection: scientific knowledge surely changes over time, but does not necessarily march towards an ultimate goal. (166)

It is in the theory of incommensurability that Kuhn's ideas are most fruitful in understanding the culture clashes between the American Orthodox Jewish views and the views of the regnant American secular medical culture: both groups use the same terms but with contradictory definitions that arise from their entirely different worldviews. The key is that it is possible to understand both positions from an objective standpoint—this, indeed, is the role of the social scientist—but it is not possible to adhere to both views in practice. Kuhn devised the notion of paradigms to describe how scientists answer questions. The paradigm helps to establish both what the question is and how it should be answered. In this case, the two competing definitions of death are mutually exclusive. One cannot define the body as both alive and dead within a medical context. If the body is alive, then it requires medical treatment as a patient; if the body is dead, medical treatment is not applicable.

Although Kuhn's ideas were formulated initially to explain phenomena in the history of science, his ideas have been applied fruitfully in the social sciences as well. The idea of incommensurability is essentially a notion of sociology of thought that plays out in the individual, making it at once sociological and psychological. Alexander Bird, a scholar who has emerged as a major interpreter of Kuhn, emphasizes the importance of psychology for Kuhn, especially in the use of Gestalt psychology and the work of optical illusions, like the duck–rabbit paradox, as referenced by Kaiser.⁹⁴ As the image in Appendix C shows, an optical illusion will allow the viewer to perceive either one image or the other but not both simultaneously, even when the viewer knows that both images are possible to perceive.

In this exercise it becomes clear that the social meanings given to the individual by their accepted paradigm will determine (at that specific moment of perception) how information is understood. As Kuhn explains: “the same stimulus can produce different sensations ... the route from stimulus to sensation is in part conditioned by education” (Kuhn 1970:193 in Bird 2012:866).

The lighthearted example of the duck–rabbit opposition highlights the more serious stakes of incommensurability in the understanding of BSD. In the cases seen in chapter four, the Orthodox Jewish families see their loved one who has suffered BSD as alive, while the medical professionals, who have adopted a different paradigm, see that same person as dead. For the family, the patient is a living person with a contemporaneous identity; for the medical personnel, the patient has become a perfused corpse.

⁹⁴ “Gestalt psychologists...[are] exemplars for Kuhn's thinking about cognition in science, concerns the nature of perception and, in particular, how perceptual experience can be moulded by training and experience. These set up expectations that cause us to perceive (literally) the world in certain ways. It follows that changes in experiences can bring about different perceptions, and so also that the same object may look different to various observers, depending on their previous experiences. A simple example of one object leading to more than one perceptual experience is a multistable image, such as the Necker cube or the duck–rabbit” (Bird 2012:865-866). See also Bird (2013, 2000) for Kuhn's interaction with psychology.

Although Kuhn's views have been criticized by some scholars in the history of science, Aronova (2009) details the essential role that the Kuhnian paradigm concept plays in the sociological subfield of Science and Technology Studies, especially as it relates to questions of medical ethics: "In the 1970s and early 1980s....the discourse in medical ethics became a fertile ground for a dialogue between philosophically minded bioethicists and the philosophers of science who responded to Thomas Kuhn's challenge" (7)—a challenge implicit in the publication of Kuhn's *Structure of Scientific Revolutions*. For philosophers (of science, of medicine, epistemologists, metaphysicians) critical of Kuhn, he became a caricature of scientific relativism, seen as calling into doubt the nature of science itself.⁹⁵ The concept of incommensurability was singled out as the keystone of his relativism.⁹⁶

The accusation of relativism and "constructivism" (Bird 2012:867-868) is intelligible in context of the conceptions of science that he was writing against. Of special concern was Kuhn's rejection of a progression of history towards greater and greater truth. As Borradori (1994) explained in her prefatory remarks before her interview with Kuhn "For Kuhn, there is no single, universal scientific method: researchers cannot compare their results with those of the universal 'protocols' of observation, as the neo-positivists had thought nor with any Popperian 'base-assertions' available at any point in history. There is no absolute truth that constitutes the goal toward which science is heading" (155).

Ironically, in contrast to the philosophers' accusations of relativism and rejection of a teleology to science, Kuhn has been criticized in the area of history as espousing a simplistic

⁹⁵ Aronova (2009:6, f1) points out how Kuhn's theories were "singled out as the official strategy of the Republican party in the 1992 mid-term elections, with the candidates being urged by a Republican pollster 'to continue to make the lack of scientific certainty a primary issue in the debate [on global warming]' (cit. in Oreskes, Conway 2008)." Besides relativism, Kuhn is also criticized for slippery definitions, even of his main term "paradigm:" Kaiser (2012:166): "British philosopher Margaret Masterman famously isolated 21 distinct ways in which Kuhn used the slippery term throughout his slim volume."

⁹⁶ See Gieryn (1995:400-404) and Bird (2012:879, and the numerous sources on the bottom of that page).

form of structuralist historiography (Jasanoff 2012:436-437, Hacking 2012:xi-xii). There is merit to the critique of Kuhn's work as a historian; however I choose to employ his theories as they relate to the sociology of knowledge and of science, noting in particular his insistence that paradigms of thought may recur in cyclical fashions, with evidently more "progressive" paradigms coming into conflict with apparently "older" ones. Indeed, Kuhn himself considers his work to be appropriate for application in sociology: "Today I would consider [the *Structure of Scientific Revolutions*] part of a discipline that at that time did not even exist: the sociology of knowledge." (Borradori:157).

Evidence of Kuhnian Paradigms: Rhetoric Surrounding the Brody Case in the Press and in the Language of Lawyers and the Hospital

The rhetoric contained in the newspaper articles and interviews about the Brody case show the Kuhnian concept of incommensurable paradigms at work. Boston University law professor George Annas was asked by the newspaper about the Brody case and explained, "the case law is clear: once you are dead, you are dead" (Wilber 2008). For Annas, there is no nuance allowed: the medical professionals at the hospital were not only adamant that Brody was dead, but were claiming moral high ground, asserting 1) that continuation of life-support constituted disrespect to a corpse, 2) that the staff were impacted negatively in providing care for a corpse, and 3) that resources were being wasted.

The continuing coverage by *The Washington Post* of the Brody case mentions that the patient was briefly removed from the ventilator as part of the testing of his viability (Labbé-DeBose et al. 2008). According to this article, the hospital's attorneys claimed that the ICU had

32 beds, “all but 12 in use. By keeping the boy there, the Hospital is putting other children at risk.” The article states further, “Some Orthodox Jews base the definition [of death] on brain activity, while others base it on a heartbeat.” As explained in Chapter 3, this description exaggerates the influence of the Tandler position accepting BSD as death; this position is not held by the overwhelming majority of Orthodox *poskim* and laypeople. (Comments from the web site *Vos iz Neias*, a site frequented by Orthodox readers, will be discussed below as representatives of the lay position.)

The Associated Press (Associated Press 2008) picked up the story, and its report includes further quotations from the court filing that provide insight into the cultural divide. The key points are as follows:

- (1) The hospital claimed, “this is death at its simplest.” This statement is remarkable given the 1981 Commission Report, which was composed to address the fact that definition of death is anything but simple. The fact that the hospital issued such a statement with confidence demonstrates the severity of the cultural divide.
- (2) The hospital refers to the patient’s “earthly remains,” another phrase that indicates the single-minded perspective from which its staff viewed the case.
- (3) The Brody family’s lawyer, Zuckerman, “stressed that the family’s demand for continued life support was based on their obligations under religious law, not an unrealistic hope that their boy will recover. ‘You can always hope for a miracle, but if you are asking if they are in denial about their child’s medical condition, no, they are not,’ Zuckerman said.”
- (4) The hospital claimed, “we respect the family’s beliefs.” Nevertheless, it dismissed the family’s wishes. It seems possible that the hospital’s intended meaning was that

its staff and lawyers understood that the family had beliefs, and that they did not intend to discriminate against Orthodox Jews. Nevertheless, their statements do not show any attempt to conform to the family's religious position.

(5) The hospital was "inundated with harassing and threatening calls" about the case.

The AP article also includes a statement by noted bioethicist Arthur Caplan:

Arthur Caplan, a professor of bioethics at the University of Pennsylvania, said physicians aren't obligated to provide care that can't possibly be medically helpful. "Doctors are well within their rights to say, 'We are stopping,'" he said. "I don't think medicine can become subservient to religious, spiritual or mystical hopes and beliefs concerning how to manage death."

The lawyer for the Brody family asserted that the issue was about religious law, and not about the family's unreasonable hope for a miracle. The most commonly held position in Jewish law holds that BSD patients are not dead. Thus in the view of the patient's family, Motl Brody was alive.

Caplan's position that he does not "think medicine can become subservient to religious...beliefs" raises questions with respect to the rights of minority groups to determine their medical care. And again, given that the 1981 Presidential Commission was formed because of the scientific and ethical complexities of BSD, his confidence that BSD constitutes death is striking.

Furthermore, Caplan's perspective, shared by the hospital, seems to view religion as a mechanism for coping with death, rather than as a legal system. Whereas Caplan saw American law as binding, he did not grasp that for the Brody family, Judaism was not just a religion, but also a legal system (see Chapter Five on the pre-modern identity of Orthodoxy as encompassing

law, religion, and ethics, as explained in Batnitzky 2011), and that this legal system carried equal import. Thus not only in their definition of BSD as life or death, but in their very understanding of the role of Judaism, the family and the hospital were operating within utterly different paradigms. This sharp divide is underscored still further in a statement by Kenneth Rosenau, an attorney for the hospital, quoted in the *Washington Post* as saying that Brody had “ceased to exist” (Alexander 2008). “What we have left is not a human being.” On the other hand, Zuckerman, the Brody family lawyer offered the opposite judgment: “This hospital wants to kill him instead of treat him.”⁹⁷

Evidence of Kuhnian Paradigms: Rhetoric Surrounding the Brody Case in the Popular Orthodox Press

The Brody case caused a great deal of reactions among Hassidim in particular, many of whom responded in writing in support of the Brody family and their point of view. The web site *Vos Iz Neias*, a popular site among the Orthodox and Hassidic public, presents comments by members of these groups that apparently reflect their Orthodox culture.⁹⁸ I do not take these comments as being in any fashion representative samples of Orthodox Jews given that most are anonymous, but they do have value in showing how some self-identified Orthodox Jews describe their feelings about the case. The ideology that animates their words echoes the positions of the rabbinic authorities on record. In addition, these comments reinforce the conception of BSD

⁹⁷ The article added further information: “In September, the hospital planned to move the boy to a hospice, but the family objected to the move because it was around Yom Kippur.” Motl stayed in the hospital and died when his heart stopped beating on November 15, 2008, a Saturday.

⁹⁸ <http://www.vosizneias.com/22273/2008/11/09/new-york-hospital-in-motl-brody-case-we-are-being-inundated-with-harassing-and-threatening-calls-by-ny-jews/>. It seems possible that posts with words written with Yiddish pronunciation are the product of primary Yiddish speakers and thus likely from Hasidic Jews (e.g. #47, named “770” and so likely Chabad, writes “fillings” for “feelings”).

patients as alive, thus illuminating further the paradigm within which these commenters are operating.

A full transcript of the page is reproduced as Appendix B. The following are selected comments that seem particularly telling in the present discussion.

Comment 4 implies that the Brody is alive, and that the hospital is attempting to kill him: “Keep it up rabosai, don't stop calling and emailing. LET MOTYL BRODY LIVE!!” Comment 16 cited adherence to the position of Orthodox *poskim* that only the status of the heart and lungs can determine life or death: “The NY Times had today a listing of all rabonim that said that you are NOT aloud [sic] ti [sic] stop giving the medication... they all said that life is detirmined [sic] only on heart and lungs as per halacha not on the brain and therefore [sic] we have to fight and fight.”

Comment 20 acknowledges that logic may not enter into the determination of the *halakhic* position: “the majority of poskim hold we can even be mechallel Shabbos [break the laws of the Sabbath] to try to keep him alive even at this point. It has nothing to do with a lack of understanding of the medicine or biology or science, just an understanding of Hashem’s [God’s] will.”

Comment 24 demonstrates confusion about higher brain death and BSD, or even PVS: “There have been cases where people who were labeled brain dead came back to life. Maybe this case is worse but we have to listen to chazal [the wise ones].” A mistrust of the medical establishment is evident in Comment 34, which suggests that the doctors are only telling the family that their son’s body is decomposing in order to convince them to remove care: “Sometimes, many time [sic] in fact, doctors use this ‘decomposing’ argument to attempt to portray death to families who are in denial. It is old hat, and not always factual. It is meant to

elicit negative thoughts and emotions and intended to override religious thoughts. They believe that the religious thoughts are based upon the families' denial of the patient's situation, and if they could 'just make them understand' that the situation is hopeless the family will stop being 'unreasonable.' They do not understand the concept of simple obedience to Hashem's word even with we are fully cognizant of the facts and are not in denial." This mistrust is echoed in Comment 52: "Decades ago. a woman of my kehilla lay 'brain-dead' in a hospital for over a year. Every day mishpachah [family] members sat at her bed and told her family news. The doctors told them they were meshugah [crazy]. Finally, she WOKE UP AND KNEW ALL THE NEWS THEY SAID TO HER! THE DOCTORS 'DROPPED DEAD.'"

Although some comments at this web site do acknowledge the scientific basis for accepting BSD as death in secular culture, they nevertheless view their religious laws as binding. Some hold out hope that Brody would awaken, while others recognize that this would be impossible. Their paradigm of thought is informed by a religious system that permeates their actions and mentalities, and simply will not allow them to accept BSD as death.

Whose Ethics? Evidence of Kuhnian Paradigms in the Smith–Flamm Case

A medical case occurred in Cleveland in 2011 that bears similarities to the Brody case in that it concerns an Orthodox Jewish family and a BSD patient. I use this case to corroborate many of the impressions recorded with regard to the rhetoric of the medical professionals in the Brody case. Brody's situation was reported with great concern in the popular media; the case described by Martin L. Smith and Anne Lederman Flamm was evidently not. (Since the patient and family in the case were anonymous, I refer to it hereafter, using the names of the authors of

the study, as “Smith-Flamm.”) While the Brody case is useful in offering the perspective of the Orthodox community, the Smith-Flamm case offers a window onto two other perspectives: that of the medical professionals in the case, and that of the academic ethicists, whose description of the case is anything but impartial.⁹⁹

The details of the Smith-Flamm case are simple for our purposes: it revolved around two sisters—Sarah and Rebekah—who were unmarried and in their twenties. Sarah suffered BSD, and Rebekah was the proxy decision-maker. The authors of the study describe the family’s point of view:

[The neurologist] then relayed that Sarah had died, despite all bedside observations to the contrary—acknowledging that her heart was still beating and she was breathing and looked alive. Rebekah and her father objected. They explained their belief that Sarah was very much alive and would remain so until her heart and breathing stopped. The Rabbi supported them by reviewing the opinions of highly respected and learned Rabbis. The ICU physician proposed that, at a minimum, a Do-Not-Resuscitate (DNR) order should be written. The Rabbi countered that any treatment or intervention that could provide even one day of additional life was obligatory. In his view CPR must be attempted, and only if Sarah’s heart did not re-start would discontinuing life-saving measures be appropriate (57).

Here the staff understood that for the family, the position that BSD constitutes death would be counter-intuitive; yet the family and their rabbi held the most conservative position in Orthodox *Halakhah*: not only did they reject BSD as death, but they insisted on resuscitation until the point of complete heart failure. This position is rooted in the idea that every moment of life is of infinite value, and must be preserved and acquired by any possible means.

⁹⁹ For further background in cases similar to Smith-Flamm, see Anderson et. al. (2007), Bard (2007), Bosek (2007b), and Davis (2007).

While the hospital felt compelled to keep Sarah on the respirator, the authors note that the staff members were unhappy with this decision: “One nurse wondered whether what they were doing was disrespectful to Sarah’s body, and she questioned whether the temporizing delay reflected kindness toward Sarah’s family or actually harmed them by obscuring the reality of her death.” (57) This is a clear example of a paradigm conflict: from the nurse’s paradigm, treating a corpse as if it were alive constituted disrespect, yet from the Orthodox Jewish paradigm, the corpse was alive!¹⁰⁰ The nurse’s paradigm of thought made it impossible for her to see the position of the family—that Sarah was alive. As noted in Chapter Three, the report of the Presidential Commission, too, acknowledged that this apparent illogicality would exist. And yet, even if the family did acknowledge the illogicality, it would likely still have felt bound by the laws of Orthodoxy as interpreted by their *posek*.

The second concern of the nurse—that the family was being harmed through the illusion of Sarah’s life—is reflective of a psychoanalyzing tendency. This tendency in turn reflects a different understanding of religion: whereas Orthodoxy encompasses laws as well as beliefs, the nurse seems to have been unfamiliar with this system. To the nurse, the family was “in denial” and it was in their best interests to accept the reality of the death. This contrast between psychology and law is another clash of Kuhnian paradigms.

Smith and Flamm describe that “many nurses grew more distressed,” and further, that “the inherent inconsistency of providing prolonged and intensive care for someone who had died was taking a toll” (58) during the dispute. This facet of the BSD cases is given great weight by the hospitals but is often absent in the literature presented by Orthodox Jewish *poskim*; that literature seems to operate from the assumption that the status of the patient should be the sole

¹⁰⁰ This objection may be seen as ironic given the lengths to which Orthodox *poskim* goes to preserve the dignity of the human body; for example, most *poskim* prohibit tattoos because they mutilate the body.

concern of the decision-makers. Indeed, the clinical reports and court documents pertaining to the Brody case emphasize the needs and stress of the staff. The Orthodox Jewish writers do not bring this topic up at all, again showing the divergent paradigms within which proponents of the two sides were operating.

Smith and Flamm write that the 1981 Commission Report was a key document in the determination of BSD as death. Yet the ethical nuances reflected in the Commission Report seem not to have made their way to the level of the medical practitioners who were dealing with the family. As Smith and Flamm write, “Despite the legal clarity, clinicians continue to encounter families who object to the categorization of their loved ones as “brain dead,” and to struggle, as Sarah’s case exemplifies, with the moral ambiguity of how to respond” (59).

The authors corroborate that as of 2011, only New Jersey and New York (perhaps because of their large Jewish populations) had enacted religious exemptions to determinations of death in BSD cases. Such legal exemptions might raise awareness of cultural differences in the understanding of BSD. Yet even Smith and Flamm resist the possibilities elicited by the New York and New Jersey exemptions: “The approach neglects the practical and clinical challenges posed by extending somatic support of these patients, and ignores clinicians’ ethical struggle with treating patients they perceive to be dead” (60). The authors note further that the stress felt by the staff was augmented by the religious basis of the family’s resistance: “The religious foundation of the family’s objection heightened the moral uncertainty and emotional distress that accompany, under any circumstances, the prospect of disregarding family wishes for continued medical intervention” (60).

This concern with the medical practitioners' ethical sense stands in contrast to the apparent lack of concern with the ethical and legal framework of the patient's family. In fact, I suggest, this may constitute a substitution of secular ethics for religious ethics.

From the family's point of view, Sarah's care was a question of saving a life and arises from a Divine Mandate; the family's own personal psychology had nothing to do with the case, and the family might even have perceived an implication to the contrary to be morally offensive. The salience of psychology is seen later in the article. "Some caregivers questioned whether accommodating Rebekah and her father's request for delays actually served the family's best interests; they worried that accommodation instead fueled their non-acceptance of Sarah's fate and impaired the family's progression through anticipated and necessary stages of grief" (62). This apparent (perhaps paternalistic) concern for the family's psychological well-being again neglects the *halakhic* basis for the family's objections to the removal of care.

Remarkably, Smith and Flamm's tacit support of the position of the medical practitioners while criticizing the family for the stress they caused among the hospital staff ignores or fails to understand the underlying reasons for the family's position. The authors write, "Is placation of family members a sufficient reason to justify resource expenditures and the imposition of burden on patients who will not benefit?" (62). The perspective inherent in this question is that the family is acting individually and autonomously, as their ensuing comments elaborate:

While some might assert that Sarah, embedded in her family's religious and cultural beliefs, would support her family's desire to sustain her body after a declaration of death by neurological criteria, assertions grounded in individual autonomy and nonmaleficence fail to abate concerns about expending resources on a dead body (62).

The dismissive phrase “some might assert” appears not to recognize the universality of this view among Orthodox Jews. The authors further claim that the family was operating under the ethical umbrella of “individual autonomy and nonmaleficence,” which in the authors’ mind does not outweigh the consideration of “expending resources”—a secular ethical consideration.

Finally, the authors consider the family of Sarah as having had no real right to protest the removal of care: “The long-held tenet against bedside rationing references living patients. No such proscription applies after death; no sanctity of life principle is protected by funneling health care resources into a dead body” (61). Thus even these authors of an academic study—scholars whom one might expect to approach their subject from an unbiased perspective—have difficulty seeing Sarah’s case from the perspective of the family—so foreign is the Orthodox Jewish paradigm to them.

Another demonstration of the clash of paradigms is seen in the authors’ attempt to contrast what the Orthodox Jewish family requests with the medical protocol that precedes organ donation. The authors note that “The published literature offers substantial direction on sustaining brain-dead bodies” (61) for organ donation. However, organ donation is a secular ethic, while the family is requesting continuation of care for religious reasons. As the authors write,

This guidance is usually oriented toward maximizing the value of organs intended for transplantation, **an accepted goal in American society**. The ethical justification for organ transplantation itself supports the act of maintaining the body, i.e., **anticipated benefit** accruing to the transplant recipient justifies resource expenditures to preserve organs and the **potentially undignified or unusual treatment** of a dead body. Organ preservation not only defines a morally acceptable goal of care but clarifies the clinical parameters for the care itself. (61, emphasis mine)

Here the authors accept that there are circumstances in which a corpse should be kept on a ventilator and identify the goal of organ donation as being societally accepted. But the authors do not consider the family's religious views a similarly acceptable goal. In this, the authors, and/or the viewpoint they are describing, demonstrate a lack of understanding of the religious grounds in favor of a perceived American secular cultural goal. The authors describe organ donation as a "morally acceptable goal of care" (61) despite the goal being for others and not for the patient herself.

At certain points the authors attempt to reflect the attitude of the family. For example, in describing the moral issue of triage, i.e., denying care to one patient in favor of preserving the resources for Sarah, they write,

For the ICU staff, allocating a bed to a patient with a reversible medical condition rather than to a corpse would be an obvious choice to preserve life. However, merely acknowledging this possibility manifested to Sarah's family a willingness to allow her to die for the sake of another. From their perspective, this was a moral horror exacerbated by the implication that Sarah's ICU stay was wasteful. (61)

As mentioned above, an important lesson from the paradigm conflict evident in these BSD cases is the demonstration of a robust secular ethics that is perceived as superior to that of the Orthodox Jewish family. The paradigm conflict makes proponents of the competing ethical claims unintelligible to each other. As seen in the work of Breitowitz (see Chapter Three), the secular medical establishment is presumed to have mercenary goals that are placed within a context of similar antagonists from Jewish history.

Rebekah's behavior toward the medical staff is described as negative and intimidating. The authors of the study echo the conclusions of the medical staff that Rebekah was suffering from a psychological malady:

day-to-day aspects of Sarah's support then became matters of further dispute as Rebekah monitored and challenged the nurses' activities. Rebekah's focus on such details fueled concerns that the family's rejection of Sarah's death reflected psychological denial along with religious opposition to the concept of brain death" (61).

The authors elaborate on this concept in the last section of their paper. In trying to explain Rebekah's behavior, they first acknowledge that "Strict fidelity to tradition and rabbinic authority has sustained the Jewish Orthodox community through thousands of years of being a persecuted minority" (63). This comment might constitute an acknowledgment of the cultural heritage that informed Rebekah and motivated her to adhere to divinely mandated religious law. However, the authors instead see the religious heritage through purely psychological—rather than legal—terms:

Rebekah and her father standing in solidarity with this tradition enabled them to affirm their identity within this close community and experience the security deriving from membership. Rebekah's religious faith and commitments likely provided her with a sense of existential meaning and identity when she was confronted with the frightening boundary between life and death. (63).

The authors further reduce the family's position to a coping mechanism, wondering why the family does not simply abandon its religious strictures: "For many persons, religious faith takes on particular value during such a life crisis, perhaps explaining why a believer would

refuse to abandon religious tenets no matter the countervailing arguments and evidence” (63). This comment clearly reflects the paradigm of thought of the authors, which is utterly incommensurable with the paradigm of the family. Most adherents to Orthodox Judaism do not see their religious obligations as optional, to be discarded in the face of “countervailing arguments and evidence.” The authors do not comprehend the legal nature of *Halakhah*. The family on one side, and the hospital and secular ethicists on the other, are operating within two completely different and incommensurable paradigms, which hampers their communication at the most basic and essential levels.

Conclusion

The legal nature of Orthodox Judaism means that for its adherents, its strictures are binding. Since the majority of Orthodox *poskim* see BSD patients as alive, their followers must adopt the same opinion. American law views BSD as death; secular ethicists and medical practitioners adhere to this position. Smith and Flamm wonder why the family members of the BSD patient in the case they describe do not simply depart from their religious strictures in this case. In asking that question, they betray a lack of knowledge concerning the nature of Orthodox Judaism as a system encompassing religion, ethics, and law—a theme that I have explored throughout this dissertation. For adherents to Orthodoxy, no amount of scientific argument will change their position – unless that scientific argument is framed in terms that are compelling within their own *halakhic* framework. While the 1981 Commission Report allowed for multiple views on the subject of BSD, and religious exemptions to the acceptance of BSD as death have

been enacted in New York and New Jersey, cases arise in which incommensurable paradigms pit families of patients against hospital staff and secular ethicists.

Chapter Five

Taking One Life to Save Another:

The Case of the 1977 Conjoined Twins

In 1977, conjoined twins were born to an Orthodox Jewish family in Lakewood, New Jersey; they were treated at Children's Hospital in Philadelphia. Following legal deliberations, as well as religious deliberations within the Orthodox Jewish, Protestant, and Catholic communities, the twins were separated by surgeon C. Everett Koop (later Surgeon General of the United States).¹⁰¹ Evaluation of the medical decision-making process in the 1977 case illustrates the distinctly legal character of Jewish Medical Culture—a feature discernible through the juxtaposition of the Orthodox Jewish rabbinic response to this complex medical problem with the responses of Catholic, Protestant, and secular authorities. Indeed, the legalistic apparatus of Jewish Medical Culture is also discernable from the report of a panel on conjoined twins convened a decade before the 1977 case. That report, which compared the views of Jewish, Protestant, and Catholic thinkers on conjoined twins, serves as a backdrop for study of the 1977 case.

The thesis that Jewish Medical Culture is legal in nature resonates with Batnitzky's (2011) argument that Orthodox Judaism conforms to pre-modern definitions of religion in rejecting a distinction between law, faith and morality. This tri-partite definition of Orthodoxy

¹⁰¹ For background on the medical history of conjoined twins, as well as cultural attitudes, see Aird (1954), Dominus (2011), and Wyszynski (2001).

stands in contrast to the modern understanding of religion as encompassing faith alone. Indeed, Jewish Medical Culture is so legalistic in nature that it echoes the methods and proceedings of secular courts, and in some cases Orthodox decisions are even cited in secular courts.

The 1967 Panel on Conjoined Twins

That medical and religious leaders were concerned about the ethical issues involved in the separation of conjoined twins is evident from the committee formed in 1967—ten years before the 1977 case—to evaluate the “Ethical and Moral Considerations in the Separation of Conjoined Twins” (Pepper 1967)¹⁰². As C.K. Pepper noted in his article summarizing the panel’s work, of which he was a member, the topic of “medical ethics” was seen as the domain of the clergy; therefore, members of the clergy were included in the panel along with medical practitioners (Pepper 1967). The fourteen members of the panel included distinguished physicians, clergymen, and psychologists of the then three major religions in the U.S.: Protestant, Catholic, and Jewish. Only one of the members of this panel was a rabbi: Jack Segal, DHL (Doctor of Hebrew Letters), a practicing Conservative Rabbi whose ordination was from the ultra-Orthodox Mesivta Rabbi Chaim Berlin.¹⁰³

¹⁰² The article does not explain the reason for this committee being formed by the Institute of Religion at Houston's Texas Medical Center, but Aronova (2009:9 f5) explains that the rise of the field of medical ethics came at this time, specifically because of significant events such as “the Thalidomide scandal following the identification of the side effects of this drug in 1961, Henry Beecher's 1966 exposé that revealed the mass violations of the principles of beneficence and informed consent, and the revelation of the Tuskegee Syphilis Experiment in 1972.” For more about the impact of medical scandal on the creation of the field of medical ethics, see also Gamble (2006, 1997), and Lepicard (2009).

¹⁰³ According to the website of Congregation Beth Yeshurun, a Conservative synagogue in Houston, Texas, in 1965: “Rabbi Jack Segal began as an Associate Rabbi, then after eight years, served as Senior Rabbi of the congregation for 23 years, retiring in August 1996. Rabbi Segal was ordained at Mesivta Rabbi Chaim Berlin in 1954. Earlier,” he earned undergraduate degrees in Physics and Mathematics at New York University and the University of Pittsburgh, respectively; and advanced degrees at Oregon State University, Hebrew Union College, and the University of Houston” (http://www.bethyeshurun.org/staff_details.php?id=6).

This article is significant, and cited by many who write about conjoined twins, because it is the earliest scholarly publication of this topic as it relates to a religious-ethical point of view and it provides an early view of what emerges as relatively consistent positions in the later incidents of conjoined twins.¹⁰⁴

There are two sections in the paper, as indicated by the article's subtitle: "A Summary of Two Dialogues Between Physicians and Clergymen." The first section, labeled "psychologic considerations" is the domain entirely of the physicians.¹⁰⁵ The second section contains "theologic" considerations, and includes three subsections entitled "The Protestant View" (130–133), "Catholic Position" (133) and "The Jewish View" (133–134).¹⁰⁶ Comparison of these three sections reveals the legal nature of Jewish Medical Culture.

Within the "theologic" portion of the article, the section on "The Jewish View" is the only one that contains textual references. In addition to the endnotes are the references inserted internally in the text, as the following citation illustrates:

An infant younger than 31 days of life lacks human status in respect to the redemption of the firstborn (Yoreh Deah 205:11, 12); in that he does not exempt a widowed mother from the duty of contracting or dissolving the levirate bond (Even Ha'ezer 156:4); in that expiring, the family does not tear a rent in the garment for him (Yoreh Deah 311:30); and in that one does not mourn for him (Yoreh Deah 374:8). (134)

¹⁰⁴ We are also provided with how a formalized study of medical ethics was conducted before there was a specific field of bioethics; at least in 1967, in Texas, the religious point of view was considered important.

¹⁰⁵ In retrospect, the views of psychology expressed in Pepper's essay seem disturbing, especially in its unabashed acknowledgement that surviving twins are near monstrous; see Crane 2012 for a Jewish response to this anathematizing.

¹⁰⁶ That there are these three categories supports and follows the famous division of Herberg's *Protestant, Catholic, Jew* (1955). Moreover, I do not know why the Catholic position is introduced with different language; possibly it is for stylistic reasons.

The references here are to the *Shulchan Aruch* (a code of Jewish law); altogether there are nearly two dozen references to legal works in the Jewish section. The legalistic tone of the Jewish section stands in contrast to that on the Protestant view, which contains no references at all. This contrast makes sense: the modern concept of religion, as detailed by Batnitzky, does not have a legal culture, and in this respect Judaism stands apart from other religions. Even the section outlining the Catholic view contains no legal citations, despite the long-standing legal culture of Catholicism. The Catholic Church has a centuries-long history of cultivating an ecclesiastical–legal tradition, yet in this single 1967 case, the Catholic representatives did not cite their own canon in a legalistic manner.¹⁰⁷

The Protestant view of a hypothetical conjoined twins case is described as follows (eerily, this hypothetical case pre-figured the actual case in 1977 even down to the fact that it considered a set of “thoracopagus twins in whom a single heart is shared”):

In regard to the ethical considerations in the sacrifice of one conjoined twin to save the other twin, when both seem certain to die if no separation is achieved, Protestant ethics seem to pose no obstacle to the surgical act; the disjoining act should be viewed more as a positive act of saving or preserving than as a negative act of destroying life. The emphasis is that life is more than quantity of days; that life is measured by quality as well as longevity.” (Pepper, 130)

¹⁰⁷ By contrast, in the context of the 1977 case, the Catholic priest who gave religious counsel to the nurses overseeing the case at Children’s Hospital wrote a full explanation of his reasoning. This document, published in 1978, allows us to view the priest’s ecclesiastical–legal deliberation on this topic. However, as I will argue, even this document reads like a philosophical discussion rather than a legal one: the principles upon which the priest based his decision appear to emerge from a divine source, rather than a system of logic or reason.

In contrast, the Catholic view expressed discomfort with the surgeon making an active choice to kill one life in favor of another. This attitude, as we will see, came out in the 1977 in the discomfort expressed by Catholic nursing staff with the surgery performed by Koop:

As a guide in arriving at a mature moral judgment, Catholic moral theologians in such cases employ the principle that an innocent human life cannot be directly suppressed. ... This principle in turn is based on the fundamental fact that every human being derives his right to life, not from his parents, or from society, but directly from God. In the situation under consideration, the surgical procedure would involve basically the allocation of the common heart to one twin ... [yet] no matter what benefits may accrue to one twin, the indisputable fact remains that one twin is necessarily killed in the process of being surgically deprived of a heart. From this point of view, the Catholic moral theologian would have to render the judgment that it would *not* be morally permissible to separate conjoined twins where such separation would certainly result in the death of one or both twins. (133)

Segal's contribution to the 1967 report follows a structure familiar from the responsa literature: he begins by reporting the opinions of other authorities; he then engages the legal literature that informed both those earlier opinions and his own understanding; and he concludes with his final decision. This structure contrasts with that of the other contributions to the report: in beginning by presenting the conflict, Segal situates his contribution within a multi-vocal legal tradition to which he contributes his tie-breaking decision.

As he explains, "Of the four Jewish scholars asked for opinions [unidentified], two favored separation of the twins, even though it was quite obvious that one would die, and two stated that traditional Judaism would not permit this act" (133). The contributions by representatives of the other two religions in the report present an unambiguous conclusion, yet the Jewish source reports multiple opinions.

Segal's full discussion of the Jewish legal sources stands in contrast to both the philosophical language of the Protestant section, and the broad ethical reasoning of the Catholic section. The end of Segal's contribution describes his own ruling: "In summary, the participating rabbi felt that in a situation where conjoined twins are joined in such a manner that if they were not separated they would *both* die, and if they were younger than 31 days of age, and if the chance of survival for one of the twins were better than the other, Judaism would require a surgical separation be performed." (134)

The methodologies of the three religions in the 1967 panel highlight the divergent approaches of the different religions as a whole: the Catholic and Protestant discussions are philosophical or broadly ethical in nature, while the Jewish discussion is clearly framed as engaging a body of texts and a distinctive legal tradition constituted by those texts and their interpreters. This early 1967 discussion thus provides preliminary evidence that Jewish Medical Culture operates within a legal framework.¹⁰⁸

The 1977 Conjoined Twins Case

Facts of the Case

Conjoined twins represent one of the rarest forms of births, occurring in roughly 1 in every 200 identical-twin pregnancies. The incidence of conjoined twins vs. normal births ranges from 1 in 50,000 to 1 in 100,000 live births (Rees et. al. 1993). In most cases one of the conjoined twins is stronger than the other, and without medical intervention both twins may die. With surgery, it is possible in some cases to save the stronger twin while causing the death of the weaker one. Such intervention poses considerable ethical and religious issues. Although these

¹⁰⁸ For a discussion of Islamic approaches to the separation of conjoined twins, see Raffensperger (1977:250).

cases are relatively rare, advances in medical technology and surgical procedures mean that the dilemma about intervention in cases of conjoined twins arises more often than it might have in the past.

In September, 1977 a young Orthodox Jewish couple from Lakewood, NJ, “deeply religious” (as they are described in Drake 1977a), awaited the birth of a child. The mother gave birth on September 15 at Monmouth Medical Center in Long Branch, NJ (Shapiro 7A) to twin girls with a combined weight of 8 pounds, 10 ounces. They were conjoined twins and were “immediately transported to the infant intensive care unit at Children’s Hospital [in Philadelphia] to be treated for respiratory problems” (Shapiro 7A). The twins represented an anomaly: they were, in medical parlance, “thoracopagus twins,”¹⁰⁹ commonly known as Siamese twins. Their distinctive physiology was extremely rare in that they shared one six-chambered heart. According to *Philadelphia Inquirer* medical writer Donald Drake, whose article on the case is quite detailed and has been reprinted many times in subsequent retellings of the case,

Special X-ray studies the next day showed that the twin designated as Baby Girl B had an essentially normal, four-chamber heart that was fused to the stunted two-chamber heart of her sister, Baby Girl A.

The hearts were joined along the walls of the left ventricles, the main pumping chambers that push the blood through the body.

The connecting wall was only one-tenth of an inch thick - far too thin to be neatly divided in order to give each twin what belonged to her.

And even if this were possible, the stunted heart of Baby Girl A would not be able to support the child for long.

The doctors felt that they could not leave the babies the way they were either. They knew it would be only a matter of time before the overworked one and one-half hearts would start to fail, killing both babies. No twins joined at the heart like this had ever lived more than nine months. (Drake 1977a)

¹⁰⁹ University of Maryland Medical Center, “Facts about the Twins” <http://umm.edu/programs/conjoined-twins/facts-about-the-twins> (Accessed September 29, 2013).

When the parents learned that one twin (Girl A) would have to die in order to save the life of the other baby (Girl B), who had the normal heart, they believed that the ethical question “was much too difficult and important a question for the young rabbinical scholar [involved in the case], only in his early twenties, to try to answer on his own, so he consulted the rabbis in his community and the rabbis in his and his wife’s families. Soon Rabbi Moshe Feinstein, dean of Tifereth Jerusalem seminary in New York City, was called in” to offer his rabbinic decision determining the correct course of action (Drake 1977a).

Reports of the chronology of the decision-making process throughout the 1977 case situate the events in September and October. Until the present analysis, no previous description of the events have noted that this case took place during a significant time within the Jewish calendar, a time fraught with somber reflections on life and death decisions, referred to as the *yamim noraim* (days of awe) of Rosh Hashanah (the start of the new year) and Yom Kippur (the Day of Atonement). According to Drake (1977a) and others, the twins’ father and rabbis met with the pediatric surgeon, Dr. Koop, on September 20.¹¹⁰ And then, three days later, the rabbis met again with Dr. Koop, but this time without the parents. Within the Jewish calendar, the twins were born on the day after Rosh Hashanah¹¹¹ and the first meeting, on September 20, was the day before *Kol Nidre* eve, the numinous eve of Yom Kippur and the most solemn day of the year. The “three days later” (September 23) referred to by Drake was the day after Yom Kippur. In the Jewish calendar, the period when the team of doctors were waiting for the rabbis to make their decision, was the Biblical holiday of Succoth, which began that year on the eve of September 26, and ended with *Simchat Torah* on October 5. The concurrence of the religious

¹¹⁰ Dates in this paragraph are taken from Drake (1977a, 1977b, 1978).

¹¹¹ This day is called *Tzom* (The Fast of) *Gedaliah*, which is a day of fasting that is alluded to in Zechariah 8:19.

holidays in all likelihood played a role in the length and difficulty of communication between the rabbis in New York and the doctors in Philadelphia. The rabbis returned with a decision the day after all the holidays were over: October 6.¹¹² Once the decision was made to permit surgery to separate the twins, it was scheduled for October 11.

On October 10, Children's Hospital, with the future Senator Arlen Specter as its lawyer, went to court to ask for the court order that would sanction Dr. Koop's method of surgery—that is, to kill the debilitated twin, sacrificing one child for another. It happened that October 10 was Columbus Day, a day when the court would usually be closed in honor of that secular holiday. Ironically, given the inability for the Jewish “court” to expedite deliberation on the Jewish holidays, the secular court met in special session to prepare a court order giving Koop the right to perform the surgery legally.

In the newspaper report the day after the surgery, the hospital staff explained to an interested public: “there had been only six known surgical separations of Siamese twins joined at the heart and that only three of those were described in medical literature. Only one person has survived” (Shapiro 1A). This would be the third separation surgery to be done at Children's Hospital by Dr. Koop; the first was in 1957, the second in 1974, and both resulted in at least one surviving twin (Shapiro 7A). While previous efforts at separation of thoracopagus twins had failed, this time, at Children's, it was to be attempted by Dr. Koop, a renowned and skilled surgeon who had performed separation surgeries on other cases of twins. Still, none of those other cases involved twins with a shared heart.

¹¹² It is possible that were the rabbis convinced that a decision fell under the legal rubric of saving a life that the “court” would have been able to override the travel and communication restrictions of the holiday and provide the hospital with a ruling. That the rabbis did not do this can indicate a number of possibilities. It is possible that the rabbis were responsible for many activities related to the “high holy days.” I do want to tentatively suggest that many people involved in these cases, including parents (as since in the 2000 UK case) seem to subconsciously hope that with slow enough deliberation, the case will resolve itself if “nature takes its course.”

Following the surgery, Dr. Koop commented that “the surviving girl had only a 5%-10% chance of staying alive after the separation. “Right now, I feel very hopeful” (Shapiro 1A). While the intricate surgery separating the hearts of the twins was considered successful, other complications led to the death of the surviving Baby B forty-seven days later. The medical reporter Drake noted that once the weak twin had been sacrificed to save the child with the stronger heart, “it was not the abnormal heart that eventually killed Baby Girl B, but liver trouble and an infection that doctors could not stop” (Drake 1978 1A). Specifically, Baby B died as a result of contracting hepatitis B from a blood transfusion (Bleich 1996, 100).¹¹³

The details of this case from both medical and ethical perspectives have been described in only a small number of articles and thus an accurate historical account of the events is not reliably available.¹¹⁴ However, the family insisted on complete anonymity and to this day their names have not been revealed.

The Religious Context

Through happenstance, the 1977 twins case involved representatives of Herberg’s “three religions”—Protestants, Catholics, Jews—also the three religions represented in the 1967 panel. Dr. Koop was a devout Protestant; many of the nurses were Catholic; and the family of the twins

¹¹³ An important aftermath of the story is that the family, which up to that point had been following the rulings of Rabbi Feinstein, rejected a ruling of Feinstein’s spokesman, Tendler, by refusing to allow an autopsy. As Drake explains, “The parents, Orthodox Jews, refused to permit an autopsy. Rabbi M. D. Tendler, an authority on Jewish law, had advised the parents, who called him yesterday morning, that an autopsy would be permissible in such’s case as this. In fact, he said, there was a religious obligation since such an autopsy would not be a “fishing trip” but something that might help prevent similar deaths in the future. But Baby Girl B’s grandfather, himself a rabbi, felt differently, and the family declined” (Drake 1978). The question of autopsy is another important case for Jewish medical culture as it relates to the inviolability of the human body (called *kavot ha-met* in *halakhic* terminology). Considering the extreme rarity of thoracopagus conjoined twins, every autopsy would give information that would add to medical knowledge and potentially help save further lives.

¹¹⁴ The most authoritative account appears to be from the contemporaneous reporter, Donald Drake. There are no other contemporaneous accounts. Koop’s autobiography was written 13 years after the event and is brief in its description. Furthermore, Koop’s sole biographer, Gregg Easterbrook, does not seem to be wholly reliable in his account (see below). Drake is still alive but he has not yet responded to my request for an interview.

were Orthodox Jews. How the three groups conducted their ethical inquiries around the decision-making process follows a pattern that reflects each of these religions' medical culture. These cultures are reflected not in the conclusions reached by each group but in the methods preferred to reach the conclusion. Each community has advocates who promote inaction as well as those who would call for the surgery—often for the same basic reasons—yet the means by which they reach those conclusions vary widely.

The Jewish Family

The young Lakewood couple came from a “prestigious family of Torah educators” (Tendler, 26) yet they did not rely on their family or their Lakewood community for assistance with the decision-making process, but instead sought out Rabbi Moshe Feinstein to review the details of their case and to render a decision as to what they should tell the doctors: should they do nothing, letting nature take its course, or should they agree to an operation that would almost certainly kill one child to save the other?

Rabbi Moshe Feinstein (1895–1986) was born in Uzda, White Russia, immigrated to the United States in 1935, and was already recognized as a budding rabbinic leader among the Torah scholars in Europe.¹¹⁵ When he arrived in the U.S., a large contingent of rabbis came to welcome him, including the rabbinic head of Yeshiva University, Rabbi Moshe Soloveitchik. In the words of Tendler, Feinstein “was the moral and halakhic conscience of the Torah community. Nowhere was his leadership more keenly felt than in the area of critical care medicine, where his empathy, sensitivity, and intellectual integrity were so widely recognized” (Tendler vii). At the time of the

¹¹⁵ Tendler 1996, Introduction. The information about Rabbi Feinstein is derived from Rabbi Tendler's “Introduction” found in *Responsa of Rav Moshe Feinstein: Translation and Commentary*, Vol. I: Care of the Critically Ill. Hoboken, N.J.: Ktav Pub. House.

1977 case he was a world-renowned *posek*, serving as an authoritative adjudicator of Jewish Law for the world's Orthodox Jews.

Rabbi Moshe Dovid Tendler (1927–) married Feinstein's daughter Shifra¹¹⁶ and is both a rabbi as well as a professor of biology at Yeshiva University, having received a Ph.D. in biology from Columbia University in 1957. Tendler, too, is known for his expertise in medical ethics, having written and lectured widely on several controversial subjects, including end-of-life issues. He translated the various medically-oriented responsa of Feinstein into English; this translation represents the only printed statement from Feinstein's "court" concerning Feinstein's reasoning on the conjoined twins case. Tendler acted as a proxy for Feinstein during all the discussions with Koop and the staff of Children's Hospital. Feinstein did not go to Philadelphia himself.

Koop the Protestant

Koop's historical fame as U.S. Surgeon General has lent this case a measure of prominence.¹¹⁷ But more than his fame, Koop's identity as a religious doctor—a key factor in his appointment to Surgeon General—is important to our understanding this case as it relates to Jewish Medical Culture.

Koop was a devout Presbyterian, and he appeared to share the sentiments of the Orthodox Jewish family. He also had a relationship with religious Jews, as he described in his autobiography:

The operation was very tense....After producing the death of one twin it took me a little time to separate the body from that of the survivor. I then tenderly wrapped the body in a

¹¹⁶ It is not uncommon for rabbinic leaders to form dynastic succession through sons-in-law, as we saw above with Rabbi Z.N. Goldberg.

¹¹⁷ For background on Koop and his surgical renown, in addition to his autobiography (1990a), see Anonymous 1957 for his earliest cases, and Anonymous 1974 for the most celebrated case before the 1977 Lakewood twins.

sheet and carried it to the door of the operating room, where I was told a rabbi would be waiting to take the body for burial. When I opened the door, I found an old friend. Rabbi Mandelbaum, whose presence somehow made me feel better about the whole affair. I had operated on many of his innumerable children (Koop 1990a, 113).¹¹⁸

Koop was chief surgeon at Children's Hospital of Philadelphia from 1948 to 1981.

According to Koop's biographer Gregg Easterbrook, "he was celebrated within the medical community as the founder of modern pediatric surgery" (Easterbrook 2001). In Philadelphia he was known as the doctor who saved many children whose cases were considered hopeless, and most notably, for his work with the conjoined twins.

In his autobiography, Koop notes that "my colleagues and I operated on over ten pairs of Siamese twins while I was at Children's Hospital, but three pairs became well known" (Koop 1990a, 144). The first case of conjoined twins that Koop had dealt with arose in 1957. Patricia and Pamela Schatz, who were joined at the base of their spines, were successfully separated. Although Pamela later died at the age of nine from a congenital heart defect, the surviving twin, Patricia, lived on to marry and invited Koop to her wedding (Koop 1990a, 144).¹¹⁹ Koop urged the parents to treat the twins as "normal kids"; his philosophy was that they were not "hot house children" (Lowry).

¹¹⁸ I have not been able to identify this Rabbi Mandelbaum, nor is there record of Koop asking him for specific Jewish insight into the medical ethics, or even for how to deal with the family and their rabbis. Many years later, in 2012, Koop still recalled his encounter with Rabbi Mandelbaum and its profound effect on him. The medical reporter, Drake, had turned the story of the 1977 conjoined twins into a play. An article reporting on an interview following the premier of this play includes the following description of Koop's response: "The reading brought back to mind his own '**religious**' **moment** during the surgery. He explained that at the children's hospital he had been caring for the children of a rabbi [Mandelbaum], and talked to the rabbi about the twins. Still, Koop had not planned on what to do with the body of the baby destined to die during surgery. 'When I tied off one carotid artery and killed a child,' Koop said, 'I'd given no thought about what would happen to the body... I had one dead baby and one live baby; I separated them. One of the nurses took the child who was now dead and carried it to the door of the operating room. The door opened and there stood the rabbi.' He continued: '**The fact that he was there seemed almost like God's blessing on what I had just done.**'" (emphasis mine)

¹¹⁹ In a strange coincidence, the conjoined Pamela and Patricia Schatz were born on Sept 27, which was the second day of Rosh HaShana, and then separated on October 5, 1957, which was Yom Kippur on the Jewish calendar, 5718.

Koop's fame as a pediatric surgeon began in 1974, with the successful separation of conjoined twins from the Rodríguez family, from the Dominican Republic. In recollecting the surgery eight years later (in 1982), he wrote, "I began the day with prayer, I also read the Bible. A verse in Psalms which said the Lord will support the righteous became my help in time of need" (Nason, 16). Both twins survived the surgery. Despite his affiliation as a Presbyterian, he went to the Dominican Republic to preach in the family's Roman Catholic Church "in a service of Thanksgiving...after the separation and again on the first anniversary" (Nason, 16). Tragedy struck two years later, however, when Alta, one of the twins he saved, died in an accident by swallowing a bean that became lodged in her throat. Koop went again to the Dominican Republic, to speak at the funeral. In commenting on his motivation he said, "It was only fitting that I go down at the time of sadness and remind the townspeople that God is sovereign in all things, that we had thanked Him for the separation, and now we should thank Him for taking Alta home to Himself" (Nason, 16).

In a *People Magazine* report describing the event, the terms used in this popular magazine reveal the common attitude regarding such anomalies: When the Rodríguez twins were born they were "doomed...to sharing the same grotesque body"; the surgery, according to this magazine article, "made each little girl a reasonably normal human being." While the Rodríguez family called Koop and the doctors "gods," Koop described himself as "a pretty deeply committed Christian, a Bible-believing conservative evangelical" (*People* 1974: 19).

In his description of Koop, medical reporter Drake includes the crucial information that he was a Presbyterian, and, like the parents of the 1977 twins, "a deeply religious man" and one "who has frequently spoken out nationally about the sanctity of human life" (Drake 1977a).

Easterbrook's description resonates with Drake's; in Easterbrook's portrayal Koop was deeply committed to a religious world view:

Generally, Koop paused to pray before beginning an operation, though he says he did this not in the sense of asking for some dusting of magic but to help concentrate his thoughts on the task ahead and what really matters in life. But in events like the death of a child, the world of faith takes on additional meaning. In Protestant doctrine, one who has tried to live a moral life and has accepted Christ not only goes to heaven, but is in every way better off than when on earth. So there is no cause to mourn his fate. Several Christian interpretations say that the real victim in the untimely death of a righteous person is not the deceased, but the surviving family and friends, who must go forward with a ray of light removed from their lives. Even if the loss is difficult, however, this view teaches that Christians must accept it as a manifestation of God's divine plan" (Easterbrook 1991, 19–20).

Koop is quoted as commenting that "[H]e attributes his self-possession to 18 more years of experience plus what he calls 'my anchor—a complete belief in the sovereignty of God. 'Having that, knowing that someone else is running the show,' he says, 'gives me a tremendous amount of comfort'" (Snider).

Koop himself suggested that his religious outlook defined his work as a surgeon. He regarded the human body with awe, and said he felt the sanctity of human life (Drake 1977a). He indicated that for him, surgery was an ultimate expression of his sense of awe. In his autobiography he wrote, "I love surgery because I have always had an abiding reverence for the human body, reverence for the ways its anatomical details allow it to function...reverence for the tissues themselves, especially the delicate ones of infants" (Koop 1990a, 99). This outlook, combined with his compassion towards helping children, led him to champion the field of pediatric surgery, significantly improving survival rates and developing numerous surgical techniques. His fame in later years was directly tied to the advances he made in the field of pediatric surgery and to his opposition to abortion and the ill-treatment of children.

It was this public advocacy that attracted the Reagan administration to appoint him as Surgeon General. As surgeon general, Koop advocated strongly for the protection of the lives of children, especially those with severe disabilities, as seen in the “Baby Doe” case, as he says: “Having devoted my career to saving the lives of hundreds of such infants [like Baby Doe], I could not remain detached (Koop 1990a, 240).”¹²⁰ “Baby Doe” was the name given to a severely handicapped infant born in 1982 who perished after being actively denied medical care that would have allowed it to survive. Koop used his role as Surgeon General to lobby Congress to create legal protections for such “futile” children. In 1984 the Baby Doe law was passed as part of legislation against child abuse.¹²¹

Koop’s self-identified devotion to handicapped children, as seen in Baby Doe, would have had him see any solution that required passively standing by while both children died as infanticide. As with Baby Doe, he likely believed he had a mandate to protect Baby B.

A vital point about Koop’s religious attitude towards medicine is that he saw complex cases as opportunities to help heal, given his ability and knowledge. As seen in “Baby Doe,” in instances where others might see the birth of conjoined twins as a sign that the babies were *meant* to die,¹²² Koop felt that he had a divine mandate to help and to heal based on his knowledge and skill. He saw his work as helping to perfect nature: “I loved the technical challenge of surgery when it could repair what nature had failed to complete” (Koop 1990a, 101). For Koop, knowledge could turn a crisis into a possibility of health. His knowledge of

¹²⁰ See also Koop (1990b) for a specific essay he wrote about end-of-life.

¹²¹ See Koop (chapter 10, 240-261), as well as the NIH section of Koop’s papers (<http://profiles.nlm.nih.gov/QQ/Views/Exhibit/narrative/babydoe.html>)

¹²² The notion of being “meant to die” can be from a secular or religious perspective. Many secular ethicists responded to conjoined-twin cases – e.g. the 1993 Lakeberg case – with appeals to institute protocols of “medical futility”; see Brandon (1994), Dougherty (1993), Thomasma et al (1996), Zucker (1993). From a religious perspective, tacit acceptance of futility would be present in those who advocate a perspective of medical naturalism (Zohar 1997).

medicine and pediatric surgery led him to strive to save lives and not condemn patients to death through neglect or inaction. For example, in the case of the Rodríguez twins, “The parents didn’t want the operation if it meant that one of the girls had to die so that the other could live.” Koop reassured the parents, as recalled by the translator in the case, a Mrs. Zimnoch, and they agreed to move ahead with the surgery.

As an adult, Koop, together with his family, was active in his Church. This became crucial when his own college-age son, David, died in a freak mountain climbing accident. Koop’s good friend, Dr. Patrick Pasquariello, a pediatrician at Children’s Hospital, told Easterbrook that “After his son’s death, religion may have become even more important in the life of this already religious man” (Easterbrook 1991, 18). Easterbrook supports this claim by noting that “Koop’s family had long been churchgoers, active in the Evangelical Presbyterian denomination; the Bible in David’s dorm room was open on his desk the day he died” (18–19). Koop did not talk about this link to David in his own writings.

Indeed, as noted above, Protestant doctrine would have mandated an acceptance of David’s death as a result of divine will. But this acceptance of death after the fact does not mean that Koop was willing to let death take its “natural” course when he could intervene medically to prevent it.

Because of his moral and religious philosophy, Koop was particularly sensitive to the parents’ need to await a rabbinic decision before they would agree on the medical path to follow for their children. In his autobiography, written years later, Koop summarized for us his reasoning for his decision to do the surgery:

The twins had one six-chambered heart, which was failing because it could not support the life of the two growing children. In order for one twin to survive, the other would

have to be sacrificed. This was an extraordinarily unusual and difficult situation. Religious issues made it even more difficult. Both of the grandfathers were Hasidic (sic) rabbis, and they insisted on a seven-day Talmudic argument on the ethical issues involved. I was just as concerned, but I wasn't sure the children would survive the long argument. Eventually we all came to the same position: One twin, the smaller, was essentially a parasite on the other. It was clear we had no choice about which twin would have to be sacrificed" (Koop 1990a, 112).

While medically, it might have been "clear," the parents of the conjoined twins followed traditional Orthodox practice and first went to their rabbinic authorities to determine what should be done in this terrible medical dilemma—a situation in which a birth became a question of life and death. In the end, both Koop and the Orthodox Jewish parents of the twins reached the same conclusion—namely, that the surgery should proceed despite the certainty that one of the twins would die. However, the distinctiveness of Jewish Medical Culture lies in the process: whereas Koop meditated on the problem in a spiritual, solitary manner, the Orthodox Jewish parents of the twins engaged in a lengthy legal process—a thumbprint of pre-modern Judaism.

The Catholic Nurses

As described above, the family of the twins and their chief surgeon were both animated by religious concerns about proper medical treatment. Drake's account adds a third group with such concerns: many of the nurses at the hospital, mostly Catholic women, were vocally worried about the proposed treatment, especially as it would lead to an active killing of an infant. They are reported to believe that Catholicism considered an inviolate sanctity of each life without regard to "quality of life" concerns. Drake summarizes the issues of the nursing staff with respect to the case:

Word spread through Children's Hospital that surgeons were planning to sacrifice one of the Siamese twins. [...]

Mrs. Jane Barnsteiner, who is Catholic and the associate director for clinical nursing, was asked about the twins by head nurses as she went about the hospital each day on her rounds.

The Catholic nurses, of whom there are many, were particularly concerned that the surgeons might be doing something that violated the teachings of their church.

The word "sacrifice" was used so much by the nurses in discussing the matter that Mrs. Barnsteiner herself became concerned and decided to consult a priest.

At the same time, the nurses in the operating room were becoming particularly uneasy because they knew that they would be called upon to participate in the surgery, if it took place. [...]

Miss Betsch said that she would consult a priest. A Catholic herself, she would not want to participate in the surgery if it went against her church" (Drake 1977a).

Complicating these concerns was the knowledge by the nursing staff of Koop's "pro-life" advocacy: "[The] Roman Catholic nurses [were] aware of Koop's pro-life's stance," and so his "decision [to perform the surgery] shocked his hospital staff" (Kattner 1).

As seen, the word "sacrifice" was of particular concern to the Catholic nurses. At the time, Koop did not seem to consider his decision to be sacrificial. The nurses "at first refused to help him kill one of the babies. Koop said that he told the nurses, 'I can watch two babies die slowly or one die swiftly'" (Kattner 1). It appears from Koop's comments that his concern was not that he would "sacrifice" one child for another, but that there was a way to save the life of a child who was being threatened with imminent death because of her rare condition.¹²³

¹²³ Nevertheless, the word "sacrifice," which the nurses were so distraught about, was used later by Koop himself, in his autobiography: "In order for one twin to survive, the other would have to be sacrificed" (Koop 1990a, 112). Shapiro, a Philadelphia Inquirer staff writer, presumably at the press conference on October 11 following the surgery, did not use the term "sacrifice" either; rather, he employed the more clinical wording, writing that Baby B was "separated" from her sister and that "the other girl died." (Shapiro, 1A). On November 20th, Drake, the *Philadelphia Inquirer* medical writer, followed up on the condition of the surviving twin, who at that point was suffering from many post-operative ailments; he was the first to use the term "sacrifice" relating to Baby girl A in the paper (Drake 1977, 14A). In the January 12th article, Drake reported on the death of Baby B and used the phrase "purposely let die" to describe Baby A's previous death. (Drake 1978, 1A). The operation was done on Oct 11 and Baby B survived until January 11th, the third of Shevat 5738.

Meehan (1978), an associate professor of moral theology at a Catholic seminary, acted as a consultant to the Catholic nurses in the case. He writes, “A few days before the operation I was called into consultation by a priest, who himself had been contacted by some nurses. These were Catholic nurses, who were scheduled to assist at the operation, and who were puzzled about the problem of the operation ending in the death of one of the twins” (157). Ultimately Meehan advised the nurses that it would be permissible to participate, despite the opposition from the 1967 report, because of the doctrine of “double effect”: “any action having two effects—one good and one bad—is permissible, if 1) the good effect does not come by means of the bad effect, and 2) there is proportionate reason for permitting the bad effect.” He does not cite a source in canon law for this concept; however, he does refer to the reasoning of the Jewish theologians in the case.¹²⁴ Meehan alludes to the analogy, which he says was “used by the Rabbis considering the case and also used to obtain the court order”—namely, the analogy to a mountain climber whose life is endangered by a fellow climber (158).

Meehan’s statements about the Catholic position mention that the death of Baby A would be indirect: “It is an inevitable side effect and therefore not a bad means to a good end... The moral indirectness of Baby A’s death is reflected in the physical realities of the case, namely, the impossibility of saving both children.... These realities give flesh to the concept of moral indirectness. They are such as to allow that the death of Baby A is unintended and that it is therefore not a morally evil means, but rather a premoral physical incidental misfortune” (163-4).

This reasoning is especially significant because it conflicts with the Catholic position in the 1967 report, and also, as we shall see, with the position of the Catholic authorities involved in

¹²⁴ The absence of references to canon law in Meehan’s discussion is noteworthy, as it represents a departure from a legal methodology with a long history in Catholicism. For an example of a more legalistic approach to medical issues in Catholicism, see Moodie 1993. When asked to deal with religious law, the Catholic contributors to the Moodie symposium adopted that rhetorical strategy.

the 2000 conjoined twins case in the United Kingdom. Furthermore, Meehan's is a very tightly argued legal-philosophical piece, which the author even describes as "Catholic casuistry" (160), yet there are no references to legal works. He himself suggested that he was influenced by the rabbinic legal argument.

In 2000 a case of conjoined twins arose in the United Kingdom, and the Catholic authorities reverted to the 1967 position. A set of conjoined twins was born to a Catholic couple living in Malta, who brought the children to England to be treated.¹²⁵ This case is similar to the 1977 case only in two points. First, the medical consensus was that one twin would have to be "sacrificed" (see footnote above) so that the other twin could live; and second, like the parents in the 1977 case, the parents in the 2000 case were attempting to follow their religious beliefs in arriving at a decision. Their interpretation of their Catholic tenets led them to refuse to allow the operation, and to let "God decide" (Anonymous 2000 in *Christianity Today*). The apprehensions of the Catholic nurses in the 1977 case may be readily understood in light of the 2000 case. In the 2000 case, however, the state intervened to force the operation to save the stronger twin. She is still alive as of 2015.

In the 2000 case the Catholic British clergy (including the Archbishop of Westminster as cited in Phang [2001b:108]) ruled against separating the twins, and in doing so, they rejected the arguments of Meehan. They explicitly abandoned the principles of "double effect" (Watt 2012 and Wenkel 2006). Phang suggests that other Catholic authorities might have ruled in favor of separating the twins; he cites the statement of Germain Grisez (108-109), for example, whose

¹²⁵ For the primary source facts about this case, see England and Wales Court of Appeal (Civil Division) Decisions (2000a, 2000b), and *In re A* (2001). For perspectives on this case by legal scholars, see Anonymous (2002), Davis (2011), Freeman (2001), Hewson (2001), McEwan (2001), Sheldon and Wilkinson (2001), Uniacke (2001), and Watt (2001); for commentary by bioethicists, see Cowley (2003), Harris (2001), and Paris and Elias-Jones (2001); and for the view of Roman Catholic experts see Latkovic (2001), and Phang (2001a, 2001b).

reasoning follows that of Meehan: “[I]n my judgment, if one baby certainly or probably will not survive the surgery, the attempt will be unfair to that one unless two conditions are met: (1) without the surgery, the abnormality of the babies’ shared organ(s) is likely to result soon in the death of both, and (2) with the surgery, the prospective survivor's prospects are greatly improved” (Phang 2001b:109f260).

The Involvement of the State

The decision to seek legal protection as described by Drake seems to have been motivated by a quirk in Pennsylvania law that would allow prosecution to be brought by anyone—even a person with no direct ties to the case.¹²⁶ Koop’s autobiography notes that his motivation was due to a specific political concern: “A friend warned me that my pro-life position had made me some enemies, and I might be taken to court in a civil suit in Pennsylvania if I deliberately brought about the end of life of one twin. I therefore demanded a court order to do the separation” (113).

As a result of Koop’s pursuit of legal protection from the government, documents exist that attest to the similarities between the Jewish authorities’ argumentation and the legal argumentation of the secular court; in particular, the analogies they use are strikingly similar¹²⁷:

The lawyers then went to their second line of reasoning and judicial precedent, which said that what might appear to be a crime is not a crime if a court rules that the good

¹²⁶ I have not been able to find any vestige of the court record of these deliberations. Davis (2011:432 f13) confirms that “there is apparently no written record of the hearing or decision.” It is noteworthy that when the British Court in 2000 cited our 1977 case, they too did not use the court records; rather they depended on the secondary accounts of the case, specifically from Annas (1987).

¹²⁷ The similarity between the analogies is such that some later articles that reference the 1977 case conflate the arguments of the two “courts”—that is, the secular court and the Jewish “court.” (Thomasma 1996:6).

outweighs the bad and accordingly hands down a court order. Because there is greater good served by saving one child instead of losing both of them, the court would be justified in issuing such an order, the lawyers insisted” (Drake 1977).

As shown in this excerpt, Koop was protected in this case by the law of “**justification of necessity**” —a law later used by the British Court in the 2000 conjoined twins case, as I will show below— which stipulates that an action that seems like a crime is justifiable because of the greater good.¹²⁸ One of the precedents cited by the hospital’s lawyers in the 1977 case dealt with a fire on a boat: most of the sailors were unable to escape because the porthole that would have led them to safety was being blocked by a panicked sailor who was not moving. The other sailors threw him aside to his death in order that they could escape. In that case, the sailors’ action was justified because it saved so many lives.

Not only was the pursuit of a legal defense used by Koop but in a remarkable coincidence at the very same time there was another American case of conjoined twins that also pursued legal protection for separation. As detailed in a medical article in the *Journal of Pediatric Surgery*, on September 14, 1977, conjoined twin girls were born in Arkansas—a day before the New Jersey twins birth (and, in the Hebrew calendar, the second day of Rosh HaShanah). These twins are described as “dicephalus dipus tribrachius;” and unlike the New Jersey twins each had a heart. In contrast to our Philadelphia case, Golladay et al. (1982) describe an almost clinical assessment of the need to separate the twins as well as a need to secure legal protection:

“During analysis, it became increasingly apparent that the twins could not be successfully separated with survival of both. After considerable discussion with the parents, with the

¹²⁸ Justification “is a reason for committing an act which otherwise would constitute an actionable wrong or tort. It is an ancient principle of the common law that a trespass may be justified in many cases.” (<http://definitions.uslegal.com/j/justification/>). Related to this concept is “necessity” (<http://definitions.uslegal.com/n/necessity/>) where “defendants argue that their actions were necessary to prevent a greater evil. A person can use physical force upon another person when s/he reasonably believes that it is necessary to defend himself/herself or a third person....Necessity amounts to a defense of justification in most states.” See Summers (1997) for more about the linkage between justification and necessity.

[Arkansas] State Attorney General, and the County Prosecuting Attorney, a decision was reached. The parents desired separation. The Prosecuting Attorney, with the Attorney General concurring, concluded that surgical separation of the twins was protected by the **law of justification** in the constitutional **right of privacy** and that no criminal prosecution would result from the demise of the right twin as a result of the surgical separation.” (Golladay et al, 259, emphasis mine)

While in both cases the parents agreed to separate the twins, the New Jersey case is noteworthy—especially in light of Jewish Medical Culture—in that the parents required religious guidance to come to that decision.

It is significant that, in the Arkansas case, the Attorney and the Attorney General (future president William Jefferson Clinton¹²⁹) connected the issue of justification with the right of privacy. Golladay describes the right of privacy as one of the principles established in the Quinlan case (1975), to the effect that a family has the right to determine its members’ medical fate. The Constitutional right to privacy had been most fully established in the case of Roe v. Wade in 1974, though this right was and remains controversial. The Arkansas twins case was occurring simultaneously with the case in Philadelphia and in both, the principal actors sought legal protection for the medical staff and family.

However, in the Arkansas case, as described in *Journal of Pediatric Surgery*, the need was for legal clarity as the case was not weighed down with the political overtones related to the

¹²⁹ The account in Clinton’s autobiography reads as follows: “Another really interesting problem I faced as attorney general was literally a matter of life and death. One day I got a call from the Arkansas Children’s Hospital. It had just recruited a gifted young surgeon who was being asked to operate on Siamese twins who were joined at the chest, using the same systems to breathe and pump blood. The systems couldn’t support them both much longer, and without surgery to separate them, they both would die. The problem was that the surgery would certainly kill one of them. The hospital wanted an opinion saying that the doctor couldn’t be prosecuted for manslaughter for killing the twin who wouldn’t survive the surgery. Strictly speaking, I couldn’t guarantee him that, because an attorney general’s opinion protects the person receiving it from civil suits but not from criminal prosecution. Nevertheless, the opinion would be a powerful deterrent to an overzealous prosecutor. I gave him an official letter stating my opinion that the certain death of one of the twins to save the life of the other would not be a crime. The doctor performed the operation. One twin died. But the other one lived.” (Clinton 373–74).

views of Koop. Ultimately, the Arkansas lawyers referred to principles similar to those that were used in Pennsylvania.

The Jewish Process

Phang (2001b) notes that the Jewish argument “may be consistent with Koop’s own reasons,” but Koop did not follow the same process as the Jewish *poskim* in determining the case. He writes, “it is clear that this was not the focus of his own process of reasoning, save, perhaps, by way of confirmation of what he felt was God’s will in the matter.” (108) Phang believes that Koop operated according to Christian principles in decision making, specifically “*the requisite guidance by the Holy Spirit is the key*” (108, emphasis in original). Herein lies the most significant difference between Koop’s process of determination and that of the Jewish *poskim*. While Koop was guided by faith, Feinstein followed a legal process. In this, as I will suggest below, he was adhering to an understanding of Judaism that encompassed not only spiritual aspects, but also legal and ethical aspects as well (Batnitzky 2011; see below).

Tendler’s description of the case relates that he specifically went to meet with Koop to ascertain the pertinent medical facts:

On September 20, I met with Dr. Koop and his staff to determine the medical facts. The first halakhic concern was to establish that we were, in fact, dealing with two separate human beings. Although they were joined at the chest and their livers were co-joined, as were the hearts, the girls were separate human beings with their own brains and nervous systems. Dr. Koop recommended that the twins should be separated as soon as possible, because there were signs that the heart was failing and could not maintain the load of supplying blood to two infants. It was emphasized that even with surgery the chance was slim that one could be saved. Never before had Siamese twins been successfully separated from a ventral connection, and certainly not when they had a joined liver and a single heart between them. (Tendler, 126–27)

For *halakhic* reasoning, it was important to know that the conjoined twins were two separate human beings. Koop and his team did keep the rabbis informed as to changes in the medical condition of the twins. At one point, on October 3, (which was an intermediate day of Succoth), Feinstein was told that there had been changes in the heart rate and respiration (Drake 1977a). Feinstein then asked Koop (through Tendler) another key medical fact: “Was Dr. Koop sure that the six-chambered heart could only be given to Baby B? Could it not also be given to Baby A and have Baby B die? Dr. Koop responded that there was no doubt that the only infant who could be helped by surgery was Baby B, because in addition to the shared liver and heart, Baby A also had a circulatory defect that would not permit her to survive any length of time, even if she were given the six-chambered heart” (Tendler, 127).

On the basis of these and other pertinent data, Feinstein was able to make his deliberations and render a decision. His reasoning was not written down at the time, but was recreated from memory by Rabbi Tendler for publication in Feinstein’s medical writings in 1996. All the subsequent commentaries rely on Tendler’s rendering of the story as well as the articles by Drake. According to Tendler,

Rav Feinstein compared the case of the Siamese twins to this classic case of the conflict for survival between a mother in childbirth and the fetus. Baby A had no independent ability to survive. Her entire survival was completely dependent on her sister, who had the circulatory system to back up the functioning of the heart and liver. To Rav Feinstein’s critical question, “Can the heart be given to Baby A and she would live?” Dr. Koop had responded, “No, there is no way to save Baby A. The issue is only should both die or should Baby B be saved.” Without the attempted separation, both would surely die, and therefore in halakhic terminology we classify the baby that had no independent survival, Baby A, as the pursuer, as if she were pursuing her sister and threatening her life. (Tendler, 129–30)

Tendler also added that this line of reasoning, the analogy to a mother in difficult childbirth, was Feinstein's perspective, but that "an objection was raised" (Tendler, 130). Tendler then devotes the rest of the chapter to an elaboration of what he calls "a second approach that leads to the same conclusion, but based upon a different halakhic principle" (Tendler 1996, 131). He recorded it "since it was presented in great detail during the discussions that led to the final permissive ruling." In a close reading of this comment, we should note that Tendler introduced himself into the discussion and this presents a confusing point in discovering Feinstein's reasoning. Tendler reported in the passive voice "a second approach," without identifying the originator of this other line of reasoning, which Feinstein ultimately rejected. It is as if a Supreme Court decision reached by the majority is presented by the author of a concurring second opinion that had been rejected by the majority; yet author of the second, rejected opinion presents it in a manner that gives pride of place to the rejected opinion and confusedly displacing the major reasoning. Remember that Feinstein did not publish his reasoning in his own voice, and what we read is Tendler's narrative of the events.

According to the Mishna, it is forbidden to give one life for another with the only exception is for a mother delivering a baby (Mishna Ohaloth 7:6). According to that passage, one may sacrifice the fetus if it is still fully enclosed within the mother's womb. However, once the head of the baby emerges, it is considered alive, and neither life may take precedence over the other.

This Mishna is expanded in the Babylonian Talmud Tractate Sanhedrin (72b), which asks whether the baby is considered a *rodef*—a pursuer. The answer given in the Talmud is that the pursuer is not the baby, but Heaven itself. It is not the baby who is attempting to destroy the mother's life, which means that the baby cannot be sacrificed to save the mother's life.

According to Tendler, Feinstein reasoned that the mother's life takes precedence when the fetus is dependent on the mother for life. Hence, once the head emerges, the fetus becomes a baby and can live even if the mother is dead. Similarly, in the case of the conjoined twins, Baby B is analogous to the mother in the case in the Mishnah. Baby A is analogous to the fetus in the sense that she is completely dependent on the life of Baby B. This is clearly seen from the fact that Baby B was able to survive without Baby A. By contrast, there was no chance that Baby A could have survived if Baby B had died. Koop confirmed, once the surgery started, that Baby A would not have been able to survive independently.

The reasoning laid out in the Mishna Ohaloth cited above provides an explanation for the questions that Feinstein is reported to have asked (Drake 1977a). In asking whether the six-chambered heart could have been given to Baby A instead of Baby B, he was asking whether Baby A was truly dependent on Baby B for life. According to Drake,

Dr. Koop could not understand why he was being asked such a question, but he told them no. The circulatory system was set up in such a way that the transfer could be made only to Baby B.

Then Rabbi Tendler asked whether Dr. Koop was certain that Baby Girl B would also die, even with the surgery.

Dr. Koop said that Baby B probably would die regardless of what was done, but that it was not a certainty (Drake 1977a).

In Tendler's narrative, significantly, it is only after Feinstein received the answers to these questions that he gave his decision that surgery was allowable:

The halakhic concept of dependency was, indeed, the relationship between the twins. The two-chambered heart, which was the heart of Baby A, was receiving its blood through two apertures leaking from the four-chambered heart. Except for that contribution of blood to the two chambers Baby A would have died in utero. This was the analysis that allowed the surgery to proceed" (Tendler, 130).

Based on the knowledge that one life was dependent on the other, Feinstein reached the conclusion that the independent life must take precedence.

Since Feinstein's opinion was not written in the accepted form of a responsum, the path of his reasoning can only be guessed at. One wonders why he did not write it down. Perhaps he considered the issue so specific that it merited the level of a *pesak*, and did not fall into the category of a responsum, a genre of writing from which one may derive generalizations applicable to analogous cases (Breitowitz 1996).¹³⁰

Nevertheless, one prominent rabbinical scholar, J. David Bleich, Talmudist and professor of Jewish law at Yeshiva University, did attempt to elucidate Feinstein's reasoning and then offer his commentaries on the decision—commentaries that reveal his hostility to Feinstein's decision. Bleich contributes a column in every issue of the journal *Tradition* called "Survey of Recent Halakhic Periodical Literature." In 1996 he was prompted to deal with the topic of conjoined twins because of the focus on a recent case of the Hensel twin girls that appeared in *Time* and *Life* Magazines at that time. In his characteristic manner he covered in detail the science and the history of conjoined twins as well as the place of conjoined twins in *halakhic* literature. He devoted a major section of his essay to the 1977 case, which he entitled "The Philadelphia case of 1977" (Bleich 1996). Bleich offered his understanding of Feinstein's reasoning in this case based on his knowledge of Rabbi Feinstein's other responsa and also based on "various accounts of his decision" that have been published already" (100). Bleich provided other responsa from Feinstein dealing with the issue of "giving one life for another," and he used those other statements to explain the consistency of Feinstein's views. As Breitowitz has noted,

¹³⁰ See also Glick (2012); thank you to Prof. Yehudah Mirsky for this source.

Feinstein's philosophy of *pesak* does request that rabbis who read his decision should look into the original sources themselves and in this way, Bleich was following the process that Feinstein's mandated (Breitowitz 1996). It should be noted that Tendler also attempted this reconstruction.

In going through the various sources that Feinstein is said to have used, Bleich provided his own assessment of the applicability of the sources and his criticisms of their relevance. For example, with regard to a story of two men who jump from a burning airplane: if one of the men is designated as a *rodef* (pursuer) that means that "through his actions [he] will bring about the death of the first" (101).

Bleich then offers a third section of his essay—an "objection to Rabbi Feinstein's ruling" by another rabbinic scholar (103). Bleich himself appeared to sympathize with the critics; he even questions Koop's *medical* reasoning. This critical stance is further developed in letters to *Tradition's* 1997 issue (Low and Bleich 1997). A letter reports that Rabbi Jacob Kaminetzky rejected Rav Feinstein's decision, and Bleich added: "[it is] not at all surprising. Indeed, I would be hard pressed to name any rabbinic authority of stature who was in agreement" (Bleich 1997:80). Despite his disagreement, Bleich still attempted to understand Feinstein's reasoning.¹³¹

Conclusion

The 1977 case represents a fascinating moment in history, and it offers insight into the approaches to medicine by prominent doctors, politicians, laypeople, and theologians from a

¹³¹ Bleich, 1996.

variety of religions.¹³² In the only two books written about Koop—his autobiography and the much more brief biography by Easterbrook—the saga of the conjoined twins is given pride of place. When Tendler wrote a book about his *halakhic* collaboration with his father-in-law, his discussion of the conjoined twins case stands out as extremely significant: whereas all other essays in the book are translations of existing responsa of Feinstein, the account of the 1977 case is Tendler’s original composition.¹³³

One additional rendering of the 1977 case was penned by Donald Drake, the key medical reporter whose coverage of the event provides most of the primary source material known. Drake turned his experience into a play, premiered in 2012 and entitled *Choice*; a reading of the play, presented in 2012 in Philadelphia, was discussed in an article in *The Forward* (Brown 2012), which highlighted the fact that one of the key participants, Dr. C. Everett Koop, was in the audience at that time.

It is to be expected in a fictionalization of history that the drama differs from the historical events of this case. In *Choice*, Drake used the outline of the events, but created fictional conflicts among the Jewish participants where in reality there had been none. As Brown noted, Drake’s play presents a religious Jewish couple who are torn apart by the decision they must make with regard to their twin daughters.¹³⁴ The fictionalized Dr. Koop, as the surgeon,

¹³² Annas (1987, 2001a, 2001b), Anonymous (2008, 2009, 2012, n.d.), Bleich (1996, 1997, 2000), Brandon (1994), Breitowitz (n.d.), Brown (2012), Crane (2012), Davis (2011), Easterbrook (2009), England and Wales Court of Appeal (Civil Division) Decisions (2000b), Enker (2008), Halperin (2001), Harari et. al. (2008), Jachter (2012), Kattner (1985), Kuhse & Singer (1985), Levy (2009), Meehan (1978), Morrison (2013, note that this is in Koop’s obituary in the *Philadelphia Inquirer*), Pfeffer (2012), Phang (2001b), Raffensperger (1997), Simmons (n.d.), Smith (1987), Steinmetz (n.d.), Tatz (2010:197), Thaler (2007), Thomasma (1996), Weinstein (2012), .

¹³³ In fact, it is in this book that an entirely new facet of the case is introduced, a purported quote by Koop about his reliance on Feinstein’s judgment. Tendler quotes Koop as saying, “The ethics and morals involved in this decision are too complex for me. I believe they are too complex for you as well. Therefore, I referred it to an old rabbi on the Lower East Side of New York. He is a great scholar, a saintly individual. He knows how to answer such questions. When he tells me, I too will know” (Tendler, Responsa, 130). This statement by Koop has become a popular touchstone in the many further recounting of the twins case.

¹³⁴ All discussion of the play is taken from Brown’s article.

tells them that since the girls share one and a half hearts, only one child can live, while the other, with half a heart, will die. Drama is added when the parents are faced to make a choice between the children—a sure death sentence for one so the other may live. The questions brought up include these: “And is killing one to possibly save the other justified? Is it a violation of Jewish law? Should the babies live joined for as long as they can?” (Brown). However, as Brown notes, “In real life, the choice was wrenching but ultimately clear. Saving a life is paramount. And one of the babies contained the greater share of the heart. But Drake uses the liberty of art to make the decision even more fraught, with the couple warring against each other, the hospital staff threatening to boycott, and the rabbis disagreeing on Jewish law” (Brown).

As we have seen, none of the disagreements inherent in Drake’s play existed in the real situation. In naming his play *Choice*, Drake was referring to the multiple options that existed in the decision-making process for the parents of the twins. Should they do nothing and see how nature takes its course? In the play, the rabbis are in disagreement as to what path to follow, while in reality, any dissention that occurred was anonymously given years after the decision handed down by Rabbi Feinstein.

In addition, the husband and wife depicted in the play are in disagreement and argue about what to do. In reality, however, the Orthodox religious beliefs of the parents were another key factor to explain why they did not dissent about what to do in this situation. Jewish law dictates that they do not assert their personal autonomy, but rather seek rabbinic authority in order to know what is to be done. Drake’s dramatic rendering introduced conflicts that would be understandable to a modern secular audience; in reality, however, the legalistic character of Jewish Medical Culture meant that “choice” is the wrong paradigm.

Drake's decision to entitle his play *Choice* highlights one final, significant component of the 1977 case—namely, that the actors in this case had a choice to make. The importance of this point becomes clear when this case is juxtaposed with the 2000 case in Britain. There, the parents attempted to reach their own decision based upon their religious beliefs, but the state intervened. In the 1977 case, the parents were able to draw on precedents in United States law that allowed for privacy and autonomy in determining the medical fate of their family-members. This level of autonomy has changed over time, even in the United States, where the government is increasingly acting in line with certain religious doctrines (see Chapter Two on the Schiavo case).

Moreover, what the 1977 case shows are the circumstances that arise in a religiously pluralistic country like the United States. Not only are there different perspectives within the major U.S. religions regarding life and death issues, but within Orthodox Judaism there are also conflicting ways of interpreting *Halakhah*. The religious identities and affiliations of the doctors, the parents, the nurses, the press, the rabbinic authorities, even the judges on the court bench, came into play in determining the outcome of the 1977 case. Reception of the case in the intervening years—both within American society and within the Orthodox Jewish rabbinic community in particular—further highlights the complexities of these cases, and the competing motivations and values that might drive decision-making in the future.

Conclusion

Recent advances in medical technologies have introduced complex new issues in the care of patients at the end of life. As I have argued throughout this dissertation, the complexity of these issues and their significance on both personal and societal levels render them important windows on understandings of medicine among Jewish *halakhic* authorities, laypeople, and medical practitioners. They reveal deeply ingrained aspects of the nature of Jewish thought and practice, about the relationship between Jews and the larger society, and about the significance of Jewish history for contemporary Judaism in America.

To explain the persistence of these deeply ingrained features of the relationship of Jews to medicine, I have posited what I call Jewish Medical Culture. The cases I have studied and the analyses I have undertaken represent only a first step in the exploration of this concept, but it is one that I think represents a fruitful avenue for further study. Indeed, the principles of Jewish Medical Culture should not be applied exclusively to end-of-life decision making. Instead, I argue, Jewish Medical Culture can be used to explain much more pervasive tendencies in the relationship between Jews and American society today.

My discussions of specific cases and concepts highlight key aspects of Jewish Medical Culture. The Schiavo case attests first and foremost to the efforts of Jewish authorities and laypeople to participate in discussions about medicine and end-of-life discussions in contemporary society. I have highlighted the issue of secularization, using the theories of Katz, Batnitzky, and others, to show the tension within Jewish Medical Culture about the encounter

with secular ethics. In the Schiavo case, response of numerous Jewish authorities was to encourage the secular government's intervention, even though it meant compromise of the principle of autonomy.

The contrasting understandings of brain stem death among secular and *halakhic* authorities shows an important conflict between Jewish Medical Culture and that of the surrounding medical culture. However, it is significant that both the authors of the 1981 Commission Report and the *poskim* in BSD cases view their positions as continuations of past understandings of death, as shown in Chapter Three. The cases discussed in Chapter Four demonstrate the cultural contingency of the definition of death. Moreover, they point to the dramatically different paradigms within which Jewish and secular authorities operate. The application of Kuhn's theory of incommensurable paradigms (1) elucidates the high stakes of the conflicts between Orthodox Jewish patients and the medical practitioners involved and (2) provides an explanation for the extreme difficulties that these two sides have in communicating with one another.

Finally, my discussion of the conjoined twins case of 1977 sheds light on the legal nature of Jewish Medical Culture—a nature that, as I argue, persists from the period of Emancipation, as described by Batnitzky. The remarkable circumstances and personalities involved in this case mean that it offers a perspective not only on the legal nature of the Jewish deliberations in medical cases, but also the contrast between this aspect of American Jewish Medical Culture and approaches to this same case among Protestant and Catholic authorities and medical practitioners.

Frameworks for Understanding Jewish Medical Culture

By way of conclusion, I would like to propose a series of four frameworks for understanding Jewish Medical Culture in contemporary America: the interpretive, the historical, the cultural, and the philosophical. In my view, each of these frameworks has left a mark on the nature of American Judaism, and each has distinctive applications within the medical context—not only in cases around the end of life, but in approaches to medical care more broadly. Indeed, each of these frameworks bears important implications for the interaction of Jews and non-Jews in American society, and for the character of Judaism in the modern world.

1. Interpretive Framework for Jewish Medical Culture: Ingrained Paradigms

In my discussion of Brain Stem Death in Chapter Four, I applied the notions of “paradigms” and “incommensurability” as expounded by Thomas Kuhn. I contend that these notions find application throughout the interactions between secular American medical culture and Jewish Medical Culture.

The two sides of the debate over Terri Schiavo present a manifestation of conflicting paradigms. There was no debate, in fact, over the nature of Terri’s medical condition: all agreed that she was in a Persistent Vegetative State. The subject of debate, rather, was how to *interpret* the intervention of the secular government—the paradigm within which that intervention should be understood. For Michael Schiavo and a minority of Jewish voices, including Michael Broyde, the role of the secular government was to allow individual autonomy in medical decision making; Michael, acting as proxy for Terri, was simply using his autonomy to carry out Terri’s wishes. By contrast, the religious groups opposed to withdrawal of care—among them vocal

leaders in the Orthodox Jewish community, including Adlerstein—depicted the case as one of euthanasia, in which the secular government was jettisoning an “unwanted” individual; the rhetoric that they used sometimes went so far as to equate the behavior of the American government to that of the Nazis. The paradigms within which each group operated led them to “read”—to interpret—the actions of the government in sharply opposing ways.

The chapter on Brain Stem Death presents a fascinating view of conflicting paradigms in competing medical cultures. The doctors in the Smith-Flamm case viewed the family as behaving unethically, suggesting that they were in denial about what the doctors viewed as an “objective” medical reality—the death of the family member. Although the reaction of the family in that case is not well documented, the reactions of Orthodox Jews to similar cases suggest that they did not accept this “reality” as objective at all; instead, they held a cultural attitude informed by *Halakhah* that saw the patient as alive and in need of medical care. Thus they viewed refusal of the medical practitioners to treat patients in such cases as unethical. This conflict highlights the extent to which definitions of death are socially and culturally contingent. That each side saw the other as acting unethically is a strong indication of incommensurable paradigms. What one side might view as a clear-cut case of “science” may be seen by another side as a matter of subjective ethics.

In the case of the conjoined twins there were as many as four parties involved: the Orthodox Jewish family and their *poskim*, the Catholic nurses, the devoutly Protestant surgeon, and the secular American court. At issue was how to consider an end-of-life decision: for Dr. Koop, the decision about how to handle the case was made through contemplation and prayer in solitude; for the Catholic nurses, a decision was sought from Catholic authorities, but these involved spiritual rather than legalistic methods; for the Orthodox Jewish parents, the decision

was made in a profoundly legalistic method that mirrored with a remarkable degree of precision the decision-making process of the American legal court. Here, the paradigm conflict was not over the facts of the medical case itself, but over how to perceive a question in what secular society generally describes as “bioethics.” The fact that the Jewish proceedings were used by the British high court in the 2000 conjoined twins case demonstrates the congruency between the Jewish “ethical” paradigm and the legal paradigm. As I will show in the following section on the historical framework for Jewish Medical Culture, this case brings to the fore the lingering echoes of pre-modern Judaism encompassing religion, morality, and law.

2. Historical Framework for Jewish Medical Culture: Judaism as a System of Religion, Ethics, and Law

One of the many hallmarks of Jewish Medical Culture is its legal nature, and the legal obligations that it places on its adherents. In contemporary society, Robert Cover (1987) has traced the principle of “obligation” within Jewish law, contrasting it with secular ethics (Solomon 1995 and Toulmin 1982). I will return to this distinction below. First, however, a summary of the historical framework for this legal nature of Judaism may be found in the work of Batnitzky (2011). Supporting the notion that Judaism traditionally shows hallmarks of a legal culture are the following factors addressed in the chapter on conjoined twins: (1) the ways in which non-Orthodox writers in the field of Jewish medical ethics employ legal language; (2) the contrast within inter-religious discussions of Jewish and Christian medical ethics; and (3) reactions to the conjoined twins problem itself, both in 1977 and in the case in the United Kingdom in 2000.

A historical basis for the legal character of Jewish Medical Culture lies in the history of Judaism itself. As Batnitzky has shown, Judaism, historically, was not a religion in the modern Western sense; rather, it preserves aspects of its pre-modern manifestations in encompassing and addressing every aspect of social life—especially the areas of culture, morality and law. While most scholars today treat Judaism as a religion, adherents to Orthodoxy in particular—and, to some extent, other denominations as well—view Judaism as an integrated culture. Even in the modern age, the pre-modern notion of Judaism persists for many self-identified Jews.

The implications for this understanding of Judaism as a pre-modern religion are extensive.¹³⁵ For example, in sociology, Smith (2005) used this nature of Judaism to justify his analysis of Judaism as both a religion and an ethnicity. In history, Sarna (2004) recognized this as part of his refusal to consider the religious divisions of American Judaism (Orthodox, Conservative, Reform) as movements and not denominations. As my study of the 1977 conjoined twins case shows, the concept of Judaism as a pre-modern religion provides the historical underpinning for explaining how a central part of Jewish Medical Culture is its legalistic nature.

¹³⁵ I follow Batnitzky when I adopt the term “pre-modern religion”; yet this, and all alternatives, carry a good deal of baggage. Alternative terms might include civilization, nation, culture, ethnicity, ethnoreligion, or traditional society. “Civilization” as a concept is likely indivisible from the whole ideology of Mordechai Kaplan. “Nation” is accurate in a pre-modern sense but contemporary use of the term is equivalent to Zionism, and it connotes “nationalism.” “Culture” could suffice, except that anthropology has consigned that term to their domain and “culture” is used scientifically (as it were) for whatever anthropologists seek to analyze, from a population of millions to a small group of people. “Ethnicity” or even “ethnoreligion” are also scholarly terms like “culture,” and are thus too complicated for my use. Katz’s “traditional society,” while useful for him and his study is from Max Weber and carries with it that baggage. I prefer then to use “pre-modern religion” in part because it signals a paradox: there were no “religions” before modernity, as Batnitzky emphasizes; however every contemporary religion that existed before modernity and persists to this day follows the same basic “civilization” model that modernity (Protestantism) attempted to eliminate. Those pre-modern religions, like Roman Catholicism, Eastern Orthodoxy, Islam, Buddhism, Hinduism, and Judaism, would thus share a characteristic in considering themselves to be totalistic worldviews, and not Protestant-style private devotional (non-political) practices. Yet, these pre-modern religions do not necessarily share the legal culture of Judaism, although Islam is likely very similar. My argument here is not that Judaism is distinct from all other religions; instead, I intend to be descriptive of Judaism itself.

Batnitzky states quite starkly that the modern definition of religion emerged from a Protestant model, and that its application to Judaism was a purposeful project of Moses Mendelssohn. Her definition of the difference between the pre-modern and modern definitions of Judaism mirrors my findings; furthermore, it explains the roots of those findings: “Prior to modernity, which I will define in the pages that follow as the acquisition of citizenship rights for Jews, Judaism was not a religion, and Jewishness was not a matter of culture or nationality” (2). She states further,

the question of whether Judaism and Jewishness refers to a religion, nationality, or culture is a particularly modern one. It simply was not possible in a premodern context to conceive of Jewish religion, nationality, and what we now call culture as distinct from one another, because a Jew’s religious life was defined by, though not limited to, Jewish law, which was simultaneously religious, political, and cultural in nature. Jewish modernity most simply defined represents the dissolution of the political agency of the corporate Jewish community and the concurrent shift of political agency to the individual Jew who became a citizen of the modern nation-state. (4)

Batnitzky shows as well that the contemporary struggles over how to understand Judaism in the modern Western world stem from this purposeful redefinition of Judaism as a religion. As she notes: “In characterizing Judaism as a religion, Mendelssohn is aware of and actually emphasizes the implicit problems that follow from trying to define it thus in a German Protestant vein” (13). Batnitzky’s characterization of Mendelssohn’s struggle follows the pattern of a paradigm revolution (see chapters three and four), and the continued struggle against the definition follows the pattern of a paradigm conflict—with the adherents of both finding their views incommensurable—similar to what is seen over the definition of death in chapter 3.

As Batnitzky shows, Jews from Eastern Europe (and presumably even more so from the non-Christian, Muslim world of Sephardic Jewry, which she does not discuss), did not have the

need to employ the concept of religion, initially because they did not interact with German Protestantism and Mendelssohnian Judaism to the same extent as central European Jews, and because their communal structure and social and political circumstances were different from Western European Jews' and from one another:

Eastern European Jewish individuals, like their premodern ancestors, nevertheless were still defined legally, politically, and theologically as members of the Jewish community. For this reason, the idea of Jewish religion was largely irrelevant to eastern European Jews. By the nineteenth century, however, eastern European Jews were engaged in a dialogue with their western counterparts and rejected in multiple ways the idea that Judaism was a religion. (6).¹³⁶

Most contemporary American Jews, especially those in the Orthodox communities, are from Eastern European (and Sephardic) ancestry.¹³⁷ Ultra-orthodox Judaism, especially Hasidic sects, are the most rejectionist: "ultraorthodoxy can be understood as a wholesale rejection of the modern attempt to divide human life into different spheres (such as religion, nationality, and culture), and thereby as a refusal to engage the question of whether Judaism is or is not a religion." (5) I agree with this definition but believe it can be broadly defined to most of those who identify as Orthodox.¹³⁸ This assumption is supported by the recent work of Benor (2012),

¹³⁶ An example of the Eastern European view, this from a Zionist position, is that of Moses Hess. Batnitzky explains that "Hess criticizes and rejects the idea that Judaism is a religion, calling this notion a modern and particularly Protestant invention...[and] that the denial of Judaism's national dimension...cannot be taken seriously. Emancipation, argues Hess, has decimated the fullness of Jewish identity, reducing Judaism and Jewishness to an unsustainable individualism" (149).

¹³⁷ She recognizes that American Judaism, because of the large influx of Jews from Eastern Europe came from a background of the premodern "integrated" non-religion view of Judaism: "the dominance in the United States of descendants of eastern European Jews who...had different conceptions of Judaism than their western European counterparts; and the complicated interplay between religion and political life that has marked the United States since its founding." (166) As Katz claimed (1958 [1986]:6) American Jews were not emancipated in the same manner as European Jews did because in America all people were emancipated in the same way at the same time.

¹³⁸ I have a number of disagreements with her characterization of Modern Orthodoxy, especially her contention that Joseph B. Soloveitchik considers Judaism as part of the modern (Mendelssohnian) definition of religion (59–60), and her attempt to characterize the ultra-Orthodox Satmar as adhering to this "religious" definition. However, that is a disagreement about analysis; I agree with her on the starting definitions and premises.

who shows that Orthodox Jews across their specific spectrum have an integrated view of religion. Most significantly, she shows that for most of the self-identified Orthodox, there is a contiguous and blurred continuum among the subgroups, from “yeshivish black hat” to “modern orthodox machmir.” (115).¹³⁹ This corroborates my claim that there is considerable similarity in the Orthodox community from even those who Batnitzky labels as “modern Orthodox” (Samson Raphael Hirsch, Joseph Soloveitchik) to the “ultraorthodox.”

Batnitzky also shows how the modern definition of religion—with its emphasis on private life and on belief—is chiefly a Protestant invention, as established by Kant and Schleiermacher and adopted by Mendelssohn. As Batnitzky writes, “the modern concept of religion was not a neutral category. Rather, for Kant only Protestantism was the historical vehicle for pure rational faith.” (25) This it is opposite of a Jewish paradigm: “Although Judaism as it has historically been practiced conflicts with this idea of religion for a number of reasons, which I will discuss, **the most basic one is that Judaism and Jewish life have been largely, though not entirely, public in nature**” (13, my emphasis). It is Schleiermacher who provides the most familiar definition of religion as it is understood in the modern scholarship:

Schleiermacher alleges that the essence of religion constitutes a unique and separate dimension of experience—by definition, separate from all other spheres of life, such as politics, philosophy, morality, and science—and is characterized by what Schleiermacher calls intuition and feeling: “religion’s essence is neither thinking nor acting, but intuition and feeling.” (25)

I suggest that the historical process by which Judaism was made to conform to the Protestant model of religion, as described by Batnitzky, was never completed. Instead, Judaism

¹³⁹ The only group that is different significantly from that continuum is the “modern orthodox liberal.” This finding has implications to the study of the rising liberal community within Orthodox Judaism.

retains aspects of its pre-modern status, encompassing religion as well as ethics and law. The 1977 conjoined twins case demonstrates the legalistic thinking of the rabbis and family members involved, in contrast to the ethical and philosophical thinking demonstrated by representatives of Catholicism and Protestantism. In addition, the Jewish legal process mirrors closely the process of the secular courts in the case. Indeed, in the 2000 case in the United Kingdom, the secular court there made reference to the legal reasoning employed by the rabbinic authorities involved in the 1977 Philadelphia case.

I would propose a linkage between Batznitzky's work and the work of Robert Cover (1987) on the principle of "obligation" in Jewish law, as outlined in the literature review of my introduction. My analysis of Jewish Medical Culture provides a more complete picture of how this pre-modern aspect of Judaism persists in contemporary Judaism.

3. The Cultural Framework for Jewish Medical Culture: Katz's Notion of "Ritual Instinct"

As mentioned in the introduction, the purpose of this thesis has been to study the end-of-life decision-making practices of Jews in America from a sociological perspective. The position of Smith (2005), as explained above, provides a rationale for extrapolating about the broader American Jewish landscape—including non-Orthodox denominations—from the behavior of Orthodox Jews. In order to draw out the conflict between the normative opinions of Orthodox *poskim* and ethicists and the behavior of Jews in actual practice, I have surveyed the important *halakhic* responsa on these cases from the Orthodox literature. A next step for this study would be an evaluation of the *non*-Orthodox responsa literature in relation to the practices of American Jews.

This would in turn lead to a larger project within the study of the sociology of *Halakhah*

(a category within which my work may be placed), dealing what Jacob Katz, in *The Shabbes Goy* (1989), calls “ritual instinct.” This distinction between the elite intellectuals of Judaism and its ordinary adherents is a key factor in Katz’s work. Katz analyzes the discrepancies between the directives of the leaders and the behavior of the nominal followers. His thesis is that until the *Haskalah* (Jewish Enlightenment) movement, which began in the late 18th century, the method of *halakhic* interplay in traditional communities was for the rabbinic leadership to assume that the community of Jews was loyal to *Halakhah*. As such, whenever a public practice contradicted the *halakhic* norms in the Talmud or responsa, the rabbis assumed that the people were correct and found *halakhic* backing for their practice. This process of community-led change was based on the authorities’ trust in communal “ritual instinct” (231), and that there were even occasions in which Talmudic logic allowed a leniency but the community would reject it, based on this ritual instinct.

Haym Soloveitchik’s *Rupture and Reconstruction* does not employ the term “ritual instinct,” but it constitutes a further investigation of Katz’s idea: “It is no exaggeration to say that the Ashkenazic community saw the law as manifesting itself in two forms: in the canonized written corpus (the Talmud and codes), and in the regnant practices of the people. Custom was a correlative datum of the *halakhic* system. And, on frequent occasions, the written word was reread in light of traditional behavior” (67).

While Katz locates a major shift in rabbinic attitudes towards the Jewish masses in the Enlightenment period, Soloveitchik describes a similar change in the middle of the 20th century, when “a dramatic shift occurs....From then on, traditional conduct, no matter how venerable, how elementary, or how closely remembered, yields to the demands of theoretical knowledge. Established practice can no longer hold its own against the demands of the written word” (69).

Soloveitchik considers American culture's acceptance of the secularized Enlightenment definition of religion—which reduces the application of *Halakhah* to only a few contexts:

As large spheres of human activity were emptied of religious meaning and difference, an intensification of that difference in the remaining ones was only natural....As the inner differences erode, the outer ones must be increased and intensified, for, progressively, they provide more and more of the crucial otherness. (77)

As less and less of the world is necessary to be understood through the lens of *Halakhah*, what remains is treated more stringently.¹⁴⁰ In summary:

In contemporary society, however, Jewish identity is not inevitable. It is not a matter of course, but of choice: a conscious preference of the enclave over the host society. For such a choice to be made, a sense of particularity and belonging must be instilled by the intentional enterprise of instruction. Without education there is now no identity, for identity in a multicultural society is ideological. Once formed, this identity requires vigilant maintenance, for its perimeter is continually eroded by the relentless, lapping waves of the surrounding culture. (93)

I believe that understanding the mechanism of “ritual instinct” would reveal much about the process of religious behavior. The context of end-of-life decision making is well suited for that study, especially because of the extremity of views, the high stakes, and the rarity of the encounters for each particular person or family. “Ritual instinct” is best studied through comparison of the work of the elites with the empirical behavior of the lay population.

¹⁴⁰ It is helpful to note that Soloveitchik does corroborate the concept of how the paradigms of lay acceptance of medicine has changed over time:

When a medieval man said that his sickness is the result of the wish of God, he was no more affirming a religious posture than is a modern man adopting a scientific one when he says that he has a virus. Each is simply repeating, if you wish, subscribing to the explanatory system instilled in him in earliest childhood, and which alone makes sense of the world as he knows it. (100).

4. The Philosophical Framework for Jewish Medical Culture: Maimonidean and Nachmanidean Modes of Thought

As explained in Chapter One, following Clifford Geertz, I claim that the validity of the theory of Jewish Medical Culture need not depend on a monolithic or uniform understanding. Indeed, the multi-vocal nature of Jewish tradition means that its manifestations in the modern world will also be diverse, multi-faceted, and dialectical. Among the most profound sources for this diversity in Jewish Medical Culture are the conflicting views of medical “naturalism” and medical “humanism” as identified by Zohar (2006). As Zohar as shown, the tendency toward “naturalism” is aligned with the tradition associated with the Medieval philosopher Nahmanides, who perceived medicine as merely “a tolerated practice, a compromise with human frailty.” As Nahmanides himself wrote, “when Israel are in perfection and numerous, their affairs are not governed at all by the natural order of things...For God blesses their bread and their water, and removes sickness from amongst them” (23). Health, in this view, is essentially linked with morality. In Zohar’s words, “Nahmanides has thus marshalled biblical support for his opposition to seeking medical help” (24). By contrast, medical “humanism,” associated with the work of Maimonides, views the role of human beings as interventionist: it is incumbent upon medical care providers to intervene in medical cases, to influence the outcome in favor of life. As Zohar writes, “in [Maimonides’] view, God acts in the world chiefly or even solely through natural causality. Sound medicine, like sound technology in general, is itself an instance of God’s providence; there is no alternative mode of turning directly, as it were, to divine help. So the permission to heal is no special case, no granting of a license to human agents to trespass upon a divine realm” (31). This distinction, then, is between religion as an active changing of the world,

associated with Maimonides, and an almost mystical subservience to natural occurrences as expressions of the divine will.

In our cases, Tendler represents the Maimonidean view. The conjoined twins case of 1977 demonstrates this: Tendler, speaking for Moshe Feinstein, advocated active intervention to save one of the twins, rather than acceptance of their “natural” fate. Koop’s words echoes this position of medical-religious humanism: he states that since God gave him the ability and knowledge to save lives through surgery, he felt a responsibility to use them. Bleich (1997) later espoused a Nahmanidean approach, expressing sympathy with a position attributed to Yaakov Kamenetsky indicating that he viewed the surgery as forbidden because it involved the active killing of one of the twins. Indeed, this naturalistic approach was later adopted by the Catholic British family in the 2000 conjoined twins case, who considered the twins’ conjoined state to be an indicator of divine will; they wanted to resist human intervention through the killing of the dependent twin, instead allowing nature to take its course. This shows a fascinating sympathy among religious perspectives, not just within Judaism. Koop’s view may be aligned with the humanistic approach of Maimonides, while the Catholic family’s approach resonates with the naturalistic approach of Nahmanides.

Avenues for Further Research

The implications of the concept of Jewish Medical Culture are far-reaching, and I have been able to explore them only in a limited number of cases in this study. Avenues for further research include the following:

Application of Qualitative and Quantitative Methods to End-of-Life Issues

A full understanding of the conflicts in BSD cases between the Orthodox families of BSD patients and medical professionals would require the full array of quantitative tools (e.g. opinion surveys or epidemiological analysis) and qualitative methods (including interviews and fieldwork). In addition to the constraints over resources for accumulating quantitative data and time required for qualitative observations, there exist the added ethical hurdles of protection and confidentiality for any social science project involving medicine. These hurdles would need to be overcome in order to continue the research begun with this dissertation.¹⁴¹

Gender and the Schiavo Case

The Schiavo case involves a curious gender angle that is echoed in other high-profile PVS cases in recent American history. Rosner (2006) for example, discusses the two most

¹⁴¹ One particularly contentious area to further explore is a theme that ran through every case here, that of the concept of “medical futility.” To have added this angle to this paper would have reduced the clarity of argument that is necessary for the elaboration of a claim of Jewish Medical Culture. But the battleground of futility (with the underlying concept of ‘quality of life’) versus a Jewish concept of the inherent (many say ‘infinite’) value of human life, also illustrates a clear clash of cultures and paradigms. Futility is often framed as a medical or scientific fact but many authors argue that it is obviously a value judgement, and thus a product of culture, and not a medical determination at all. To address this concept, two outside PVS cases are highly instructive, that of Helga Wanglie (an earlier battle over PVS, for a non-Jewish American family, often cited in the literature of futility), and that of Samuel Golubchuk (a recent case in Manitoba which provides a stark difference between not only secular and Jewish medical cultures, but between the secular medical cultures of America and Canada.

Lastly, futility claims in American bioethics must be seen in context of the phenomenon of “granny dumping” (as it was labeled) and the subsequent Federal law of EMTALA (The Emergency Medical Treatment and Labor Act) which required hospitals to deliver life-saving treatment to everyone who enters an emergency room. Before EMTALA, hospitals would often turn away indigent patients – including women in labor and accident victims -- which resulted in numerous preventable deaths. Appeals by ethicists for medical “justice,” the underlying basis for “medical futility,” must be put in context of the many needless deaths caused only by the goal for profit. For the material on Wanglie, see Angell (1991), Capron (1991), Charatan (1991), Cranford (1991), and Rie (1991); for Golubchuk, see College of Physicians and Surgeons of Manitoba (2010), Gesundheit (2010), Jotkowitz et. al. (2010a, 2010b), Paris (2010), Pope (2010), Zivot (2010), and Zuckerberg (2009); for “granny dumping” and EMTALA, see Ansell and Schiff (1987), Buckner (2002), Conard (1992), Lipton and Hayward (2003), Miles (1991), and Roemer and Mera (1973); for futility in general, see Callahan (1991), Caplan (2012), Clark (2002), Cowley (2003), Fleck (1992), Kass (1991), Levinsky (1996), Malloy (1998), Reitman (1996), Supreme Court of Delaware (1991), Truog (2007), Truog et. al. (1992), and Volokh (2003).

Related to a religious rejection of futility, is the correlation between conservative religious views and high demand for expensive, and possibly untimely, medical care at the end of life; see Connors and Smith (1996), Jecker and Schneiderman (1995), Martin (2007), Rabin (2009), and Sifton et. al. (2011).

significant PVS cases before Schiavo: Nancy Cruzan and Karen Ann Quinlan; he also provides a longer list of PVS cases, including Helen Corbett, Elizabeth Bouvia, Paul Brophy, Claire Conroy, Nancy Cullen Jobes. All but one of the PVS cases he mentions involve women as the patients.

The work of Wolf (1996), expanded by Raymond (1999), Parks (2000), and George (2007) among others, initiated the focus of gender issues at the end of life. Wolf claims that (1) women live longer, (2) they are therefore more likely to survive their spouses and thus (3) live longer on a fixed income and often die alone. In addition, (4) more women live in poverty than men, especially as seniors, (5) women suffer more depression, (6) women attempt suicide unsuccessfully more frequently than men (men, by contrast, complete the act of suicide more than women). (7) Using the work of Carol Gilligan (1982), Wolf points out that there is a cultural impetus for women to view themselves and/or be viewed as having a loss of autonomy as well as (8) an ethic of self-sacrifice. Wolf concludes, prescriptively, by suggesting that the desire for physician-assisted suicide should be resisted because of these cultural forces, especially with regard to gender-related biases.

Parks (2000) acknowledges the possibility of Wolf's implicit narrative behind women's end-of-life requests, but brings up the opposite possibility as well: "women's requests to die may be discounted, trivialized, and ignored for the same reasons that Wolf claims they are too likely to be heeded" (31)—that is, because of the denial of female autonomy.

In analyzing Schiavo, Quinlan, and Cruzan, I would say that since these were all young women without children, they should not be considered within the context Wolf uses for her analysis, but rather that described by Parks. They weren't women who lived lives of self-sacrifice; rather they were still "young" and thus subject to a cultural discourse of infantilizing or

at least of taking away their autonomy. Supporting this, as far as I have seen, are the narratives of Schiavo's bulimia and the accounts of alleged spousal-abuse. The abuse helped the process of discrediting Michael's ability to decide on her life (as seen above) but also could be part of a process of declaring Terri a permanently disempowered victim whose desire to have care removed was a result of duress and abuse.

Schiavo's bulimia is a complex issue; it was declared as fact in the 1993 malpractice trial but denied as present by the medical examiner (Thogmartin 2005). Bulimia is understood in our society as a "woman's disease" and as a result of the culture of aesthetics that oppresses women and affects their self-concept. I argue that the imputation of her bulimia, while it was instrumental in attaining a malpractice settlement, also served to further disempower or infantilize Schiavo, placing her in a narrative of female weakness.

Furthermore, I would suggest that a third perspective is needed, especially in regard to the "desire to live" angle as opposed to the "desire to die." Why are there so many fewer prominent cases of men in this condition? It is possible to speculate that the narrative of male autonomy is to presume that "no man would want to live hooked up to a machine," but that assumption is not logically extended to women. I believe this is a fruitful area to pursue, but for now it remains pure speculation.

Other Aspects of Jewish Medical Culture

There is an extensive literature on the history of Jews in medicine, medicine among the Jews, and Jewish opinions about medicine, much of which I have identified in the literature review in Chapter One. A number of hallmarks of a Jewish Medical Culture emerge from my reading of these works, but each would require a dissertation of its own. These hallmarks include

(1) a mandate for patients to seek medical care; (2) a mandate for doctors and other medical personnel to provide medical care; (3) the autonomy of the patient in the face of hospital caregivers and/or government authorities; (4) especially in the Orthodox community, the *lack* of autonomy of the patient subject to the will of God; (5) the notion of the infinite value of human life; (6) the weighing of the value of human life against the *quality* of life; (7) a reluctance to alter nature (*shinui hateva*); (8) a requirement to use the scientific and medical knowledge known to be most correct during the present day; and, perhaps most importantly, (9) the inherent value of *both* body and soul, and of *both* life in the present world and life after death.

Conclusion

In an era when cultural competency is seen as increasingly important within the field of medicine and in society as a whole, the understandings offered in this dissertation would seem to have important applications. Increased understanding of Jewish Medical Culture should offer a clearer means of communication among patients, their families, and their medical caregivers. The insights gleaned from this study would thus seem to have practical application.

Beyond this practical perspective, however, I argue that the knowledge of Jewish Medical Culture may be seen as important in its own right. It attests to the consistency of Jewish thought over long periods, to the efforts of Jews to grapple with new medical realities in tandem with their religious identity, to both the intractability and the adaptability of *Halakhah* in the modern age. Indeed, beyond what my study demonstrates about Jewish Medical Culture, it bears important implications for the field of Jewish sociology itself—for how Jews are studied. The understanding of Judaism as encompassing not only religion but also ethics and law—as in the pre-modern world—is at present not reflected in the field of sociology. Within sociological

studies, the study of Judaism happens in the subfield of the sociology of religion, while the study of ethnicity is studied within the sociology of immigration. Legal systems, moreover, appear within studies of sociology of law, and the sociology of culture is separate as well. What all this means is that a holistic sociological study of Judaism—including all of the thumbprints of its pre-modern, pre-disciplinary character—cannot be accommodated within the contemporary academy. It is my hope that this thesis will contribute to a reassessment of the sociology of Judaism. The results of such a reassessment will provide a richer, more complete understanding of Jews and Judaism in the contemporary world.

Appendix A



142

¹⁴² From *Life* magazine online, <http://www.life.com/image/53111760>

Appendix B: Comments from *Vos Iz Naeis*

This comment section on the Brody case is transcribed from

<http://www.vosizneias.com/22273/2008/11/09/new-york-hospital-in-motl-brody-case-we-are-being-inundated-with-harassing-and-threatening-calls-by-ny-jews/>.

Original spellings have been retained.

#2 Nov 09, 2008 at 12:31 AM Anonymous Says:

Does anyone know the email add where to write emails to the hospital, I think if everybody writes polite letters, they'll relaise the amount of people in the case they'll give in, BTW the NY times had a article today about this

#4 Nov 09, 2008 at 12:41 AM Anonymous Says:

Keep it up rabosai, don't stop calling and emailing. LET MOTYL BRODY LIVE!!

#6 Nov 09, 2008 at 01:06 AM Anonymous Says: Reply to #5 Shaul in Monsey Says:

“ It is disgraceful that the hospital has received threatening and menacing calls - hardly motivation to help the family. If the body is decomposing - the article says the brain is doing so - what impact does that have on halacha? “

I was thinking the same thing. If the body is decomposing.... Isn't the boy dead?

#8 Nov 09, 2008 at 12:54 AM emes Says: Reply to #2:

but whoever e-mails etc. do it with resprct --MENTSHLECH -- the torah way, in order you should be respected and be heard and with g-d's help we'l prevail REFIEH SHLIEME

#9 Nov 09, 2008 at 12:54 AM Anonymous Says:

Also there is ways through halacha to stop certain medications maybe a rav has to get involved to tell them right from wrong.

#11 Nov 09, 2008 at 01:14 AM ahh Says:

Oh Such a sad story!! I feel so bad for the family. “when the sword is by your throat don't give up have faith in HASHEM” What's the boy name I really want to daven for him.

#12 Nov 09, 2008 at 01:33 AM SamTheManInBocaRaton Says:

I always thought that the Halacha was, "If the brain stem shows zero on a scale of 1-10. Then the brain IS DEAD. Even though medical machines are keeping the HEART pumping & LUNGS bringing oxygen through the body". Whats NOT TO UNDERSTAND ?! If NO BRAIN ACTIVITY, THEN HALACHALY THE BOY IS NIFTA! Let the BODY be interred so the NESHOMA rise to the heavens! Those who think otherwise are grossly mis-informed. Will some Rav speak out & inform the masses!

#13 Nov 09, 2008 at 01:44 AM Understand Says:

Some of you are such chachumim its amazing. Dont you think they have asked shaylos on what to do? Why do you paskunyaks think they havent?

On a similar note, a relative of mine was in a coma in a very large NY hospital and we had a farshtinkina nurse coming over to us and saying things like, "you know he is gona die here?," and brainless things like that. We told her the vort of v'rapai yerapei -- that HKBH only gives them permission to heal people and not to decide when people are supposed to die. She was smart and walked away very quickly and quietly. Fin dest vegen, we made sure to file a complaint about her as soon as we had the chance.

#14 Nov 09, 2008 at 01:21 AM Anonymous Says:

The NY Times had today a listing of all rabonim that said that you are NOT aloud ti stop giving the medication, they know what you guys know they called all heimeshe rabonim and they all said that life is detirmined only on heart and lungs as per halacha not on the brain and thereefore we have to fight and fight. I agree that the emails should be written with some respect, (its true that the hospital was unbelievable nice all along for the family and really tried to please them) but know we have to do everything to save his live! Yes we can! U r mechuyev to be mechallel shabbos for a patient in the matzav

#17 Nov 09, 2008 at 02:34 AM Anonymous Says:

I wrote a letter, but it was respectfully written.

#19 Nov 09, 2008 at 07:02 AM Milhouse Says: Reply to #12:

You "always thought" this? Since when? What gave you that idea? What qualifies you to make this sort of radical determination? Just because Tendler holds this way doesn't mean the whole world has to agree with him.

#20 Nov 09, 2008 at 07:54 AM Anonymous Says: Reply to #12:

Sam, most Frum rabbonim do not agree with what you wrote. Yes, some in AY have ruled that way, but the majority of poskim hold we can even be mechallel Shabbos to try to keep him alive even at this point. It has nothing to do with a lack of understanding of the medicine or biology or science, just an understanding of Hashem's will. We hold he is still 100% alive, even though we do understand that it may be completely hopeless to expect any improvement through teva. Even if we KNOW he will be niftar in a matter of days or weeks, we must keep trying up to the last minute. May not make sense to us, but Hashem's will is Hashem's will, whether it is logical to our understanding or not.

#22 Nov 09, 2008 at 07:50 AM Yona Says:

I happen to know the family well , and to say they were not there since july is a lie. The parents have been at his bedside from the begining of this ordeal and have not left since. May Motl have a Refua Shlaima Bekorov.

#24 Nov 09, 2008 at 04:11 AM Anonymous Says:

There have been cases where people who were labeled brain dead came back to life. Maybe this case is worse but we have to listen to chazal.

#25 Nov 09, 2008 at 02:15 AM moshe in bp Says: Reply to #16

Anonymous Says:” are u a rabbi or what ? I am sure they have their own rav or diyen who tells them how to deal with this matter r’l so please use a little common sense before u write anything “

He is stating the opinion of some liberal rabbi in america and of the rabbanut in Israel.

#26 Nov 09, 2008 at 02:12 AM moshe in bp Says: Reply to #12

You are wrong rov the rabonim in america do not subscribe to this opinion. Dead is when the heart stops beating, and breathing stops.

#28 Nov 09, 2008 at 08:29 AM Anonymous Says:

This brain dead child is being kept alive because of a halachic (Torah) mandate.
Derech Eretz Kadma L’ Torah!

I just do not understand the chachma of calling the hospital with threats and acting in a menacing manner are yidden supposed to act like street tugs?

#30 Nov 09, 2008 at 08:54 AM Anonymous Says:

The poor child is going through terrible suffering. There is an exact moment that the suffering will end and his ‘tikkun’ will be completed. There are rules for how we are to behave in these situations. We are not supposed to play G-d. The doctors always think they know everything. We have rules and regulations for a reason...Wait till they see whats on the other side...Tov Shebarof’im Le’Gehinnom

#34 Nov 09, 2008 at 09:20 AM Anonymous Says:

Sometimes, many time in fact, doctors use this ‘decomposing’ argument to attempt to portray death to families who are in denial. It is old hat, and not always factual. It is meant to elicit negative thoughts and emotions and intended to override religious thoughts. They believe that the religious thoughts are based upon the families’ denial of the patient’s situation, and if they could “just make them understand” that the situation is hopeless the family will stop being “unreasonable.” They do not understand the concept of simple obedience to Hashem’s word even with we are fully cognizant of the facts and are not in denial. Bottom line is that, even if, chas v’sholom the person’s guf is decomposing, halacha is halacha, and we must wait until halachic death occurs.

But, please keep in mind the horrific feelings this precious family is going through, and be careful in what we write here.

Another thought, the family may be visiting daily, but avoiding that doctor since they know his agenda. He, on the other hand, may be the one in denial saying if they don't walk into his office, they are not there.

#36 Nov 09, 2008 at 11:31 AM BIG MASMID Says:

THIS IS WHERE YOU CAN WRITE TO:

Children's National Medical Center:

Main Hospital Address:

111 Michigan Ave., N.W

Washington, D.C 20010

tbear@cnmc.org or mshaw@cnmc.org (Subject: DON'T TAKE MOTL BRODY OFF LIFE SUPPORT!)

Volunteer Services: 202-476-2062

Public Relations: 202-476-4500

General Information: 202-476-3000

Advocacy and Community Affairs: 202-476-4930

<http://www.childrensnational.org/ContactUs/default.aspx>

#37 Nov 09, 2008 at 11:37 AM Milhouse Says: Reply to #28

"I just do not understand the chachma of calling the hospital with threats and acting in a menacing manner are yidden supposed to act like street tugs?"

To prevent a murder? Absolutely. Whatever it takes. You'd rather let someone die to be polite?

#38 Nov 09, 2008 at 11:52 AM anonymous Says: Reply to #33

"Anonymous Says: " The body is not decomposing its only the brain since there is no blood circulatory action the rest of the body is getting blood due the heart still functioning and having the blood oxygenated by the ventilator, "

I called the hospital friday, respectfully . The first thing they said was how they can not release any info because of the privacy act. At the same time the public relation department had said how the parents have abandoned their child. I spoke to the director and she was very upset at the rude comments from others. I told her putting evrything aside for the hospital public relations what is the purpose to tell evryone calling that the parents haven't been there. Just say its private information. I'm not involved and nobody can judge these parents. I'm sure they have voliunters such as family freinds, bikur cholim, chai lifeline and others involved.

Let's be misspallel that no body should ever have to go through what motti and his parents are going through. And a swift resolution should come and no chillu hashem should occur.

#40 Nov 09, 2008 at 01:00 PM Anonymous Says:

Mordechai dov ben miriam shaindel should have a miracle refuah shelaima.

i wrote a very respectful letter. we can only gain by being respectful and nice.

#41 Nov 09, 2008 at 12:56 PM SG Says:

Davining in the shuall on Rosh Hashna and hering the Father of this Child Say
SHLACH REFUEA SHLAYMA L'CHAYLY AMECHA You cannot STOP to davin
for Child MORDCHI DOV BEN MIRUM SHINDEL
IN THE MERIT OF KEEPING HIM ALIVE MY THE ALMITY G-D BLESS ALL THE
STAFF AT THE HOSPATEL NEVER NEVER TO EXPERIANCE IT IN THER FAMELY

FROM A FREAND THAT CAERS

#42 Nov 09, 2008 at 01:27 PM GezelNot Says: Reply to #24:

“Anonymous Says: “ There have been cases where people who were labeled brain dead came back to life. Maybe this case is worse but we have to listen to chazal. “

Can you please tell us of such a case where a brain dead person came back to life? and not a rumor, but a real case? Of course you can not.

#43 Nov 09, 2008 at 02:31 PM mnachem Says: Reply to #42:

“GezelNot Says:” Can you please tell us of such a case where a brain dead person came back to life? and not a rumor, but a real case? Of course you can not. “ “

even not you have to do evrythink lhaluche you can mechullel shubeth on this case

#44 Nov 09, 2008 at 02:25 PM Anonymous Says:

I am very familiar with this case having spent considerable time at that hospital this past summer and while I don't know whether the parents have been there during the fall, I do know that they would return to New York for extended periods of time. There was a good reason for this, however, as they have six (I believe) other children to attend to and another family member was always there while the parents were gone.

I also know that the doctors, nurses and staff at Children's hospital in DC have worked tirelessly not only to help Motl, but to help his parents and family as well. They have gone out of their way to enable the family to be in the hospital and maintain their Shabbat observance (which was sometimes very complicated) and to help them be as comfortable as possible during this difficult time.

So please do not speak lashon hara against the people at the hospital. Most of you have no idea how hard these people work and how difficult the job is that they do.

From the hospital's perspective, there is nothing more that they can do and it is very expensive for the hospital to keep him alive. In a perfect world, that shouldn't matter, but we don't live in a perfect world so it does. According to medical science and American law, the child is technically dead, and while for most of us that is not the law to which we first adhere, we must try to understand the hospital's point of view even as we disagree with it.

We should all pray for the family during this difficult and tragic time, and hope that Motl's neshama can return to HaShem in peace, if that is indeed the plan.

#47 Nov 09, 2008 at 02:58 PM 770 Says: Reply to #36

thanks big masmid who ever you are, for the vital information, now that we have the info. please call and write respectfully make a Kidush-Hashem but bring out your fillings loud and clear.

#50 Nov 09, 2008 at 04:51 PM Shaul in Monsey Says:

I would never ever want to be in this family's shoes, the family must be special special because this is an incredible nisayon. Therefore it is important to manage their expectations. Those of you posting that you never know, there could be a neis and he recovers, that does not sound reasonable. I am davning that the RBSO should have rachamim on this boy and end his suffering. Lack of brain function means his lungs and heart will never function on their own bderech hatevah, and we should not daven for anything that is kneged hatevah.

#52 Nov 09, 2008 at 06:05 PM retired rav Says:

Decades ago. a woman of my kehilla lay "brain-dead" in a hospital for over a year. Every day mishpachah members sat at her bed and told her family news. The doctors told them they were meshugah. Finally, she WOKE UP AND KNEW ALL THE NEWS THEY SAID TO HER! THE DOCTORS "DROPPED DEAD."

Unfortunately she passed away some months later because she had become too weak and could not be brought back to health. But she had a great reunion with all of them, and with me as well. It was astounding.

[P.S. This case sounds worse - but who knows? It looks like the doctors DON'T!

#55 Nov 09, 2008 at 07:42 PM Jewish mother Says:

My sister was a cardiac intensive care nurse at Deborah Hospital near Lakewood 20 years ago. My sister told me several stories about so called brain dead people who woke up and walked out of the hospital.

#56 Nov 09, 2008 at 07:35 PM Anonymous Says:

heard of a source involved with the case and the family, "there were NO THREATS OR HARASSING phone calls whatsoever as far as to their knowledge", this claim of being harassed, is apparently just a way of the hospital officials to play "nirdof" while they're just the opposite

#58 Nov 09, 2008 at 08:20 PM Anonymous Says: Reply to #56

Right. Brooklyn's finest were asked to make phone calls to the hospital and none of them were rude.

Half of us can't buy a danish in the local diner without being rude to the server, the cashier and at least one customer!

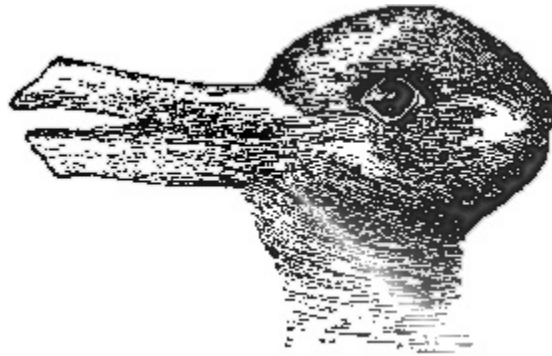
#62 Nov 10, 2008 at 01:38 AM Miss Williamsburg Says:

Thanks #36 for posting the info. I'd just like to add. Please everybody who's considering sending, writing, calling or emailing the hospital. Please start and finish with a positive. I like

what #41 wrote which would be a great line to finish off with: IN THE MERIT OF KEEPING HIM ALIVE MAY THE A-LMIGHTY G-D BLESS ALL THE STAFF AT THE HOSPITAL NEVER EVER TO EXPERIENCE IT IN THEIR FAMILY.

Please while trying to save a life, let's make a Kiddush Hashem and may it be a Zchus for a Refuah Shelaimah for this precious little boy Mordechai Dov ben Miriam Shaindel

Appendix C: The Duck-Rabbit¹⁴³:



¹⁴³ Image taken from: <http://mathworld.wolfram.com/Rabbit-DuckIllusion.html>

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