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Experiments in Judaism:
Jewish Sources, Ethics, and Research with Human Subjects

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ABSTRACT

Experiments in Judaism: Jewish Sources, Ethics, and Research with Human Subjects

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Although religious ethics has been a contributing presence to many debates within bioethics, insights from religious traditions rarely enter into conversations about the ethics of using human subjects for medical experiments. Instead, the implementation of clinical research ethics emphasizes legal and regulatory compliance, focusing almost exclusively on the content of informed consent disclosures. This manuscript argues that religious ethics’ prophetic voice can challenge the idea that anything is acceptable if subjects give voluntary and informed consent. Religious ethics broadens and strengthens clinical research ethics discourse by offering a framework for thinking about respect, exploitation, and fairness in research.

To this end, this manuscript draws on texts from the Jewish canon to develop a distinctly Jewish approach to clinical research ethics that looks beyond consent form disclosures and regulatory compliance. A general framework for the proposed Jewish approach is shaped by rabbinic discussion indicating the limits of informed consent, as well as the Talmudic concept of lifnim mishurat hadin, or the duty to act more generously or mercifully than the letter of the law requires. Within this framework, two case studies place Jewish interpretations of biblical narratives in conversation with persistent challenges in clinical research ethics to offer new insights. One case study utilizes the narrative of the Akedah, or “Binding of Isaac,” to reinvigorate ethical analysis of the 1963 Jewish Chronic Disease Hospital case. Placing the two narratives in conversation with one another draws attention to the ethical significance of dignitary harms—harm that occur absent physical injury—and encourages reflection on the role
of researchers’ character, and the professional ethos of research with human subjects, for ensuring ethical research practices. The second case study utilizes the narrative of Job to frame debates about the kinds of compensation owed to subjects suffering research-related injuries. This case study emphasizes the need for a no-fault approach to compensation by comparing the plight of the injured subject with Job’s, and by analyzing the details of Job’s compensation at the narrative’s end.
ACKNOWLEDGEMENTS

This dissertation is the result of countless hours sitting alone in front of my computer, writing, and then deleting, and then rewriting (and re-deleting) the words on the screen. But it is also the result of encouragement and support I received from so many people who believed in me, even when I doubted myself, and who invested in my growth as a scholar and a person. I would like to express my gratitude to some of those people now.

I consider myself incredibly lucky to have worked with such a caring and encouraging dissertation committee. Laurie Zoloth, Cristie Traina, and Barry Wimpfheimer have supported me as a developing scholar since I arrived at Northwestern. They saw my enrollment in the JD/PhD program as an opportunity for enriching the interdisciplinary nature of my scholarship and urged me to weave together my training in law, ethics, and religious studies to develop a distinctive voice and perspective in my work. Barry helped me develop the skills I would need to navigate rabbinic literature; he also introduced me to Robert Cover’s “Nomos and Narrative.” Cristie oversaw my second year paper, in which I began contemplating new sources and methods for Jewish bioethics. I have always been able to count on her to ask insightful and challenging questions about my work, and she has helped me to think about how to put my research in conversation with Christian ethics. Laurie has had faith in this dissertation even when I had my doubts, and her confidence in this project, and in me, helped me persevere through the sometimes frustrating process of writing it. She read through multiple drafts, always giving me copious notes, challenging me to stand up for my arguments, and offering me a much-appreciated cup of tea. In all three of them, I have found role models for thinking creatively, and for considering the implications of my work beyond the confines of my own discipline.
I was fortunate as an undergraduate at the University of Virginia to find two incomparable mentors. Jim Childress and John Arras (z”l) took me under their wings, fostering my love for bioethics and encouraging me when I decided to pursue a PhD. Both have always been beyond generous with their time and advice, even after I was no longer their student. John passed away in March, and I’m so sad that I won’t get to show him this manuscript—he would have groaned at the sections on dignity, and he would have asked tough questions. I have no doubt this dissertation would have been that much stronger for his feedback.

The Society of Jewish Ethics has felt like an intellectual home to me throughout graduate school—a place to reinvigorate my enthusiasm for Jewish ethics each January, and a scholarly community in which I feel I have a stake. I have benefitted from the support of its members immensely since my first SJE conference in 2007, and I have been especially lucky for the advice and mentorship I’ve received through the years from Toby Schonfeld and Martin Kavka.

Dissertation writing can be profoundly isolating, which is why I am especially grateful to Elizabeth Lenaghan, from Northwestern’s Graduate Writing Center, for organizing the Dissertation Bootcamp sessions I attended during the summer of 2014, and for inviting me to participate in an interdisciplinary writing group for the fall 2014 and winter 2015 quarters. I wrote significant drafts of Chapter Three and Chapter Four during the Bootcamps, and the women in my writing group (Desiree, Elizabeth, Leigh, Megan, and Melissa) provided regular and insightful feedback on later versions of those chapters.

I was also fortunate to find support among my colleagues and friends at Northwestern. My fellow graduate students in Religious Studies and the JD/PhD program regularly offered me feedback on my work, and my conceptualization of this dissertation sharpened significantly
through the exercise of answering their questions and exploring new sources they brought to my attention. There are a few friends and colleagues to whom and for whom I am particularly grateful. Especially throughout the dissertation writing process, Stephanie Wolfe and Elizabeth Benjamin (who is actually an art historian but has generously offered enough feedback on my work to be an honorary religious studies scholar) were frequent writing buddies, lunch dates, and sounding boards who helped me stay sane when the words on my screen stopped making sense to me. I also owe an extra special thank you to Michal Raucher, my favorite hevruta and conference roommate, and a wonderful and supportive friend. I could not ask for a better partner-in-crime for all things bioethics.

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My family has supported me throughout this entire process, since long before I knew there was even such a thing as bioethics. There is a host of aunts, uncles, and cousins who have been cheering me on, sending me news articles, and consistently reminding me that life is about more than what goes on in my brain. My grandmother, Sophia Englander, forgave me for missing more family gatherings than I care to admit on account of this dissertation. I am regularly inspired by her ability to both value and balance the importance of education and
family. I also owe special thanks to my brother, David. I was fortunate that our time at Northwestern overlapped for three years; when he left Evanston to pursue his own graduate studies (and multiple degrees!), I was lucky to have a sibling who could relate to the challenges of bridging two fields together and sometimes feeling like I did not fit in to either of them—and who could assure me that carving a new, interdisciplinary path for myself is worth the challenges it sometimes presents. David also went above and beyond the call of duty at the eleventh hour to help me format the dissertation’s works cited. My dad, Jon Henning (z”l), and my grandfather, Mal Englander (z”l), played no small part in shaping me and my interest in ethics. I can think of no better examples of acting lifnim mishurat hadin—more mercifully or compassionately than the law requires—then the two of them. I wish they were here to share in the completing of this dissertation, but I hope its pages are suffused with their spirit.

Finally, I owe immeasurable gratitude to my mom, the honorable Patti Henning, for her unwavering faith in me throughout my life but especially during the PhD process. She has been a tireless copy-editor, cheerleader, and sounding board for me, challenging me to reconsider my sometimes rash criticisms of the legal system without ever questioning why I wanted to study what I study. She has consistently encouraged me to chart my own course and proven that she has my back wherever that path may lead, “even unto Hebron.” This dissertation is dedicated to her.
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CHAPTER ONE: INTRODUCTION

I began studying bioethics during President George W. Bush’s first term in the White House—a time when the foremost bioethical debate seemed to surround embryonic stem cell research: specifically, the research raised questions in public discourse about the moral status of human embryos, which were necessarily destroyed in the process of isolating the stem cells. Some opponents of embryonic stem cell research argued that destroying embryos was tantamount to murder—an opinion that resonated with the anti-abortion agendas of the Catholic Church\(^1\) and many Evangelical Christians\(^2\) who argued that embryos, as human life, deserved the same rights and protections as human *persons*. Interestingly, Jewish tradition offered a countertext to the more publicly familiar Christian narratives about abortion and, by extension, about the status of the embryo. When I read in one of Rabbi Elliot Dorff’s articles that under Jewish law, abortion was not only permissible but in some cases *obligatory*,\(^3\) I was fascinated: it was the first time I had seen a religious argument that not only tolerated but supported abortion, even if only in limited contexts. But I was less interested in Dorff’s conclusion about the permissibility of abortion than the way in which Jewish sources could introduce new conceptual

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\(^3\) Elliot Dorff, “Is There a Unique Jewish Ethics? The Role of Law in Jewish Bioethics,” *Annual of the Society of Christian Ethics* 21 (2001): 313. 305-318, at 313. Also see Elliot Dorff, *Matters of Life and Death: A Jewish Approach to Modern Medical Ethics* (Philadelphia: Jewish Publication Society, 1998): 129 (Noting, although “Jewish law generally forbids abortion...Jewish law requires abortion when the woman’s life or health—physical or mental—is threatened by the pregnancy; Jewish law permits abortion when the risk to the woman’s life or health...is greater than that of a normal pregnancy but not so great as to constitute a clear and present danger to her.”).
frameworks into bioethics discourse. For example, Dorff discussed the rabbinic suggestion that “between the forty-first day of gestation and birth….the fetus is ‘like the thigh of its mother.’”\(^4\) He explained that while amputating a healthy thigh is forbidden, amputating a gangrenous thigh would be halakhically permitted for the patient’s health.\(^5\) By grounding the prohibition of abortion in the prohibition of self-injury, which Jewish law forbids “because God own[s] our body,”\(^6\) Dorff introduced the possibility that abortions performed for the sake of the mother’s health, and not just to save her life, could be halakhically permissible if the health risks of having the abortion were less than the risks of not having one.\(^7\) But perhaps even more importantly, Dorff’s engagement with Jewish text framed abortion as a medical procedure performed on a woman’s body and normalized abortion amongst other medical procedures a woman might undergo—a way of thinking about abortion that is easily lost in the midst of debates about the moral status of the embryo.

There is a saying in the Talmud that “God resides within the four cubits of halakhah,” or Jewish law.\(^8\) As I continued my studies in Judaism and bioethics, it became apparent that God could not be contained within a mere four cubits—that Judaism, and Jewish ethics, was so much more than just halakhah. Legal training helped me to see firsthand that law and ethics did not

\(^4\) Dorff, “Is There a Unique Jewish Ethics?” 313
\(^5\) Ibid.
\(^6\) Ibid.
\(^7\) Ibid. Also see Dorff, *Matters of Life and Death*, 129. In this case, where the mother’s health—but not her life—is at risk, abortion would be permissible but not obligatory. However, by analogy to the case of amputating a gangrenous leg, Dorff’s reasoning accepts the possibility that a woman might be halakhically obligated to have an abortion if the failure to do so would place her life at risk. For an analysis of risk-assessment and individual choice in Jewish bioethics, see Benjamin Freedman, *Duty and Healing: Foundations of a Jewish Bioethic* (New York: Routledge, 1999): 255-331.
\(^8\) BT Berakoth 8a (Soncino trans., 1990). (All BT quotations come from this translation unless otherwise noted.) “Since the day that the Temple was destroyed, the Holy One, blessed be He, has nothing in His world but the four cubits of Halachah alone.”
always have the same goals. This training also helped me appreciate that law—and the legal system—might not always be the best avenue for ensuring that medical practice or medical research remain ethical. And law’s shortcomings—its inability to secure justice in all circumstances—became increasingly frustrating for me as I spent more time in law school. The source of my frustration, I realized, was due in part to my expectation that law, a conservative institution\(^9\) intended to set minimal standards of behavior, should accomplish more aspirational goals. In the words of legal scholar and bio ethicist Dena Davis, “there are substantial areas of bioethics that have been stunted by the influence of legal thinking, and by an unstated, often unexamined, subservience to legal norms.”\(^{10}\) Thus, my time in law school further instilled in me the awareness that there is also so much more to ethics than just law. Yet, in practice, research ethics discourse is often limited to regulatory compliance, and religious ethics offers a means of looking beyond those four cubits to take a more holistic view of research with human subjects as a social endeavor.

Trained in the analysis of Jewish texts and their uses in ethical debates, I turned to Jewish narrative texts for the purpose of imagining an alternative research ethic—one that looked to more than just regulations to consider ethical concerns that could not necessarily be addressed meaningfully through legislation.

**METHOD**

My approach—using biblical narratives to provide structure for bioethical discussions—draws inspiration from Laurie Zoloth’s early contributions to oncofertility research at

\(^9\) In calling law a conservative institution, I mean that law can be difficult to change, often supports maintenance of the status quo, and cannot always “keep up” with changes in society, technology, etc.

Northwestern University. The term oncofertility refers to reproductive technologies and interventions designed to preserve the reproductive options for cancer survivors.\textsuperscript{11} The same radiation and chemotherapy that had saved so many cancer patients’ lives were also leaving them infertile, and scientists at Northwestern were investigating new assisted reproductive technologies that could offer fertility preservation for women.\textsuperscript{12} Researchers wanted to know whether it might be possible for women to freeze ovarian tissue, which contains immature egg follicles, so that the eggs could be thawed and matured in-vitro at a later date to be used in more familiar assisted reproductive technologies like in vitro fertilization (where an egg is fertilized outside of a woman’s body).\textsuperscript{13} Zoloth conceptualized the study as “The Joseph Project,”\textsuperscript{14} a reference to Joseph’s interpretation of one of Pharaoh’s dreams in Genesis 41:

“I saw seven ears of grain, full and healthy, growing on a single stalk; but right behind them sprouted seven ears, shriveled, thin, and scorched by the east wind. And the thin ears swallowed the seven healthy ears”….And Joseph said to Pharaoh, “…God has told Pharaoh what He is about to do….the seven healthy ears are seven years…..the seven empty ears scorched by the east wind…are seven years of famine….Immediately ahead are seven years of great abundance in all the land of Egypt. After them will come seven years of famine, and all the abundance in the land of Egypt will be forgotten. As the land is ravaged by famine, no trace of the abundance will be left in the land because of the famine thereafter, for it will be very severe.”\textsuperscript{15}

\textsuperscript{12} Ibid., 5-7.
\textsuperscript{15} Genesis 41:22-31 (Jewish Publication Society trans., 1999) (All biblical citations come from this edition unless otherwise noted.)
As a narrative framework, this passage highlights much of what was at stake in oncofertility research. Prior to beginning cancer treatment, patients’ ovaries contained plentiful stores of immature eggs which, over the course of the patient’s life, would mature and might be fertilized. But the chemotherapy and radiation that offer cancer patients their best chance of survival also often leave patients infertile. Just as Pharaoh needed to develop a plan so that Egypt would be able to save food during its seven plentiful years that would sustain its people through the years of famine that would follow, oncofertility researchers were looking for ways to “harvest” ovarian tissue before chemotherapy and preserve it so that it would be available for patients to use for reproduction after their cancer was in remission. And perhaps even more importantly, Zoloth noted that the Joseph metaphor also served as a crucial reminder that oncofertility research was still in its early stages—there was no guarantee that the immature eggs in the ovarian tissue, once thawed, could be coaxed into maturing, or that eggs matured in vitro would develop normally after fertilization and result in live human births, and the answers to these questions would probably remain unknown for well over seven more years. Betting on oncofertility was, in many ways, not unlike planning for the future on the basis of a dream. The narrative of Pharaoh’s dream thus acted as an important check on the enthusiasm that scientists and patients felt about the idea of oncofertility. Though the biblical text informs readers that Joseph’s interpretation of Pharaoh’s dream was correct, oncofertility researchers—and the women with cancer whom they asked to donate their ovarian tissue for the research—could not know whether the experiment would provide a successful solution to the dream of fertility preservation! When

16 Zoloth et al., “Waiting to be Born,” 23.
17 Zoloth, “Jewish Perspectives on Oncofertility,” 312
18 Ibid.
I heard Zoloth explain why she framed oncofertility as “The Joseph Project,” I became keenly aware of narrative’s potential to encapsulate and convey the entangled-ness of complex bioethical issues. The reference to a familiar narrative, like the story of Joseph, expressed more about what was at stake in oncofertility research than could be conveyed through legal analysis of relevant rules and regulations.

RE-IMAGINING ETHICS DISCOURSE THROUGH JEWISH NARRATIVES

In this dissertation, I develop a new method for Jewish bioethics and apply that method to problems in the ethics of using humans as research subjects in medical experiments—an area of bioethics with which Jewish bioethics, and religious bioethics more broadly, has not yet engaged. This manuscript draws attention to the way that narrative has functioned in Jewish bioethics. It is my contention that while appeals to narratives are surely present, they are greatly outnumbered by appeals to halakhah, Jewish law. Early scholarship in Jewish bioethics developed as a subset of halakhic reasoning, asking what Jewish law would permit or require in different (medical) contexts. Although Jewish ethics is a multi-vocal discourse that makes room for disagreement, and although more recent scholarship in Jewish ethics, including in Jewish bioethics, incorporates a wider array of sources and methodologies, halakhic reasoning often remains the most amplified voice in Jewish ethics discourse.


My approach, which utilizes ethically fraught biblical narratives and their interpretations within later Jewish Thought to re-frame questions in research ethics discourse, offers important advantages over more parochial halakhic approaches and narrative approaches grounded in Talmudic texts for advantages when engaging in pluralistic, public bioethics discourse concerned with policies and practice. Halakhic approaches are primarily responsive to the questions and needs of the halakhic system, which are not always the same questions and needs raised in U.S. bioethics policy discourse. Thus, halakhic approaches to Jewish bioethics have limited implications for broader bioethics discourse, since non-Jews (and also many Jews) are not invested in or beholden to the halakhah. Narrative approaches to religious bioethics offer a greater chance of engaging in discourse across and beyond religious traditions.

In his article, “Nomos and Narrative,” legal scholar Robert Cover described law as a bridge between current reality and an “imagined alternative.” But the society we create through law—and the laws we create to shape society—depends upon human creativity and imagination. Law is limited by our capacity to imagine bold alternative realities to which law will serve as a bridge. Religious narratives are especially useful for imagining such bold alternatives because religious texts encourage us to imagine a better future world, different from the world we currently inhabit. Unlike current narrative approaches to Jewish bioethics, which start with Talmudic texts, I develop my analyses from biblical texts that are more familiar within and beyond Judaism and that do not necessarily depend upon an understanding of halakhic norms. Turning to narratives that are also familiar in Christian and Muslim traditions, as well as within

philosophy of Emanuel Levinas); David Novak, Natural Law in Judaism (Cambridge, UK: Cambridge University Press, 2008).
U.S. secular culture, allows the proposals I develop in this dissertation to more readily become a part of broader U.S. debates about clinical research ethics. In this dissertation, I am further developing a methodology that uses religious narratives to engage with bioethics—a process of “thinking with stories.”

Literature professor David B. Morris differentiated between thinking with stories and thinking about them as follows:

Thinking about stories conceives of narrative as an object. Thinker and object of thought are at least theoretically distinct. Thinking with stories is a process in which we as thinkers do not so much work on narrative as take the radical step back...of allowing narrative to work on us.  

I understand Morris’s concept of “allowing narrative to work on us” along the same lines as philosopher Martha Nussbaum’s argument that moral character and discernment develop through the reading of literature.  

I apply their approach to narratives from the Jewish canon and create space in which those narratives may “work on” questions about the ethics of using human subjects in medical research—especially questions about respect, character, fairness, and social responsibility.

Much like the work of Talmud scholar Julia Watts Belser, “[m]y ethical framework is shaped by Jewish values, mediated by particular readings of Jewish texts and by my own engagement with Jewish traditions.”

To this end, I draw on a wide array of Jewish sources for

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24 Morris, 55
25 See Nussbaum, 24 (describing the use of literature in the ethical search for how to live one’s life).
this dissertation. These sources include texts from the Tanakh, or Hebrew Bible,\textsuperscript{27} and from collections of midrash, early rabbinic commentary on the Tanakh. Midrashic interpretation is made possible by the rabbis’ hermeneutic assumptions that each word in the Tanakh has a purpose, and that textual idiosyncrasies invite interpretation; midrash also offers the rabbis a way to elaborate upon or fill in the gaps of sparse biblical narratives. For example, in Genesis 1:26, “God said, let us make man in our image, after our likeness.”\textsuperscript{28} By the rabbinic period, monotheism has been established as dominant Jewish doctrine, rendering the phrase “let us” a curious choice of words. Thus, it is perhaps unsurprising that a midrash on the verse asks, “with whom did He take counsel?”\textsuperscript{29} The midrash offers three answers, each attributed to a different rabbi:

R. Joshua b. Levi said: He took counsel with the works of heaven and earth, like a king who had two advisers without whose knowledge he did nothing whatsoever. R. Samuel b. Nahman said: He took counsel with the works of each day [of creation], like a king who had an associate without whose knowledge he did nothing. R. Ammi said: He took counsel with His own heart. It may be compared to a king who had a palace built by an architect, but when he saw it it did not please him: with whom is he to be indignant? [S]urely with the architect! Similarly, And it grieved Him at His heart (Gen. 6:6)…\textsuperscript{30}

This particular example of midrash, in which multiple interpretations of a verse co-exist side by side, illustrates the multivocality characteristic of Jewish texts. It also illustrates the role of imagination and the ability to think in metaphors or analogies encouraged by midrash as a genre.

\textsuperscript{27} This is what Christians refer to as the Old Testament.
\textsuperscript{28} Gen. 1:26
\textsuperscript{29} Gen. Rabbah 8:3 (Soncino trans., 3\textsuperscript{rd} ed., 1961.) (All midrash quotations come from this translation unless otherwise noted.)
\textsuperscript{30} Ibid.
I also draw on texts from the Mishnah and the Babylonian Talmud. The Mishnah is an early rabbinic law code, redacted around 200 CE. It is divided into six “orders” and organized by category. The Babylonian Talmud is the most often-cited body of text in Jewish bioethics (and much of Jewish ethics more broadly). Redacted by 750 CE, the Babylonian Talmud is an extensive compilation of generations of rabbinic interpretations and glosses on the laws of the Mishnah, as well as glosses on the Tanakh and stories about the rabbis; the Babylonian Talmud is organized as a commentary to the Mishnah, but the content of the Talmud tends to meander, such that the relation between the Talmudic discussion and the original passage from the Mishnah is not always readily apparent. Finally, I also engage selected works of Jewish Thought or theology written after the Holocaust.

This project is titled “Experiments in Judaism” for two reasons. First, the phrase “experiments in Judaism” reflects my use of Jewish sources to probe the ethics of using human beings in medical experiments—to examine the ethics of medical experimentation through the lenses of Jewish concepts and canonical Jewish sources. Second, the specific texts I’ve selected and the ways in which I’ve applied them represent my own experiment in Jewish bioethics. Jewish bioethics typically deals primarily in sources from the Talmud and/or later commentaries to the Talmudic text, often focusing on *halakhah* as the appropriate framework for Jewish ethical reasoning. This dissertation is an experiment in allowing *aggadah*, or non-legal Jewish sources, to drive ethical analysis, as well as an experiment in emphasizing biblical stories over rabbinic texts. I selected biblical narratives because they are more familiar in a U.S. context, for two reasons. First, narratives from the Tanakh are canonical to both Judaism and Christianity, and many biblical stories are also referenced in Muslim scriptures. Second, many works of literature
and film\textsuperscript{31} allude to biblical stories. Starting with texts from the Tanakh, rather than the Talmud, thus provides a textual touchstone that is accessible beyond a Jewish audience and can help lay the foundation for pluralistic engagement with research ethics through religious texts. Just as Benjamin Freedman argued that Jewish bioethics must be able to “speak the language” of secular bioethics in order to affect broader discourse and practices,\textsuperscript{32} religious ethics is better positioned to effect change in research ethics policy if it is able to bring together perspectives from many religious traditions.

\textbf{CONTRIBUTIONS}

This dissertation’s main contributions are to the fields of religious bioethics, Jewish applied ethics, and clinical research ethics. In the context of religious bioethics, this project forges a path for scholars in religious bioethics to bring the resources of the traditions they study to a set of not-yet-examined ethical questions—questions related to the use of human subjects for medical research. Additionally, addressing topics such as dignity or respect in context of research may productively complicate or clarify the way these concepts are discussed in other areas of religious bioethics, such as clinical ethics. Although secular bioethicists and institutions of bioethics—including government bioethics commissions—sometimes make the effort to account for ethical perspectives from varied religious traditions, little if any opportunity is made for these different religious traditions to engage with one another’s ethical insights. By selecting


\textsuperscript{32} See Freedman, \textit{Duty and Healing}, 18
familiar biblical narratives for my frameworks, I hope that this dissertation will serve as an invitation to scholars of religious ethics who study other Abrahamic traditions to engage in dialogue about research ethics within and across traditions.\(^{33}\)

This dissertation makes three main contributions to applied Jewish ethics. First, it continues the work that Jewish bioethicist Benjamin Freedman began in his book, *Duty and Healing*, by exploring ways that Jewish ethics can simultaneously speak to and challenge secular bioethics discourse in a mutually beneficial way.\(^{34}\) It further builds on Freedman’s scholarship by complementing the work he began in an unpublished appendix to his book, in which he considered whether participating in potentially risky medical research, for the benefit of others, violated the Jewish duty to be a responsible steward of one’s own body and life.\(^{35}\) I address the ethics of research with human subjects from an alternate angle, turning Freedman’s duty-based approach onto the responsibilities of researchers and society, rather than those of the subjects.

Second, this project offers another example of a narrative-based approach to applied Jewish ethics, in the same vein as works by Jewish ethicists Laurie Zoloth and Julia Watts Belser.\(^{36}\) Third, by selecting *biblical* narratives as frameworks, I lay the foundation for considering more of the Jewish canon in applied Jewish ethics, making space for both the biblical narratives and later midrashic interpretations of them within the larger Jewish ethics discourse.

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\(^{33}\) My initial appeal to involving other Abrahamic traditions—Christianity and Islam—is based on the textual tradition their share with Judaism and their prevalence in the United States. These are not the only religious traditions with contributions to offer to research ethics discourse, and I would welcome the involvement of scholars of non-Abrahamic traditions in research ethics discourse, too.

\(^{34}\) Benjamin Freedman, *Duty and Healing* p18

\(^{35}\) Benjamin Freedman, “Appendix 1: Participation in Clinical Research: Convergence of Jewish and Contemporary Perspectives,” (Appendix to *Duty and Healing*), originally published online; obtained via e-mail from Charles Weijer on March 14, 2013.

Finally, this dissertation contributes to research ethics, not only by introducing religious ethics into discussions about the ethics of using human subjects, but also by productively challenging the emphasis on regulatory compliance and relieving some of the burden placed on informed consent procedures to act as an ethical magic wand in medical experiments. By thinking about research as a profession with internal ethical goods beyond “good science” and suggesting that more attention be paid to cultivating an attitude of respect for human subjects within researchers, I raise questions about how researchers are trained in ethics, too. These conversations cannot replace regulatory concerns, but they can supplement them to create a more robust concept of ethical scientific research with real-world applications that better respect the human subjects’ contributions to scientific and medical advances.

CHAPTER OUTLINE

This dissertation illustrates some of the contributions that Jewish sources, read with attention to the prophetic voice, may make to research ethics discourse. Throughout the manuscript, I pay particular attention to the limits of a legal or regulatory framework as a sole basis for ensuring or envisioning ethical research with human subjects. In each chapter, I introduce a text from the Jewish canon to re-frame an ethical question or problem with which a legal approach has failed to engage, or engage adequately.

In Chapter Two, I explain research ethics’ twin problems of overdependence on informed consent and legalism. I describe the absence of religious ethics in research ethics discourse and argue that research ethics should invite religious perspectives to the conversation because religious perspectives contribute a “prophetic voice” that resists the power of market-based arguments. I then turn specifically to Judaism, stating my case for turning to Jewish sources in
order to develop a religious discourse about research ethics. Specifically, I appeal to scholarly practices, particularly in legal scholarship but also in bioethics, that present Jewish texts, or the halakhic system, as counter-models that might remedy perceived shortcomings in U.S. systems. I present an example from the Mishnah, Bava Kama 8:7, as an ancient Jewish text that, curiously, may speak directly to the overemphasis on informed consent as a guarantor of ethical research. In this chapter, I also discuss the Talmudic idea that humans are sometimes obligated to act “lifnim mishurat hadin,” more generously than the letter of the law requires. I argue that the concept of lifnim mishurat hadin frames an approach to thinking about research ethics as more than just regulatory compliance.

Chapter Three marks the beginning of my turn to narrative, particularly biblical narrative, as a framework for ethical analysis and imagination. This chapter experiments with using the biblical narrative of the Akedah or “Binding of Isaac,” from Genesis 22, to develop a more robust analysis of the 1963 Jewish Chronic Disease Hospital case. In the Jewish Chronic Disease Hospital case, researchers used hospital patients as experimental subjects without their knowledge or consent. The main application of this case in research ethics discourse is to emphasize the importance of obtaining a subject’s voluntary and informed consent before using them in an experiment—but the important ethical lessons of why it is important to obtain informed consent are sometimes watered down to a procedural lesson: did the researcher get the consent form signed? Placing the story of the Jewish Chronic Disease Hospital in conversation with the Akedah, helps draw attention to some of the values that underlie informed consent requirements: what sort of attitude toward subjects is informed consent supposed to promote in researchers? What can be done to help researchers cultivate these kinds of attitudes?
Additionally, the Akedah, a story that is horrific even though Isaac is not ultimately physically injured or killed, becomes a framework that refuses to allow a “no physical harm, no foul” approach to analyzing the Jewish Chronic Disease Hospital case and informed consent requirements. By encouraging us to resist consequentialist analysis of the case, the Akedah also helps us to focus on the ethical significance of dignitary harm—harms that occur in the absence of physical injury—in the context of research.

In Chapter Four, I continue using biblical narratives—in this case, Job—to frame questions in research ethics, turning to debates about what kind of compensation is owed to research subjects who are physically injured as a result of their participation in an experiment and about who bears the responsibility of compensating them. This chapter explains why U.S. tort law, currently the only recourse available for many injured subjects to seek compensation, is inadequate for ensuring that research subjects’ willingness to bear the risks of research participation does not also force them to bear the costs when they suffer injuries from experiments. Then, I employ the mythical narrative that bookends the book of Job37 as a framework for thinking about what would constitute ethical compensation for injured research subjects.

The dissertation’s Conclusion summarizes the contributions that the Jewish sources discussed in this manuscript offer for a clinical research ethics discourse that accounts for more than regulatory compliance and informed consent procedures. In this final chapter, I sketch law’s capacity to facilitate the changes to research practice suggested by my analysis of the Akedah and Job. I conclude with a call for religious ethicists from other traditions to take up the

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37 Job 1:3-2; Job 38-42.
questions raised by using humans in medical research, briefly considering the ways in which
Christian liberation theology’s interpretations of Job give a greater sense of what is at stake when
the U.S. conducts research in developing countries.
CHAPTER TWO: THE CASE FOR JEWISH RESEARCH ETHICS

INTRODUCTION

The ethics of using humans as subjects in scientific research was at the heart of modern bioethics, which traces its roots to the Nuremberg trial of the Nazi doctors. The doctors’ trial resulted in the 1947 Nuremberg Code, which established voluntary and informed consent as the benchmark of bioethics. However, the last few decades have seen an increasing realization that informed consent, while crucial to both medical treatment and scientific research, is an insufficient guarantor of ethics. The discourse of clinical bioethics—concerned with treating individual patients—has become increasingly interdisciplinary: incorporating voices from philosophy, religious studies, anthropology, and sociology, and adopting narrative and feminist approaches to supplement and challenge rule-based bioethics. The ethics of research with human subjects, by contrast, appears increasingly legalistic and continues to be dominated by rules-based approaches fixated on informed consent.

Religiously-informed perspectives—generally absent from ethical debates about using human subjects for research—can help open research ethics discourse beyond technical concerns about informed consent and shift attention to ethical issues of exploitation, fairness, and justice in scientific research. In this chapter, I explain why I have turned specifically to Jewish sources, outlining specific contributions that Jewish sources and the history of Jewish ethics can offer research ethics discourse. First, however, I offer a brief history of research ethics, argue that

38 Throughout this dissertation, I use the phrases “research ethics” or “clinical research ethics” as shorthand for “the ethics of research with human subjects.”
research ethics should *invite* religious perspectives into the discourse, and provide a short introduction to Jewish bioethics.

**BACKGROUND: A SHORT HISTORY OF RESEARCH ETHICS**

Since the Nuremberg Code’s introduction in 1947, voluntary and informed consent has become ubiquitous in discussions about how to ethically use humans in scientific research, taking a central role in subsequent research ethics codes as well. The first of the Nuremberg Code’s ten provisions states that “The voluntary consent of the human subject is absolutely essential.”39 The Code defines voluntary consent as measured by three factors: (1) the person’s legal capacity to consent, (2) the person’s ability to “exercise free power of choice,” and (3) the person’s knowledge and comprehension of the risks that participation may involve.40 The third factor, concerned with knowledge and comprehension, indicates that the Nuremberg Code is concerned with what bioethics literature elsewhere calls “voluntary and informed consent,” or “informed consent” for short. The 1964 World Medical Association’s Declaration of Helsinki included ethical guidelines for “non-therapeutic clinical research”41,42 that are almost exclusively concerned with informed

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40 Ibid. “This means that the person involved should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, over-reaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved, as to enable him to make an understanding and enlightened decision.”

41 World Medical Association, “Declaration of Helsinki,” *British Medical Journal* 2, no. 5402 (1964): 177. The Declaration of Helsinki defined “non-therapeutic research” as “the purely scientific application of clinical research,” what current bioethics literature would simply call “research.” The Declaration of Helsinki contrasted non-therapeutic research with “clinical research combined with professional care,” which today might more accurately be described as the use of experimental interventions to treat a specific patient.

Since then, the Declaration of Helsinki has been revised eight times, most recently in 2008. That version includes eighteen “basic principles for all medical research,” of which approximately one third are concerned with aspects of consent. Additionally, in 1979, the US National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research issued the Belmont Report, which established three guiding ethical principles for research—“respect for persons,” “beneficence,” and “justice”—and explained the application of each principle. The first principle, respect for persons, is applied and guaranteed through informed consent procedures.

The shortcomings of informed consent as an ethical panacea for research with human subjects have been a familiar part of the research ethics literature at least since 1982, when the “therapeutic misconception” was first identified in scholarly bioethics literature. The therapeutic misconception is a term Paul Appelbaum and his colleagues applied to a disturbing phenomenon: even after researchers explained to subjects that a trial would involve both placebo and active arms,

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43 Ibid. “The nature, the purpose, and the risk of clinical research must be explained to the subject by the doctor. Clinical research on a human being cannot be undertaken without his free consent, after he has been fully informed; if he is legally incompetent the consent of the legal guardian should be procured. The subject of clinical research should be in such a mental, physical, and legal state as to be able to exercise fully his power of choice. Consent should as a rule be obtained in writing….At any time during the course of clinical research the subject or his guardian should be free to withdraw permission for research to be continued.”


45 Ibid.

46 National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, “The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research” (Washington: Department of Health, Education, and Welfare, 1979). The absence of any religious insights, frameworks, etc. in the Belmont Report is not exactly surprising, as it was designed to offer policy guidance for the U.S., but it is perhaps an interesting detail that the authors of the Belmont Report included Albert Jonsen, a former Jesuit priest, and Karen Lebacqz, a professor of Christian ethics.

47 Ibid.

and that subjects would be randomly assigned to one or the other arm by a “double-blind” process so that neither the subjects nor the researchers would know which compound the subjects were receiving, and even after subjects correctly repeated this information to researchers, subjects reported in interviews that they were certain they would be receiving the compound that was therapeutically best for them as an individual.

Scholarly response to the revelation of the therapeutic misconception focused primarily on how to better ensure that research subjects were actually giving their informed consent to participate in scientific studies, rather than questioning the sufficiency of informed consent policies to ensure ethical research practice. And ironically, as Neil Manson and Onora O’Neill noted in *Rethinking Informed Consent in Bioethics*, efforts at improving informed consent often focused on increasing the amount of information transmitted to potential research subjects—ultimately making it even more difficult to obtain informed consent as more (and less relevant) details blended together in single, increasingly lengthy consent forms. Precisely because it is so difficult to ensure that subjects are actually giving meaningful informed consent to research participation,

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49 Today, there is a growing movement, one that began within the field of disability studies, to replace the phrase “double-blind” with “anonymized” in order to stop equating blindness with ignorance.

50 Appelbaum et al., 319-329; also see Dresser, 271 (“Appelbaum’s group found that many people were unaware of the differences between participating in a study and receiving treatment in the clinical setting. Rather than understanding these differences, study participants tended to believe that therapy and research were governed by the same primary goal: to advance the individual patient’s best interests. Appelbaum’s group labeled this mistaken belief the therapeutic misconception.”).

51 Oonagh Corrigan, John McMillan, and Charles Weijer, “Introduction,” in *The Limits of Consent: A Socio-Ethical Approach to Human Subject Research in Medicine*, eds. Oonagh Corrigan, John McMillan, Kathleen Liddell, Martin Richards and Charles Weijer (Oxford: Oxford University Press, 2009), 1 (“While there has been a growing awareness that gaining a research subject’s authentic, fully informed consent is not easy to achieve in practice, solutions to the problem have tended to focus on ways to enhance the consent gaining process by improving the information given to prospective subjects and by allowing them sufficient time to consider such information.”).

52 Neil Manson and Onora O’Neill, *Rethinking Informed Consent in Bioethics* (Cambridge, UK: Cambridge University Press, 2007), 10 (referring to demands that consent be increasingly specific and explicit, but also noting that “simultaneous attempts to make informed consent easier for patients and to make it more exacting are likely to backfire”).
it is crucial that research ethics also focus on other types of concerns, such as fairness, exploitation, justice, and just how much risk society may ask subjects to bear for society’s benefit.

Current debates about research ethics also struggle against an overly legalistic approach to research ethics. Inmaculada de Melo-Martin and her colleagues at Cornell noted that research ethics has been dominated by a regulatory approach, such that for many researchers, ethical practice is conflated with regulatory compliance, leading to a failure to distinguish law from ethics. This blurring of the lines is problematic, because, in the words of Dena Davis, “law…is always minimalist by its very nature….what is appropriate for law is not necessarily appropriate for ethics….Those norms should be…more demanding than the minimalist requirements of the law.”

Research with human subjects, when funded or performed by U.S. government employees, is regulated by “the Common Rule.” Study protocols subject to the Common Rule—including studies that receive funding from the National Institutes of Health—must be reviewed and approved by an Institutional Review Board (IRB). The IRB is a committee of “at least five members, with varying backgrounds to promote complete and adequate review of research activities commonly conducted by the institution.” IRBs are only supposed to approve studies that obtain documented, voluntary and informed consent from subjects (or their legal

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55 Code of Federal Regulations, Title 45, Part 46 Subpart A. Subparts B, C, and D provide additional protections/restrictions for research with “pregnant women, fetuses, and neonates;” prisoners; and children, respectively.
56 Ibid. IRBs are local committees tied to specific institutions where research will take place, such as a hospital or university.
57 Ibid., §46.107(a).
representatives—e.g., in the case of children),\textsuperscript{58} and for which subjects are equitably selected.\textsuperscript{59} Additionally, IRBs are only supposed to approve studies where “risks to subjects are minimized,”\textsuperscript{60} and where “risks to subjects are reasonable in relation to anticipated benefits, if any, to subjects, and the importance of the knowledge that may reasonably be expected to result.”\textsuperscript{61}

The NIH identifies four “phases” of clinical research studies with human subjects; each phase aims to establish a different kind of generalizable knowledge about an intervention.\textsuperscript{62} Phase I studies test a new drug’s safety to determine what dosages of the drug are safe to consume, and what side effects may occur at different doses.\textsuperscript{63} In other words, these studies aim to determine the drug’s “maximum tolerable dose.”\textsuperscript{64} A drug’s effectiveness, or efficacy, is tested in Phase II studies.\textsuperscript{65} Phase III studies of a drug involve much larger numbers of subjects and aim to “confirm its effectiveness, monitor side effects, compare it to commonly used treatments, and collect information that will allow the drug or treatment to be used safely.”\textsuperscript{66}

After a drug has been approved for use and marketed to consumers, phase IV studies may be performed to generate more knowledge about how the drug affects different subject populations and to learn about side effects that may occur only after long-term use of the drug.\textsuperscript{67} All four phases share a common goal of producing generalizable knowledge rather than best outcomes for

\textsuperscript{58} Code of Federal Regulations, Title 45, §46.111(a)(4)-(5).
\textsuperscript{59} Ibid., §46.111(a)(3).
\textsuperscript{60} Ibid., §46.111(a)(1).
\textsuperscript{61} Ibid., §46.111(a)(2).
\textsuperscript{63} Ibid.
\textsuperscript{64} Adil E. Shamoo and David B. Resnik, \textit{Responsible Conduct of Research}, 2\textsuperscript{nd} ed. (New York: Oxford University Press, 2009), 248.
\textsuperscript{65} National Institutes of Health, “Question: What are Clinical Trial Phases?”
\textsuperscript{66} Ibid.
\textsuperscript{67} Ibid.
each individual subject. Because each phase builds upon knowledge gained from the earlier phases, it is especially difficult to weigh the risks and benefits involved in Phase I and Phase II experiments, where the drug’s safety and efficacy are yet to be determined. Depending more upon the subject’s informed consent than on risk-benefit analysis places an undue burden on research subjects, especially in Phase I and Phase II trials where the same challenges to risk-benefit analysis can make it difficult for potential subjects to make informed decisions about exposing themselves to risks of possible harms.

WHY RESEARCH ETHICS NEEDS RELIGIOUS ETHICS

Religious perspectives on research ethics could be especially helpful for engaging concerns about human dignity, fairness, and exploitation in research, because these are precisely the types of ethical considerations in which religious traditions trade. Nevertheless, arguments from religious ethics remain largely absent from discussions about research involving competent, adult human subjects, even as these voices have engaged questions about embryonic stem cell research and research involving fetal tissue. Since a key distinction between research on

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68 See Shamoo and Resnik, 256.
69 For a discussion about the limited religious discourse on research with human subjects, see, e.g., James F. Childress, “Protestant Perspectives on Informed Consent (Particularly in Research Involving Human Participants),” *Fordham Urban Law Journal* 30 (2002): 190 (“However, when it prepared its reports on research involving human subjects, NBAC did not specifically invite religious testimony…[and] I recall no specifically religious views presented to NBAC while it prepared its report and recommendations on *Research Involving Persons with Mental Disorders That May Affect Decisionmaking Capacity*.”). Childress refers to ethical debates between Protestant theologian Paul Ramsey and Catholic theologian Richard McCormick over research involving children (195-96); the Ramsey-McCormick debates stand out as an exceptional case in which theologians considered the ethics of research with human subjects; however, children are a population of potential subjects unable to give consent.
embryonic stem cells and fetal tissue, on the one hand, and competent adults, on the other, is the subject’s ability to provide informed consent, it seems as though religious voices have also ceded ground in ethical arguments about research ethics to the potential “gatekeeping” function of informed consent requirements, focusing attention instead on scenarios where consent is impossible. And yet, there are many ethical considerations about research for which informed consent alone cannot provide answers—even when the subjects are all competent adults. For example, is it right to conduct research on human subjects in a poorer developing country when the drug in question, if successful, will be priced out of reach for most residents of that country? What can be done to bridge the disconnect between the population taking on the risks of research participation and the population that stands most likely to benefit from the study’s results? What is owed to research subjects who are injured during the course of research participation—and what is the ethical grounding for the duty to injured subjects? These are not new questions, but they are hard questions crying out for discussion, if not also for answers. Religious ethics and religious texts are important tools for such a daunting task.

In clinical bioethics discourse, religious perspectives have often provided what religious ethics scholars such as Courtney Campbell, Lisa Sowle Cahill, and Laurie Zoloth refer to as the “prophetic voice.” Though each scholar has their own distinctive understanding of “prophetic voice,” their working definitions overlap to suggest that religion contributes an alternative viewpoint on social values which resists the free-market, contract-based approach (and its

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attending overemphasis on informed consent) which currently dominates research ethics discourse. For Cahill and Zoloth, the prophetic voice refers to the voice that resists the power of market-based arguments.\footnote{Lisa Sowle Cahill, “Bioethics, Theology and Social Change,” \textit{Journal of Religious Ethics} 31 (2003): 374-76; see Laurie Zoloth, “Faith and Reasoning(S): Bioethics, Religion, and Prophetic Necessity,” in \textit{Notes from a Narrow Ridge: Religion and Bioethics}, eds. Laurie Zoloth and Dena S. Davis (Hagerstown, MD: University Publishing Group, 1999), 264-66.} In the context of research ethics, this might entail sacrificing profit margins to purchase an insurance policy—not required by U.S. regulations but commonly required in Europe—to compensate injured research subjects.\footnote{See Elizabeth R. Pike, “Recovering From Research: A No-Fault Proposal to Compensate Injured Research Participants,” \textit{American Journal of Law and Medicine} 38 (2012): 7-62 (especially pages 61-62, suggesting that figures from the European Union, where researchers must have insurance coverage to compensate injured participants, suggest insurance is a relatively low-cost means of protecting research subjects).} Alternatively, it might entail researching treatments for “orphan diseases”\footnote{“Rare and Orphan Disease Center,” \textit{The Jackson Laboratory}, \url{http://research.jax.org/rodc/} (accessed July 15, 2013). (“By definition, a rare and orphan disease is one that affects fewer than 200,000 individuals in the United States. Because of the small population afflicted by any one illness, funding to investigate causes and treatments tends to be limited, slowing the discovery of potential therapies. Yet with over 7,000 recognized rare diseases, an estimated 350 million people worldwide are affected at any given time.”)}—diseases that, because they are so rare, do not attract researchers’ interest or energy—or diseases of poverty, conditions that are usually found among poorer individuals or populations. The prophetic voice thus has the capacity to work in tandem with Neil Manson and Onora O’Neill’s call to change the way we think about informed consent so that consent operates as a mechanism for ensuring trust rather than accountability.\footnote{Manson and O’Neill, 32.}

For example, by increasing attention to the fairness and justice of how research subjects are recruited and cared for in the event of trial-related injuries, religious voices can, in turn, help to promote subjects’ trust in researchers’ intentions, possibly creating space for more open dialogue during the consenting process.

For Campbell, “prophetic voices witness to the values that are already embedded in a society’s practices and ideology, which may be compromised or in need of reinterpretation in the...
context of scientific developments,” such as attention to human dignity.77 Much like the biblical prophets who reminded the Israelites of the forgotten or discarded covenantal way of life that included care for society’s most vulnerable members, religious voices in ethics discourse can elevate less-frequently analyzed values that are already embedded in research ethics discourse to the forefront of current conversations.

Campbell’s approach to the prophetic voice may be especially useful for research ethics discourse: the idea that religion, as a source for the prophetic voice, recovers forgotten but pre-existent and deeply embedded social values suggests that religious perspectives need not generate wholly new or unique approaches to research ethics. Rather, it is enough that religious sources become a lens for reconsidering values or principles such as minimizing the risks of physical and mental harm to research subjects, which have always been part of the research ethics framework,78 but which may not have received adequate or extensive attention in ethical deliberations and policy-making.

One benefit to emphasizing the prophetic voice for religious research ethics is that the concept is a component of religious ethics across many traditions, including Judaism, Christianity, and Islam—making it possible to bring a wider spectrum of religious voices into conversation, not only with research ethics, but also with each other. One of the goals of this dissertation is illustrating how approaching Jewish sources with attention to prophetic voice, helps to reorient stalled ethical debates about using human beings in medical research, and in this chapter, I present my case for drawing on Jewish sources.

BACKGROUND: A SHORT HISTORY OF JEWISH BIOETHICS

Early in the development of Jewish bioethics, scholars tended to focus on halakhah, or Jewish law, as the primary means of engaging ethical questions—often missing the opportunity for deeper ethical reflection.\textsuperscript{79} The birth of modern Jewish bioethics is often identified with the publication of \textit{Jewish Medical Ethics}, by Rabbi Immanuel Jakobovits, in 1959.\textsuperscript{80} Early Jewish bioethics was primarily rooted in the Orthodox rabbinate. Consequently, the earliest Jewish bioethics discourse was comprised entirely of male voices. Lists of key thinkers who shaped this phase vary, but the works of Rabbi J. David Bleich, Rabbi Immanuel Jakobovits, Dr. Fred Rosner, and Rabbi Moshe Tendler are generally considered exemplary of early Jewish bioethics.\textsuperscript{81} These contemporary rabbinic authors treated Jewish bioethics as a subset of halakhah, or Jewish law, turning to rabbinic literature—specifically legal portions of rabbinic literature—for the single, definitive “Jewish” answers to bioethical questions. Like other halakhic decisions, these bioethical reflections were constructed around the specific cases, rather than abstract philosophical principles.


\textsuperscript{80} See, e.g., Elliot N. Dorff, “Jewish Bioethics, Past and Future” (presentation, Annual Meeting, Academic Coalition of Jewish Bioethics, Reisterstown, MD, April 26, 2009). The title of Jakobovits’ book is ironic; however, the volume contains discussions of abortion, contraception, and euthanasia—topics which, in 1959, were being reevaluated in light of new technologies. Additionally, the 1975 edition of the book includes an appendix addressing “recent developments in Jewish medical ethics” with sections on eugenics, test-tube babies, brain death, and organ transplantation. Thus, Jakobovits’ book included discussions of bioethics, even if he did not distinguish them from medical ethics.


\textsuperscript{82} “Rabbinic literature” refers to collections of midrash, the Mishnah, and the Babylonian and Palestinian Talmuds, which were compiled and redacted during the rabbinic period, between 250 CE and 750 CE.
Jewish ethics scholar Louis Newman described traditional Jewish ethics as “a matter of finding within the received tradition the pertinent passages and norms and then applying them to the case at hand.”\(^{83}\) But which passages or norms are most pertinent for a specific case is not necessarily a foregone conclusion. As bioethicist Benjamin Freedman cautioned, “[g]iven the vast extent of Jewish sources that may be drawn upon, and their complexity, some form of selection and interpretation is an unavoidable necessity” when drawing upon Judaism’s age-old canonical sources in order to approach contemporary bioethical dilemmas.\(^{84}\) Nevertheless, Dena Davis, a scholar of Jewish bioethics, noted, “most contemporary Orthodox halakhists appear[ed] to be working on the assumption that the texts actually interpret themselves, with the decisors being no more than passive conduits, and the right answers a foregone conclusion.”\(^{85}\) In other words, early authors of Jewish bioethics often presented themselves as mere reporters of conclusive “rulings” contained within the halakhic text itself, thus obscuring their own agency and creativity.\(^{86}\)

Over time, however, some scholars within Jewish bioethics paid more attention to _aggadah_, non-legal and often narrative portions of Jewish religious texts, as a gloss for understanding or critiquing _halakhah_.\(^{87,88}\) Others in Jewish bioethics aimed to extrapolate the

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\(^{84}\) Freedman, _Duty and Healing_, 19. Also see Green, 247 (“But it is also true that all reportage is interpretive.”).

\(^{85}\) Davis, “Method in Jewish Bioethics,” 116. Also see Gereboff, 316 and Green, 247.

\(^{86}\) Concealing the logic behind bioethical positions echoes the early rabbinic suggestion that midrashim, as part of the Oral Torah, were contained within the text of the Written Torah. See Gershom Scholem, “Revelation and Tradition as Religious Categories in Judaism,” in _The Messianic Idea in Judaism_ (New York: Schocken Books, 1995; orig. pub. 1971), 282-303.


\(^{88}\) For an example from the broader field of Jewish ethics, see, e.g., Jeffrey L. Rubenstein, “The ‘Oven of Akhnai’: Rabbinic Authority and Human Dignity (Bavli Bava Metsia 59a-59b),” in _Rabbinic Stories_ (New York: Paulist Press, 2002), 80-84. In this essay, Rubenstein describes how a story commonly read as a description of legal...
underlying values driving *halakhic* positions in order to develop lists of guiding principles that could be applied to a range of bioethical questions.\(^8^9\) This latter trend may have emerged not only to fill a gap in Jewish bioethics, as *halakhic* reasoning was often tied to the analysis of a specific case, but also to conform to models of Christian and secular bioethics.\(^9^0\)

Jewish bioethics has not adequately addressed questions about the ethics of using competent human subjects for research. Much has been written within Jewish bioethics embryonic stem cell research,\(^9^1\) and there are also works in Jewish bioethics that deal with the ethics of using experimental treatments in the care of individual patients. For example, in the early days of organ transplantation, when survival rates were lower, Rabbi Moshe Feinstein, one of Israel’s chief rabbis during the 1960s, called heart transplantation a “double murder” that killed both the donor and the patient-recipient,\(^9^2\) indicating that Jewish law would not permit patients to risk their lives to receive a heart transplant.\(^9^3\) Bioethicist Benjamin Freedman dedicated a chapter of his book, *Duty and Healing: Foundations of a Jewish Bioethic*, to the subject of risk and the ethical dilemmas that may be involved when a patient must decide

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\(^9^0\) For early examples of secular “principled” approaches to bioethics, see National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, “The Belmont Report.” For examples of religious “principled” approaches, see works by Paul Ramsey.

\(^9^1\) See, e.g., NBAC, *Ethical Issues in Human Stem Cell Research: Volume III: Religious Perspectives* (including testimony about Jewish perspectives on stem cell research by Moshe Tendler, Laurie Zoloth, and Elliot Dorff).


\(^9^3\) Israel’s Chief Rabbinate Council initially banned heart transplantation within Israel, partly on the basis of Feinstein’s responsum. However, as the success rate for heart and other organ transplants improved, and as definitions of brain death were fine-tuned, the Chief Rabbinate reversed its position in 1986 to allow heart transplants in Israel. Chief Rabbinate Council of Israel, “Heart Transplants in Israel: Decision of the Chief Rabbinate Council,” *JewishVirtualLibrary*, November 3, 1986, [https://www.jewishvirtuallibrary.org/jsource/Judaism/HeartTransplants.pdf](https://www.jewishvirtuallibrary.org/jsource/Judaism/HeartTransplants.pdf) (last accessed August 7, 2015).
whether to accept medical treatment that also bears risks of harming that patient. One of Freedman’s appendices to the original online publication of *Duty and Healing*, which was not included in the printed edition of the book, was titled “Participation in Clinical Research: Convergence of Jewish and Contemporary Perspectives.” This appendix broached the question of whether the Jewish duty to guard one’s own health was compatible with a sick person participating in a research trial. But for his untimely death in 1997, Freedman might have connected Jewish bioethics with research ethics. Freedman’s scholarship addressed several issues in research ethics, including clinical equipoise, the use of placebo controls in clinical trials, and acceptable levels of risk in research with human subjects.

Freedman’s approach to Jewish bioethics, and to the contributions Jewish ethics can offer broader bioethics discourse, is instructive. For Freedman, the central contribution Jewish ethics makes to broader bioethics discourse is its duty-based approach to ethics, which he contrasted with the regnant rights-based approach in secular bioethics. Although *Duty and Healing* focused on clinical bioethics, Freedman’s approach provides a useful model for thinking about

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95 Also see Benjamin Gesundheit, “Ethics of Medical Research and Investigation in Jewish Sources,” (doctoral dissertation, University of Toronto, 2004): 148-214, which discusses the obligation or permissibility of exposing oneself to danger in order to save another person but does not connect this risk-taking to the use of human subjects for research.
96 Freedman, “Section 4 Appendix 1.”
97 Ibid.
how religion in general, and Judaism in particular, can best engage and participate in more pluralistic or policy-oriented bioethics discourse—including conversations about research ethics. Freedman understood and appreciated the need for his Jewish bioethics to “speak the language” of secular bioethics. He did not seek to replace secular bioethics with a Jewish bioethic. Pointing to secular bioethics’ emphasis on “procedural questions—who will decide” and Jewish bioethics’ focus on “substance—which decisions should be made and for what reason,” Freedman suggested that the two approaches “ought to be seen as complementary rather than contradictory, with each filling in for the other’s deficiency.” Freedman contrasted rights-based secular bioethics, focused on individual autonomy, with a duty-based Jewish ethic. Recognizing that “[a] duty perspective with no space for consent has no common language with current bioethical study and cannot benefit from any moral insight that those discussions may yield,” he recast informed consent as a necessary means of ensuring that individuals “intelligently choose how to live their lives,” in accordance with their duty to be responsible stewards over their bodies and lives, which Jewish ethics considers gifts, on loan, from God. Similarly, religious contributions to research ethics must be compatible with the existing legal and regulatory framework—including informed consent requirements—in order to be effective and useful.

TURNING TO JEWISH SOURCES

I turn to Jewish sources, in part, for a historical reason: the Nazi experiments that formed the backdrop of the Nuremberg Code and early research ethics were acts of violence performed on Jewish bodies. Though victims of the Nazi experiments and death camps were not only Jews—for example, many of the prisoners used as subjects in the Nazis’ high altitude experiments were not Jews—"only"

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103 Ibid., 141.
experiments were Poles and Russians,\textsuperscript{104} and thousands of Gypsies were among the women used in the Nazis’ sterilization experiments\textsuperscript{105}—the Holocaust’s legacy, which includes the deaths of six million Jews, is intensely connected to Jewish thought and ethics. In addition to this historical point, I turn to Judaism for constructing a religious research ethic for two more reasons. First, Jewish sources, especially the Talmud, have been used as productive counter-texts in legal scholarship, and they may be similarly utilized in research ethics discourse. Second, there are passages in rabbinic literature that speak directly to research ethics’ over-dependence on informed consent and law.

**Jewish Texts as Countertexts**

The first way in which Jewish sources may contribute to research ethics discourse grows out of the history of U.S. legal scholarship’s engagement with Jewish law as an alternative model of legal reasoning.\textsuperscript{106} This trend emerged following the publication of Robert Cover’s article, “Nomos and Narrative,” in the early 1980s. In this article, Cover argued that “no set of legal institutions or prescriptions exists apart from the narratives that locate it and give it meaning,”\textsuperscript{107} and he turned to texts from the Hebrew Bible to illustrate what he meant by “nomos,” or “normative universe.”\textsuperscript{108} Within bioethics, the use of Judaism as a counter-text or counter-model often takes the form of appeals to duties over rights in analyzing bioethical dilemmas.


\textsuperscript{105} Ibid., 79.


\textsuperscript{107} Cover, “Nomos and Narrative,” 4.

\textsuperscript{108} Ibid.
Freedman’s *Duty and Healing* adopts duty as an overarching framework for Jewish bioethics, and the concept of *pikuach nefesh*, the duty to violate most Jewish laws in order to save a life, is ubiquitous in Jewish bioethics.

Law professor Suzanne Last Stone described the trend of using Jewish sources as “counter-texts” for thinking about U.S. law and jurisprudence: “The Jewish legal tradition is being subtly reinterpreted to yield a counter-model embodying precisely the qualities many contemporary theorists wish to inject into American law;” however, she also warned that “the counter-model presented…is often more wishful than accurate and, even when accurate, has limited applicability in a secular legal society.” For example, Stone noted a 1992 article in which law professor Steven Friedel argued that “the Jewish legal system [was] a paradigm for feminist jurisprudence, despite its systematic exclusion of women from authoritative roles in the development and articulation of Jewish law.”

Stone’s warning is important to heed while developing Jewish insights for research ethics. Jewish sources can function as helpful counter-texts when attention is paid to accurately reading and reasonably interpreting them, but religious sources should not merely be used as placeholders for new ideas when those ideas cannot be (or have not been) drawn out from the religious text. But as long as we pay attention to what is—and what is not—actually contained in

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111 Stone, 813.
112 Ibid., 814.
113 Ibid.
Jewish sources, the exercise of considering Judaism’s alternative legal model may help open up conversations to imagine possible improvements to U.S. regulations of research with human subjects, even as research ethics discourse draws on Jewish sources to wrestle with the limitations of law as a guarantor of ethics.

**Rabbinic Concepts to Guide Research Ethics**

Rabbinic literature, in this case the Mishnah and Talmud, contains passages that recognize—in some cases as early as the Second Century—that consent, and in some cases the law itself, may not always be sufficient to legitimate actions that could result in harm. Because these sources speak directly to research ethics’ problems of over-dependence on consent and over-emphasis on regulatory compliance, they offer a helpful point of entry and guidance for incorporating religious discourse into discussions of research ethics. The first resource that I will discuss in this section is a passage found in the Mishnaic order *Nezikin*, part of the Second Century Jewish law code concerned with damages and torts. The second resource is a concept that appears repeatedly in the Talmud—the concept of “*lifnim mishurat hadin,*” which will be described below.

*Mishnah Bava Kama 8:7*

By the Second Century, rabbinic literature included the realization that although “freely given consent legitimates action that would otherwise be unacceptable,”¹¹⁵ an affected party’s informed consent is not ethically sufficient to justify all actions. The limits of consent are perhaps best conveyed through mishnah Bava Kama 8:7, which states:

If someone says to another person: Blind me in the eye, cut off my hand, or break my foot, [and the other person inflicted the injury],

¹¹⁵ Manson and O’Neill, 1
he is liable. [Even if the injured party had stipulated] that he would not be liable,\textsuperscript{116} he is [nevertheless] liable. [If someone says to another person]: Rip my clothing, or break my pitcher, [and the other person caused the damage], he is liable. [But if he had stipulated] that he would not be liable, he is not liable.\textsuperscript{117,118}

The liability mentioned in this mishnah refers specifically to compensatory payments for injuring someone; mishnah Bava Kama 8:1 begins, “one who injures his fellow is liable concerning him for five categories [of payment]: damages, pain, healthcare, unemployment, and shame.”\textsuperscript{119} It is possible to read mishnah Bava Kama 8:7 as a text strictly concerned with payments—to interpret the text as merely stating (in the context of research ethics), that subjects may be exposed to bodily harm with their consent, but they must be compensated for those harms. Even this narrower interpretation adds important nuance to discussions about informed consent to research, drawing our attention to concerns about exploitation: what is the minimum owed to subjects for their assumption of the risk of bodily harm?

Yet I propose that there is an additional way in which we may interpret mishnah Bava Kama 8:7. It is possible to read this text as indicating that there are limits to the harms that may be imposed upon a person, even if that person consents to those harms. After all, the payments

\textsuperscript{116} i.e., even if the injured party consented to being injured

\textsuperscript{117} m. Bava Kama 8:7 (trans. Benjamin Gesundheit, “Ethics of Medical Research and Experimentation in Jewish Sources,” 200-01).

\textsuperscript{118} A parallel version of this text, which appears in the Tosefta, states, “He who says, ‘Blind my eye, which is doing me harm,’ ‘chop off my hand, which is doing me harm’—he is exempt. Tosefta Bava Kama 9:32, The Tosefta: Translated from the Hebrew: Fourth Division: Neziqin (The Order of Damages), trans. Jacob Neusner (New York: KTAV Publishing, 1981): 58. The Tosefta’s version of the tradition indicates that if someone is being harmed by the presence of their body part (for example, a gangrenous limb whose infection is threatening to spread to other parts of the body), then the person who removes the troublesome body part is exempt from the liability to pay damages. This passage resonates with providing medical treatment to an individual; the Tosefta text also sheds light on when an individual might reasonably ask to have an eye or hand removed without expecting to receive compensation for the bodily damage.

described in mishnah Bava Kama 8:1 are intended as deterrents to injuring others. Mishnah Bava Kama 8:7 thus gestures toward the limits of informed consent. Though the Talmudic discussion of this mishnah includes questions about whether consent was actually given, or whether the permission was actually an ironic statement, an interpretation attributed to Raba states that “no man could truly pardon the injury done to his principal limbs.”[120] Interestingly, the Talmudic discussion also refers to another tradition, “[i]f the plaintiff had said, ‘Smite me and wound me on the understanding that you will be exempt,’ the defendant would be exempt.”[121] Thus, the mishnah establishes a scale of injury or harm.

In the context of research ethics, I contend that the ethical challenge presented by mishnah Bava Kama 8:7 is to consider what types of studies should not be performed—even if potential subjects consent, individually, to assume the risks of participation. In other words, which kinds of risks are equivalent to blinding someone in the eye, cutting off their hand, or breaking their foot? And which kinds of risks are closer to “smiting” or “wounding?” At the very least, the text suggests individuals cannot consent to serious, permanent bodily injuries—opening up research ethics discourse by helping to draw attention from the consent question to the question of risk assessment.

*Lifnim Mishurat Hadin*

The second resource for research ethics contained within rabbinic literature is the Talmudic concept of *lifnim mishurat hadin* (literally “beyond the line of the law”), a concept that is especially useful for elaborating upon the distinction between law and ethics—and for

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120 BT Bava Kama 93a.
121 Ibid.
ensuring that research ethics discourse does not end with mere regulatory compliance. Tzvi Novick, a scholar of Jewish law and ethics, explained that in its Talmudic context, the phrase lifnim mishurat hadin conveys “the decision to renounce or waive a property or right to which one is legally entitled.”122 Jewish ethicist Louis Newman described lifnim mishurat hadin as “[God’s expectation] that people act more mercifully than the letter of the law requires.”123 Newman explained:

The term lifnim mishurat hadin designates a willingness to waive voluntarily some benefit or right to which one is entitled by law. In each case, it is implied that the party who waives the right in question does so out of a concern for the other party, who would be harmed or disadvantaged if the right were exercised.124

Medieval halakhic authorities disagreed over whether courts could enforce the obligation to act lifnim mishurat hadin,125 but in the earlier, Talmudic use of the concept, behaviors characterized as lifnim mishurat hadin are not legally prescribed, per se, but they are still expected; someone may be morally repudiated for failing to act lifnim mishurat hadin even if they cannot be punished in a court of law for this failure.126 This is where the ethical force of Jewish sources may be found. In a similar fashion, ethical behavior in the context of research with human

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124 Newman, Past Imperatives, 29.
125 Aaron Kirschenbaum, Equity in Jewish Law: Beyond Equity: Halakhic Aspirationism in Jewish Civil Law (Hoboken, NJ: KTAV Publishing House, 1991), 119. “Among the legal authorities of Sepharad (Spain)...the voluntarism of lifnim mishurat hadin...remained essentially intact. Among the halakhists of Ashkenaz (Northern France, Germany and, later, Eastern Europe), on the other hand, the enforceability of lifnim mishurat hadin emerged with increasing intensity.”
126 See Newman, Past Imperatives, 27 (“It may still be the case that one who fails to act lifnim mishurat hadin is liable to no punishment....Rather, the point is that these are all righteous acts that, punishable or not, are part and parcel of what God expects of Israel.”).
subjects may morally obligate researchers or pharmaceutical companies to take actions that are not legally required of them, or to waive certain advantages or privileges to which they are legally entitled. For example, Western researchers conducting experiments in poorer developing countries may help to improve the healthcare infrastructure of the location in which they conduct their research. Alternatively, pharmaceutical companies might waive some of their patent rights in order to make more affordable, generic drugs available more quickly.

Newman was careful to note: “…in no case does acting lifnim mishurat hadin entail violating a legal duty. That is, we speak only of cases in which one waives a legal right, never cases in which one violates a legal duty.” This characteristic of lifnim mishurat hadin makes the concept even more useful as a tool for analyzing ethics in such highly regulated practices as research with human subjects. Approaching ethics through the lens of lifnim mishurat hadin encourages attention to power differentials and the role of beneficence as a supplement to, rather than a substitute for, regulations or institutional policies.

A similar, albeit less frequently cited, concept comes from Nahmanides, a medieval Jewish philosopher and rabbi, who warned against being “nabal birshut hatorah”—a scoundrel with the permission of Torah. Considered in conjunction with lifnim mishurat hadin, these two concepts highlight both the character of the actor as well as the quality of the action.

CONCLUSION

In closing, the ethical discourse surrounding research with human subjects has been limited by over-dependence upon informed consent as an “ethical panacea” and conflation of

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127 Newman, Past Imperatives, 30.
128 See Manson and O’Neill, 154.
regulatory compliance with ethics. An important step toward overcoming these limitations is to incorporate religious perspectives, which until now have been largely absent from research ethics discourse. Religious perspectives provide a “prophetic voice” which calls upon us to think beyond respect for individual autonomy and the market-based ethic with which is it bound up; instead, we must hold our ears to the ground and listen for quiet vibrations of other values, buried deep in the historical development of research ethics, so that we can return them to the surface and generate a more robust ethics of research with human subjects. Jewish sources and Jewish bioethics will be especially useful in this endeavor. Jewish sources, such as mishnah Bava Kama 8:7 and the concept of lifnim mishurat hadin, can provide helpful counter-models for thinking about when informed consent or mere regulatory compliance, though still required, is ethically insufficient. Jewish bioethics’ own struggles to overcome legalism by increasing attention to the narrative also serves as an example of how attending to the stories through which laws are generated can recover the ethical values that shape the types of social practices we wish to encourage in the practice of research with human subjects.
CHAPTER THREE: THE AKEDAH AND THE JEWISH CHRONIC DISEASE HOSPITAL STUDY

INTRODUCTION

In 1963, in a study partly funded by the U.S. Public Health Service, Dr. Chester Southam injected twenty-two elderly patients at Brooklyn’s Jewish Chronic Disease Hospital (“JCDH”) with live, cultured cancer cells to monitor the patients’ immune responses. In previous studies, Southam injected live, cultured cancer cells into cancer patients and healthy prisoners. He observed that the cancer patients’ immune systems took significantly longer than the healthy prisoners’ to reject the foreign cells. Since most of the cancer patients were also elderly, “debilitated,” and chronically ill, Southam needed to perform his experiment on elderly, “debilitated,” chronically ill patients without cancer in order to prove his hypothesis that the cancer patients’ delayed immune response was caused by their own cancer, not their age or additional chronic illness.

Southam expected, correctly, that the JCDH patients’ immune systems would reject and destroy the foreign cancer cells. He was confident enough in his theory—perhaps reasonably so—that he did not consider the experiment to involve any real risk for the subjects. Thus, no one told the JCDH patients that the injections were part of an experiment, and no one told

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130 Ibid.

131 Ibid. In both cases, rejection took time: it took the prisoners 4-6 weeks to reject the injected cells; it took the cancer patients 12 weeks.

132 See Ibid., 73-74.


134 Arras, 74. “According to Southam…each patient was told that the injections were being given to test their immune capacity—there was no mention of research—and that a small nodule would likely form at the site of the injections but would eventually disappear.”
them that the injections contained cancer cells. Moreover, no one offered the patients an opportunity to *decline* the injections. In fact, Southam’s fear of patients’ refusal to cooperate may have contributed to his decision not to inform the patients about the nature and purpose of the injections.

The bioethics and research ethics literatures agree that Southam acted improperly and unethically by failing to disclose the nature and substance of the injections. Since the patients did not know what the injections contained, and since they did not know that the injections were not part of their treatment regiments, any "consent" they gave to receiving the injections was invalid: it was not *informed*. According to the dominant interpretation of the case, Southam’s failure to obtain subjects’ informed consent was ethically problematic because informed consent is the mechanism by which one shows respect for an individual’s autonomy. This is a valid and important analysis of the case. But its take-away lesson, unfortunately, appears more procedural than ethical: future researchers and doctors learn the importance of getting a signed consent form, but they do not necessarily learn how to cultivate an attitude of respect for their subjects or patients. Moreover, the reigning interpretation of the case begs the question of why ethics demands respect for someone's autonomy. In short, most discussions of JCDH overlook or sidestep the role of dignity—defined as both “a metaphysical justification for human rights and

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135 Arras, 77. Interestingly, the prisoners in the earlier study *did* know that the injections contained cultured cancer cells, and had to give their consent to participate. It is possible that Southam obtained their informed consent because he genuinely did not know, at this earlier stage of research, whether the prisoners were at risk of acquiring cancer, whereas he was confident no such risk existed for the JCDH patients in the study’s later stages. “Volunteers for Cancer,” *Time*, June 4, 1956, 50; “Cancer Volunteers,” *Time*, Feb. 25, 1957, 48. However, the U.S. government also has a history of requiring informed consent procedures in experiments with prisoners, long before informed consent was a universal requirement of research, and the government frequently reported concerns of public outcry as the reason to ensure consent was obtained from prisoners. It is unclear to me why there was not comparable fear of public outcry about the experiment on the JCDH patients.

136 Preminger, 6. (“Southam and his research fellows may have recognized that full disclosure presented the possibility of patient refusal, an option they may not have been willing to consider.”)

137 And, arguably, if the consent was not informed, it cannot accurately be described as voluntarily given, either.
duties” and “a socially and psychologically rooted perspective of ‘other’ [people]”—in articulating the case’s ethical significance.

Thinking about dignity in the context of JCDH can focus attention on two broader challenges in clinical research ethics. First, it highlights the ethical significance of dignitary harms—wrongs against a person that do not cause physical injury. Absent a meaningful framework for talking about dignitary harm, research ethics educators will continue to misrepresent the wrongdoing at JCDH primarily as a procedural error rather than an ethical one. Thus, research ethics perpetuates a self-reinforcing cycle: when students—future researchers—learn that the JCDH researchers’ failure was not obtaining informed consent, without reflecting on the troublesome attitude those researchers had toward their subjects (an attitude which failed to recognize the dignity or personhood of the subjects), they rarely cultivate an appropriate attitude of respect for their subjects, leaving a lacuna in research ethics discourse where concern for dignitary harms ought to be. This raises the second challenge in research ethics that can be addressed by reflecting on dignity in the context of JCDH: how do researchers learn to recognize their subjects’ dignity? Or, in the language of virtue ethics, what kind of character should researchers aim to cultivate? One way to engage with these questions is through narrative.

In the familiar story of the Akedah, or the Binding of Isaac, which appears in Genesis 22, God tells Abraham to take his son, Isaac, to Moriah in order to sacrifice him as a burnt offering.

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to God. These instructions are described as a test, trial, or proving—words that evoke the image of an experiment or testing a hypothesis. When Abraham and Isaac ascend the mountain, Abraham builds an altar, lays wood upon it, and binds Isaac atop the wood. In a moment of dramatic climax, with Abraham's hand stretched back to kill Isaac with a knife, an angel of God interrupts Abraham, saying, “Do not raise your hand against the boy, or do anything to him”

When Abraham looks up, he sees a ram caught in a nearby thicket and sacrifices the ram to God instead. God rewards Abraham’s obedience and willingness to sacrifice Isaac, “his only son, whom he loves,” by reiterating the covenantal promise that Abraham’s descendants will be as numerous “as the stars in heaven.” The Akedah has troubled generations of readers, producing extensive commentaries and interpretations as readers struggle to make sense of the narrative’s implications.

Familiar religious narratives can help us see long-settled bioethics cases in new ways and offer tools for wrestling with complicated ethical concepts that have been overlooked or de-emphasized in research ethics discourse. In this chapter, I re-read the Jewish Chronic Disease Hospital case in conversation with the biblical narrative of the Akedah. Doing so will enable us to analyze the Jewish Chronic Disease Hospital case with renewed ethical vigor, in order to focus on dignitary harm and researcher character.

\[140\] Gen. 22:2.
\[141\] Ibid., 22:1.
\[142\] Ibid., 22:9.
\[143\] Gen. 22:12.
\[144\] Ibid.
\[145\] Ibid. 22:15-18. God already promised to give Abraham descendants as numerous as the sky in Gen. 15:5, instructing him, “‘Look toward heaven and count the stars, if you are able to count them.’ And He added: ‘So shall your offspring be.’” From the standpoint of narrative structure, it is unclear why God would offer this same promise again after the Akedah—nevertheless, Gen. 22 casts the Akedah as the reason Abraham gets to become the father of a nation.
PART ONE: THE JEWISH CHRONIC DISEASE HOSPITAL CASE, THE AKEDAH, AND THE SIGNIFICANCE OF DIGNITARY HARM

One type of harm that research subjects may suffer is “dignitary harm.” Dignitary harm is a legal term used to describe the kind of offense that occurs when a person is wronged but suffers no physical injury.146 Dignitary harm is distinct from the legal concept of “emotional distress,” which must be demonstrated through physical manifestations such as clinical depression, post-traumatic stress disorder, or the inability to sleep or eat and must be professionally diagnosed through documented counseling services.147 The concept of dignitary harm is grounded in the law of intentional torts, specifically, battery, a tort that refers to intended, unprivileged, and unconsented contact that is harmful or offensive to the person who is touched.148 Thus, even if the contact did not cause physical harm or legally-defined emotional distress, the contact may still constitute battery and the batterer may still be held liable for his or her actions. In the context of JCDH, “dignity” relates to the legal concept of “dignitary harm.” The wrongdoing in JCDH falls under the umbrella of “offensive” touching: none of the patients developed cancer or suffered physical complications from their involvement in the study, but Southam’s behavior is offensive because he failed to treat his patients/subjects as human beings with their own interests in how they are treated.149

146 See Restatement of the Law, Second, Torts, §18, especially comment 1(c); also see Forell and Sortun, 557-609; Meisel, 211.
148 Ibid., §18.
149 Unfortunately, plaintiffs rarely collect damages for purely dignitary harms. See Meisel, 211.
Twentieth century literary critic Erich Auerbach described the Akedah narrative as “fraught with background:”\(^{150}\) although the Biblical text is sparse, audiences cannot help approaching it aware of deeper background considerations at play in the narrative.\(^{151}\) We are constantly, painfully aware of what is not written on the page. Moreover, Abraham acts with awareness of this “background,” too—heightening the story’s sense of drama and suspense. In other words, Abraham approaches Moriah not merely to sacrifice Isaac as requested, but with the full weight of the knowledge that God is asking him to sacrifice the child on whom the fulfillment of God’s covenantal promise hinges.\(^{152}\) Abraham’s awareness of God’s paradoxical request, and his willingness to obey anyway, lends further layers of complexity that pervade the Akedah narrative even though they are not explicitly stated in the words of the story. As feminist biblical scholar Tikvah Frymer-Kensky explains, these particular textual gaps in the Akedah “force the reader to enter the scene and try to make sense of it.”\(^{153}\)

When we read the Akedah, we are incapable of ignoring the emotional and dramatic background by which it is colored. We cannot help but feel very uncomfortable. The story raises a number of questions that audiences must struggle to answer: Why is Abraham admirable for nearly killing his son, and what does it mean for the inheritors of Abraham’s legacy that his behavior is supposed to be praiseworthy? What kind of God is willing to ask for this kind of horrific sacrifice? Where did Sarah think Abraham had taken Isaac? What went through Isaac’s


\(^{151}\) Ibid.

\(^{152}\) Auerbach, 13.

mind when he realized his father might kill him, and how did this realization affect his relationship with Abraham?

There are three main approaches available for “making sense of” the Akedah and addressing the discomfort that the story provokes in us. One option is to simply stop reading or telling the story—effectively excising it from Jewish tradition. Interestingly, this is not the approach generally taken by Jewish communities or congregations. The Akedah is read every year in synagogues all over the world as part of the Rosh Hashanah service—a day in the liturgical year when even those American synagogues that are normally empty overflow, filled with Jews who rarely attend weekly Shabbat services but equally rarely miss services on the High Holy Days. This means that otherwise non-observant Jews attending Rosh Hashanah services hear the retelling and reinterpretation of the Akedah, year after year, making the story a liturgical touchstone for Jews across a wide spectrum of religious observance or affiliation. In most congregations, the Akedah is part of the Torah service for the second day of Rosh Hashanah; the Reform movement, which historically celebrated only the first day of Rosh Hashanah, modified its liturgy to include the Akedah, indicating the story’s importance. Thus, across denominations, Jewish tradition places the troubling narrative of the Akedah at the center of an important liturgical service rather than ignoring it.

A second approach to the Akedah is to ignore the discomfort it provokes by trying to “interpret away” the most disturbing parts of the story. For example, some midrashic

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155 Some Reform synagogues now hold Rosh Hashanah services for two days, but even these synagogues read the Akedah during the first day’s service. See “Rosh Hashanah: Customs,” ReformJudaism.org, http://www.reformjudaism.org/rosh-hashanah-customs (last accessed June 15, 2015); also see Chaim Stern, Gates of Repentance: The New Union Prayerbook for the Days of Awe, American ed. (New York: Central Conference of American Rabbis, 2008), 124-27.
interpretations of the Akedah suggest that Isaac actually wanted to be sacrificed. In one such
midrash, Isaac hides on top of the mountain, not to escape his fate, but to make sure “that Satan
would not throw a rock at him, cause a blemish, and disqualify Isaac as a suitable burnt
offering.” In another, Isaac asks Abraham to bind him exceptionally tightly so that if Isaac
trembled with fear as the knife came toward him, he would not cause a blemish and render
himself unfit for sacrifice. A third midrash on this theme describes Isaac stretching out his
neck for Abraham’s knife, presumably for the same reason.

According to Frymer Kensky, “[p]art of the impact of this story lies in the fact that it
makes us aware of our own values as we read it. We cannot remain neutral.” Instead, we must
adopt a third approach and embrace the discomfort we feel about the Akedah, channeling it into
our development as “resistant readers” who “equat[e] the text with an opportunity to engage in
meaning making.” This mode of reading entails probing the values a text appears to endorse
and resisting those values when they are incompatible with our own moral convictions.
Articulating why a text’s apparent agenda is ethically problematic turns the text into a lens for
clarifying the values we hold as individuals or societies.

When we expose the Akedah’s disturbing message, the story becomes especially useful
for probing the values at stake in the JCDH and articulating why the tendency to impose

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156 Gen. Rabbah 56:5; also see Lev. 1:3, 1:10 (Burnt offerings from herds of cow or flocks of sheep or goats must be
“a male without blemish.”).
157 Gen. Rabbah 56:8; also see Jane Kanarek, “He Took the Knife: Biblical Narrative and the Formation of Rabbinic
158 Deut. Rabbah 11:3. The outstretched neck also suggests Isaac’s calm willingness to be sacrificed.
159 Frymer-Kensky, 135 (discussing the meaning of ידיעתי in Gen 22:12, and whether God is saying Abraham
passed the test by proving his faith in God—“Now I know that you are a God-fearer because you have not held back
your son from me”, or that Abraham failed the test “Indeed I know that you are a God-fearer—but (now) you have
not held back your son from me.” (see 134) “The story can support either position.”)
160 Mark Faust, “Ways of Reading and ‘the Use of Force,’” The English Journal 81, no. 7 (1992): 45
legalistic, contractual theories of informed consent upon it are misguided. In the cases of both the Akedah and the JCDH, audiences run the risk of forgetting the horror both stories should produce in us when we become familiar with their endings: the second time someone hears the Akedah, they already know Isaac will survive—we must work, as readers, to maintain our sense of horror, and the ways we do that are also helpful for maintaining our sense of horror about JCDH.

I read Isaac as the subject in an "experiment" designed by God, and Isaac has much in common with the JCDH subjects. Both Isaac's relationship with Abraham and the JCDH subjects' relationships with the researcher-physicians were based on trust, and that trust was exploited and betrayed by both Abraham and the JCDH researchers. Additionally, neither Isaac nor the JCDH subjects were physically harmed in their respective experiments: Isaac came down from the Mountain; the subjects' immune systems fought off the injected cancer cells. Yet Isaac is surely harmed when Abraham binds him to the altar, just as surely as the JCDH subjects were harmed by researchers. In both cases, they suffered dignitary harm: they were taken advantage of and treated as though they had less than equal worth as human beings—or less than human worth altogether. In fact, Rebecca Goldstein suggested that by replacing Isaac with the ram, Abraham effectively equates Isaac with a non-human animal. Contrary to readings that suggest the Akedah heralded the end of human sacrifice, it is more likely that the trial in the

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161 Some midrashim suggest that Abraham did, in fact, kill Isaac. See, e.g., BT Berakoth 62b. At least two bible scholars have argued that in the oldest version of the Akedah, Isaac was sacrificed. See Richard Elliot Friedman, The Bible With Sources Revealed (New York: HarperOne, 2003), 65, and Tzemah Yoreh, Why Abraham Killed Isaac (CreateSpace Independent Publishing, 2013). Both scholars base their interpretations in part on the fact that Gen. 22:5, both Abraham and Isaac ascend the mountain, but in Gen. 22:19, only Abraham descends the mountain. Nevertheless, in the version of the text that achieved canonical status for Jews and Christians, Isaac survives.

Akedah elicited such horror from its audience because animal, not human, sacrifice was already an accepted cultural norm.\textsuperscript{163} Thus, thinking about JCDH through the Akedah, we conclude that dignitary harm involves dehumanizing treatment, often made possible by abuse of power differentials and/or betrayal of trust.

The rabbis also appear distressed by the way the Akedah strips Isaac of all agency. In multiple midrashic interpretations, the rabbis reimagine Isaac consenting—explicitly or implicitly—to his death. A recurring theme in these midrashim is Isaac’s concern that he remain unblemished and, consequently, ritually acceptable for sacrifice. As discussed above, multiple midrashim suggest not only that Isaac knew he would be sacrificed, but that he agreed to be sacrificed.\textsuperscript{164} One even goes on to expressly ask, rhetorically, “Can one bind a man [of Isaac’s age]\textsuperscript{165} . . . without his consent?”\textsuperscript{166} Imagining Isaac stretching out his neck for the knife\textsuperscript{167} goes a step further, making Isaac a participant in his own sacrifice. These two concerns—lack of knowledge and the absence of consent—color discussions of JCDH, too. But the rabbis read consent into the story to assuage their sense of moral horror and attempt to preserve the dignity and humanity of not just Isaac, but Abraham, too. Considering JCDH through the lens of the Akedah helps imbue our understanding of JCDH with the same sense of horror we must maintain each time we hear the Akedah. Just as the early rabbis and later readers worried about the effect of the Akedah on both Isaac and Abraham, we can use JCDH as a point of entry into considerations about what it means to treat research subjects with dignity \textit{as well as} the ethical

\textsuperscript{163} See Kanarek, 68 (arguing against reading the Akedah as an etiological narrative).
\textsuperscript{164} Gen. Rabbah 56:5; Gen. Rabbah 56:8; Deut. Rabbah 11:3.
\textsuperscript{165} According to Gen. Rabbah 56:8, Isaac was 37 years old at the Akedah, but this midrash notes another tradition according to which Isaac was 26 years old.
\textsuperscript{166} Gen. Rabbah 56:8.
\textsuperscript{167} Deut. Rabbah 11:3.
character, or virtue, of the researcher. Each of these concerns—the subjects’ dignity and researchers’ character—will be discussed in turn below.

Dignity’s Troubled History in Bioethics

Framing JCDH as an analogue to the Akedah helps focus discussion of JCDH on the importance of respecting research subjects’ dignity, and offers a means of (re)introducing dignity (and, as we will see below, “respect”) into the research ethics lexicon. But what is this “dignity” that researchers and clinicians must respect? It is not always clear what an author refers to when the term “dignity” is used, and this can confuse ethical conversations about dignity. Philosopher Richard Ashcroft observed that “[i]t is not immediately obvious whether dignity is something that admits of degrees, whether it is alienable from its possessor, whether an assault on dignity or a bearer of dignity is something that destroys dignity or whether it is a sort of insult to dignity.” The answers to Ashcroft’s questions may depend upon which definition of dignity an author employs, and according to one recent scholarly inventory, “[d]ignity is variously viewed as an antecedent, a consequence, a value, a principle, and an experience, from philosophical, legal, pragmatic, psychological, behavioral and cultural perspectives.” Mattson and Clark organized these varied definitions into four conceptions of dignity, suggesting that authors use the term dignity to describe: “(1) a metaphysical justification for human rights and duties, (2) virtuous comportment or behavior, (3) a socially and psychologically rooted perspective of ‘other’ [people] and (4) a subjective and felt experience.” Thus, disagreements over dignity

169Mattson and Clark, 303.
170Mattson and Clark, 305.
can be traced to the use of competing or conflicting definitions and the failure to articulate which definition is used.

Within mainstream bioethics, appeals to dignity have historically been viewed with suspicion by some scholars. Appeals to dignity in bioethics are most often associated with Leon Kass and his distinctive brand of ethical and political conservatism. Over decades of scholarship, Kass has wrung his hands over dignity’s “inevitable decline” due to human cloning, embryonic stem cell research, anti-depressants, and ice cream cone consumption. In 2001, Kass was appointed chair of George W. Bush’s President’s Council on Bioethics, giving his heretofore marginal ideas prominence and influence over public policy. From this platform, Kass emphasized the central importance of the dignity of the human embryo, or the dignity of humanity’s embodied uniqueness, in order to recommend that the United States ban embryonic stem cell research—a profoundly controversial recommendation.

Kass primarily uses dignity in the sense of virtuous comportment or behavior—Mattson and Clark’s second definition of dignity. For Kass, new technologies undermine dignity because

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175 The President’s Council on Bioethics, *Human Cloning and Human Dignity* (New York: Public Affairs, 2002), xxvii. Seven Council members recommended allowing embryonic stem cell research to proceed “under strict federal regulation;” ten Council members recommended a four-year ban on all embryonic stem cell research, regardless of whether the research was federally funded. Those ten Council members also recommended federal review of all research and use of human embryos.
they are obstacles to learning how to suffer gracefully through illness or aging. This understanding of dignity is not relevant to our discussion of JCDH.

In the Council’s first report, *Human Cloning and Human Dignity*, Kass’s appeals to dignity as virtuous comportment merged with other Council members’ concern for the rights of extra-corporeal embryos, which they considered to be nascent human beings. Thus, the bioethical debate over dignity during the Bush administration is best understood as a debate over whether human embryos deserved all of the protections and rights guaranteed to human *persons*. Yet this is not the question raised by appeals to dignity in the context of JCDH.

Another source of suspicion about appeals to dignity in bioethics stems from the belief that dignity is “superfluous.” This argument has been advanced in articles by Ruth Macklin and Steven Pinker. In her brief but oft-cited article “Dignity is a Useless Concept,” Macklin argued that appeals to dignity merely duplicate more robust principles like “respect for autonomy” or “respect for persons.” In his equally pithy “The Stupidity of Dignity,” Pinker remarked that “…one hardly needs the notion of ‘dignity’ to say why it’s wrong to gas six million Jews or to send Russian dissidents to the gulag.” However, one hardly needs the notion of respect for autonomy to say why those actions were wrong, either. Moreover, to say that U.S. slavery practices were wrong because they failed to respect African Americans’

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178 Paul Ramsey argued that requiring informed consent is a way of recognizing a subject’s humanity, and the subject’s equal humanity with the researcher. See Paul Ramsey, *Patient as Person*, 2nd ed. (New Haven: Yale University Press, 2002), 5. Though he does not use the language of dignity specifically, Ramsey’s understanding of consent’s purpose is comparable to the notion of dignity at play in discussions of “dignitary harm” and JCDH.
180 Macklin, 1419.
181 Pinker, 30.
autonomy practically makes a mockery of the horrible treatment slaves endured. Finally, since discussions about respect for autonomy in bioethics emphasize autonomy over respect, analyzing JCDH or other dignitary harms under the principle of respect for autonomy quickly unravels into debates about the content and procedures of the informed consent process—missing the ethical justifications for consent regulations.

Respect for persons, on the other hand, could convey the same meaning as dignity, especially as dignity relates to JCDH and the Akedah. JCDH involved adult human patients whom all parties can agree are, in fact, human persons. The problem is that these persons were not treated as such. Unfortunately, bioethics discourse generally conflates respect for persons with respect for autonomy, using the two interchangeably.\textsuperscript{182} Therese Lysaught noted that while “respect for persons” once applied to all individuals and involved “simultaneously promoting autonomy and protecting the vulnerable,”\textsuperscript{183} these two goals were decoupled early on in modern bioethics. Beauchamp and Childress’s \textit{Principles of Biomedical Ethics} introduced four principles that would guide bioethical analysis: respect for autonomy, non-maleficence, beneficence, and justice.\textsuperscript{184} Lysaught observed that, over time, beneficence became the primary justification for protecting the vulnerable,\textsuperscript{185} while the significance of respecting persons rather than their autonomy fell out of bioethics discourse about autonomous individuals.\textsuperscript{186} Thus, although “respect for persons” does convey the same ideas as “dignity” in the context of JCDH, I would argue that we need to speak about the case using the language of dignity—partly because respect

\textsuperscript{183} Lysaught, 678.
\textsuperscript{184} Tom L. Beauchamp and James F. Childress, \textit{Principles of Biomedical Ethics}, 1st ed. (New York: Oxford University Press, 1979)
\textsuperscript{185} Lysaught, 665.
\textsuperscript{186} Ibid., 678.
for persons has been subsumed under respect for autonomy, and partly because the linguistic tie to “dignitary harm” serves as a reminder that we are talking about a kind of wrong that persists even when there are no harmful physical consequences of which to speak.

**Dignity in the Context of the Jewish Chronic Disease Hospital Case**

Under Mattson and Clark’s framework, the first and third definitions of dignity are most relevant for analyzing the JCDH and the Akedah and clarifying the significance of the dignitary harms these narratives describe. The first definition, dignity as a metaphysical quality, is directly related to “pure” dignitary harms that occur even in the absence of physical or emotional effects. The presumption of this metaphysical quality—and the way it was ignored by Southam and by Abraham—defines harm even when there are no physical or emotional consequences. The third conception of dignity, which defines dignity as a quality bestowed upon us by others, is related to the first: it describes the ability to recognize the presence of the metaphysical quality of dignity in others.¹⁸⁷

Recall that the Akedah is read in synagogues on Rosh Hashanah, the Jewish New Year and beginning of the “Days of Awe,” or *Yomim Nora’im*. During the ten-day period between Rosh Hashanah and Yom Kippur (the Day of Atonement), Jews are supposed to reflect on sins they have committed since the previous Yom Kippur. Two explanations are traditionally given including the Akedah in the Rosh Hashanah liturgy. First, the ram that Abraham sacrifices in Isaac’s place evokes the shofar—the ram’s horn that is ritually blown during the High Holy

¹⁸⁷ This third definition in particular allows us to look beyond what researchers must do (i.e., obtain competent subjects’ voluntary and informed consent) and begin reflecting on the kind of character researchers must cultivate in themselves in order to respect the dignity of their human subjects.
Days.\textsuperscript{188} A second and related interpretation is that Jews ask God to spare them on Yom Kippur just as God spared Isaac on Moriah.\textsuperscript{189} I see another connection between the High Holy Days liturgy and the Akedah that is especially relevant for analyzing JCDH: The Yom Kippur liturgy reiterates Mishnah Yoma 8:9, which states, “For transgressions against God, the Day of Atonement atones; but for transgressions of one human being against another, the Day of Atonement does not atone until they have made peace with one another.”\textsuperscript{190} The re-telling of the Akedah, set against Jewish theological emphasis on the importance of making amends when you have wronged someone, can prompt audiences to “midrashically” imagine how Abraham ought to have taken to make amends with Isaac after nearly sacrificing him. Considering what it is we expect Abraham to apologize for helps to articulate the nature of how Isaac was wronged and the nature of “dignitary harm.” Frymer-Kensky suggested that,

We read with the voice of Isaac: “Don’t I count as a person? How can my own father be prepared to kill me without even consulting me?” Viewed through [his] eyes, the actions of Abraham in these events look less like loyalty to God and more like disregard for the human beings dependent on his benevolence….\textsuperscript{191}

Being taken advantage of and treated as less than fully human—or at least less than equally human to Abraham/Southam\textsuperscript{192}—constitutes the heart of the dignitary harm Isaac and the JCDH subjects experienced. Talking about the ethics of JCDH, especially in the context of the classroom, should focus on Southam’s perceptual failure to treat his subjects as fully human—as equal to himself in their humanity. This failure is tied to Mattson and Clark’s third definition of

\textsuperscript{188} “Second Day Introduction,” 120.
\textsuperscript{189} Ibid.
\textsuperscript{190} m. Yoma 8:9; Stern, Gates of Repentance, 324.
\textsuperscript{191} Frymer-Kensky, 127-28.
\textsuperscript{192} In an interview with Science magazine, Southam explained that though there was “no theoretical likelihood” of contracting cancer from the injections, he still would not inject himself or his colleagues, because “there are relatively few skilled cancer researchers, and it seemed stupid to take even the little risk.” See Arras, 79.
dignity as a quality one bestows upon others, and it is best understood remedied through the lens of virtue ethics.193

PART TWO: JCDH, THE AKEDAH, AND RESEARCHERS’ CHARACTER

Analyzing JCDH through the lens of the Akedah can also focus attention on the significance of researchers’ character and the character traits society should expect its researchers to embody. Thinking with narratives easily lends itself to reflecting upon the moral character of the characters in the narrative. Thus, the Akedah offers a narrative means of connecting with the role of virtue in clinical research ethics.194 If a researcher is attuned to ethical concerns beyond regulatory compliance, then that researcher is more likely to behave ethically even if there is no specific regulation requiring him or her to do so. A virtue-based approach to research ethics will not replace the need for laws and regulations of research with human subjects, but it will help to envision and enact a more aspirational norm of researcher behavior. This way, even if there were no law requiring subjects’ voluntary and informed consent, researchers would still obtain that consent. Even if there were no law requiring researchers to minimize the risk of harm to subjects, they would still take precautions to minimize those harms. In this way, a virtue-based approach to research ethics would encourage acting lifnim mishurat hadin, more mercifully than the law requires,195 by encouraging researchers to avoid being what the medieval Jewish philosopher Nahmanides called a “naval bir’shut hatorah:” a scoundrel with the permission of Torah. Specifically, researchers must

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193 See Mattson and Clark, 308-09.
194 There is already extensive literature on the role of virtue in the practice of medical treatment, some of which will be discussed later in this chapter.
develop and demonstrate concern for their subjects, who take on risks for the benefit of the researchers own careers and society’s well-being. Rather than exploiting possible advantages granted to researchers under the law (or by law’s silence on a matter), researchers must act out of a sense of fairness that treats their subjects with dignity and respect for the human beings they are.

As discussed in Part One of this chapter, early interpretations of the Akedah, found in midrashim and the Babylonian Talmud, indicate that the rabbis, like contemporary readers, were deeply troubled by this biblical story. Like contemporary readers, the early rabbis were not only concerned about the way the biblical narrative stripped Isaac of all agency, but they also questioned Abraham’s behavior—specifically, his apparent willingness, according to the biblical text, to sacrifice Isaac without protest or hesitation. How could an honorable Patriarch of Judaism behave this way? In response, the rabbis took the second interpretive approach described in Part One, trying to interpret away their discomfort by suggesting that Abraham did in fact resist God’s test. In one midrash, the rabbis re-imagine Genesis 22:2, “Take now thy son, thine only son, whom though lovest, even Isaac, and get thee into the land of Moriah…” as one side of a conversation that took place between God and Abraham, in which Abraham was actually stalling for time:

God: Take, I pray thee, thy son.  
Abraham: Which son?  
God: Thine only son.  
Abraham: But each is the only one of his mother…  
God: Whom thou lovest.  
Abraham: Is there a limit to the affections?  
God: *Even Isaac.*  

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196 Gen. Rabbah 55:7
According to this midrash, Abraham continues to stall or protest by suggesting he cannot possibly sacrifice Isaac because only priests can offer sacrifices, and Abraham is not a priest. One recent interpreter argues for this particular reading based on the absence of explicit speech that Abraham agrees to sacrifice his son. According to this view, the text lists Abraham’s subsequent “plodding” steps because at each step, Abraham paused to give God the opportunity to cancel Isaac’s sacrifice—which God finally does once Abraham reaches the knife back and, according to this interpretation, pauses one more time. These interpretations are supposed to present a more sympathetic Abraham—one who is obedient to God’s horrific command, but only reluctantly so. Other interpretations suggest that Abraham knew Isaac would survive the events on Moriah. For example, there is a midrashic gloss on Genesis 22:5, “Then Abraham said to his servants, ‘You stay here with the ass. The boy and I will go up there [to Moriah]; we will worship and we will return to you.’” According to this midrash, Abraham’s use of “we” in “we will return to you” indicates that Abraham knew all along that God would not force him to follow through with the sacrifice. This midrash, in particular, evokes Southam’s

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197 Ibid. There is a certain playfulness to Abraham’s imagined excuse here, because the laws of priesthood are not established until Sinai. Interestingly, the rabbis ignore this anachronism; instead, the midrash has God state that he has already appointed Abraham a priest.


199 Ibid. “First he gets up, then he dresses his animals, then he gets his retinue in order, then he gets the rope, and the wood, and then he sets off, and then he sees Mount Moriah, and then he gets of the animal, and then he instructs his retinue to wait, and then he and Isaac walk (vayelkhu), but don’t run, toward Moriah, and then there is a conversation, and then the various distinct preparations of the altar, and then he stretches out his arm, and then, finally, he takes the knife.”

200 Bodoff, 78.

201 Gen. 22:5.

202 Gen. Rabbah 56:2; But, as Tikva Frymer-Kensky noted when she dismissed this interpretation, “if Abraham was really confident that God would stop him and that Isaac would be safe, then there is no real horror, and the whole affair is a colossal game of ‘chicken’ in which God blinked first.” The Akedah narrative “is crafted to elicit horror,” and turning the trial of God’s command into some sort of cosmic staring contest “makes a mockery of our own horrified reactions.” See Frymer-Kensky, 130.
justifications for the JCDH experiment: that the subjects’ consent was unnecessary because Southam knew they would not be harmed by the injections.

**What is Virtue Ethics?**

Virtue ethics refers to ethical approaches that focus on the actor rather than the action. Virtue ethics is an important lens for thinking about research ethics because it introduces the researcher’s character—and the development of that character—into discussions about research with human subjects. Thinking about the researcher’s character offers a means of expanding research ethics discourse beyond procedural concerns or questions about regulatory compliance. This perspective also allows us to engage the social meaning of research with human subjects—i.e., to think creatively and critically about the goals of research and what kind of person is best suited to carrying out or meeting these goals.

The roots of virtue ethics can be traced to Greek philosophy, especially Aristotle. Aristotle’s thought, in particular, lays the foundation for contemporary virtue ethics, because for Aristotle, virtue can be learned through practice and exposure to appropriate role models. In the 20th century, Ascombe and MacIntyre revitalized virtue ethics, and MacIntyre’s approach is especially relevant for considering the roll of virtue ethics in research ethics and bioethics. One of MacIntyre’s most helpful contributions is acknowledging—and even championing—the idea that virtues are culturally shaped and specific. He argued that any virtue “always requires for its application the acceptance of some prior account of certain features of social and moral life in

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terms of which it has to be defined and explained.”205 More specifically, the background that makes a virtue comprehensible includes a “background account of a practice,”206 where “practice” refers to “any coherent and complex form of socially established cooperative human activity through which goods internal to that form of activity are realized in the course of trying to achieve those standards of excellence which are appropriate to, and partially definitive of, that form of activity, with the result that human powers to achieve excellence, and human conceptions of the ends and goods involved, are systematically extended.”207 Professions such as medicine constitute practices: a practice “involves standards of excellence and obedience to rules as well as the achievement of goods. To enter into a practice is to accept the authority of those standards and the inadequacy of [one’s] own performance as judged by them.”208 They are characterized by “internal goods,”209 and a “common moral purpose”210 beyond financial gain.

**Virtue Ethics and the Good Doctor**

Virtue ethics and questions about character were central to early bioethics discussions on the heels of the Nuremberg trial. The concept of physician character factored into early bioethics discussions in different ways, but a common thread was attempting to “resist” the need for external regulation of the medical profession by appealing to virtue instead.

One manifestation of resistance to external regulation and over-confidence in clinician virtue was the American medical establishment’s initial sense that the Nuremberg Code was

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205 MacIntyre, 186.
206 Ibid., 186–87.
207 Ibid., 187.
208 Ibid., 190.
209 Ibid., 188.
irrelevant to American physicians. In fact, forty-five years after the Nuremberg Code’s promulgation, law professor and bioethicist George J. Annas observed that,

Although courts in the United States may use the Nuremberg Code to set criminal and civil standards of conduct, none have used it in a criminal case and only a handful have even cited it in the civil context. Even where the Nuremberg Code has been cited as authoritative, it has usually been in dissent, and no U.S. court has ever awarded damages to an injured experimental subject, or punished an experimenter, on the basis of a violation of the Code.212

American medicine’s resistance to the Nuremberg Code’s relevance within the U.S. was based on an assumption that Nazi doctors, because they were Nazis, were qualitatively and inherently different from American doctors, who would never pursue such unethical behavior.213 Of course,

211 For example, none of the three staff physicians who expressed concern about the ethics of Southam’s experiment had ever heard of the Nuremberg Code. Arras, 74; also see Preminger, 8.


213 Yet, compare the following descriptions of two experiments. The first describes the Nazi freezing experiments:

The purpose of these experiments was to determine the most effective way of rewarming German aviators who were forced to parachute in the North Sea...the victims were forced to remain outdoors without clothing in freezing weather for 9 to 14 hours...[or]...remain in a tank of iced water for three hours at a time....Rewarming of the subjects was attempted by various means, most commonly and successfully in a very hot bath. [The following month,] Himmler personally ordered that rewarming by the warmth of human bodies also be attempted, and [the individuals in charge of] these experiments promptly produced four Gypsy women from the Ravensbrueck concentration camp. When the women had arrived, rewarming was attempted by placing the chilled victim between two naked women. (Taylor, 74.)

The second describes U.S. experiments in Guatemala about sexually transmitted diseases, conducted only a few years later and discussed at more length in Chapter 3:

On February 15, 1947, the researchers began intentional exposure experiments with gonorrhea....In total, 518 soldiers were exposed to gonorrhea, 202 of whom received some form of treatment. Methods of infection included sexual exposure [to infected commercial sex workers], superficial inoculation into the penis, deep inoculation into the penis, and superficial inoculation following sexual
this description of the Nazi doctors (and American doctors) is dangerous. Catholic bioethicist and physician Edmund Pellegrino noted that “The German physicians indicted at Nuremberg had been taught by some of the world’s best historians of medicine and ethics. They could not plead ignorance of ethics and, in fact, made constant allusions to medical ethics and the Hippocratic tradition in their testimony. They even convinced themselves that their heinous acts were consistent with those principles.”

Speaking of the wide-ranging involvement of medical professionals in different aspects of implementing the Nazi agenda, bioethicist Daniel Wikler and Dr. Jeremiah Barondess warned, “[t]o the degree that we fix our attention on the very worst offenders [like Mengele], however, we risk the error of explaining the crimes by focusing on what makes these individuals different from their fellow physicians rather than on what they had in common.”

In the 1960s, more than half of the subjects in Yale psychologist Stanley Milgram’s obedience experiment were willing to inflict increasingly painful, even dangerous shocks to a victim when instructed to do so by the experimenters. Milgram’s subjects included “postal clerks, high school teachers, salesmen, engineers, and laborers” as well as individuals with doctoral degrees. The study’s results challenged the idea that Nazis were more obedient or

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217 Ibid., 372.
inherently more violent than average Americans. Trying to draw a firm categorical distinction between Nazi doctors and American doctors is also disingenuous. Dr. Henry Beecher’s now famous article in the 1966 New England Journal of Medicine cited twenty-two unethical experiments performed in the U.S. since World War II—experiments performed at “leading medical schools, university hospitals, private hospitals, governmental military departments (the Army, the Navy and the Air Force), governmental institutes (the National Institutes of Health), Veterans Administration hospitals and industry.” Nevertheless, Beecher placed more stock in virtue than rules, asserting that “a far more dependable safeguard than consent is the presence of a truly responsible investigator” and reiterating that “there is the more reliable safeguard provided by the presence of an intelligent, informed, conscientious, compassionate, responsible investigator.”

A second way in which doctors implicitly invoked virtue ethics to resist regulation of their profession is the resistance to bioethicists’ presence in medical schools. Even if bioethics had a place in the curriculum for training future doctors, some physicians believed that bioethicists were not the appropriate instructors! Rather than bring in an “outsider,” proponents of this perspective argued that the best way for medical students to become “good”—i.e., ethical—doctors was to learn from the example of good doctors. Implicit in their argument is the assumption that unless someone has actually practiced medicine, they lack the authority and experience to make recommendations about the ethical practice of medicine. This is an interesting, problematic viewpoint, since it comes close to the assumption that only doctors

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219 Ibid., 368.
220 Ibid., 372.
define what makes a doctor “good,” when in fact other perspectives—most notably and specifically, patients’—are also relevant and important. But within this particular critique of bioethics was a kernel of truth: being—and becoming—a good doctor requires more than familiarity with and adherence to a particular set of rules. It requires developing certain qualities: the ability to listen to patients, to draw out patients’ true concerns from only a few minutes’ time together, to explain a diagnosis clearly and in plain language, empathy for the patient and the patient’s family. These qualities are best learned through example and emulation—they require a model of a good doctor on which medical students may base their own behavior and bedside manner.

**Virtue Ethics and the Good Researcher?**

As discussed above, Beecher championed the good or responsible investigator as the best guarantor of ethical experimentation. The immense professional trust placed in the “good investigator” is even evident in some responses to JCDH. For example, a 1964 *New York Times* article about the case noted that “[t]wo supporters of the manner in which the work was done, in fact, declared that if the same procedure had been followed by almost any scientist other than Dr. Southam, they would have thought it unethical, their regard for him was so high.” But inquiry into which qualities make an investigator trustworthy remained largely undeveloped. Whereas clinical bioethics discourse has, over time, maintained a dialectic between rule-based and virtue-based approaches to ethics, increased regulation of research with human subjects has pushed virtue ethics out of discussions about clinical research ethics.

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Like medicine, scientific research may be conceptualized as a “practice” or profession with its own set of internal goods. Research’s internal good is generally presented as sound scientific method; ethical conduct is generally treated as supplementary or externally imposed upon the research process. Incorporating research ethics discourse—through the lens of virtue ethics and appreciating ethics as more than a set of external regulations—creates the opportunity to see ethical conduct—specifically respect for subjects, internal goods to the research endeavor. Approaching scientific research as a practice or profession requires educating researchers about the history of research, especially research with human subjects.\textsuperscript{222} Moreover, research ethics training or education should contextualize current research ethics regulations and rules by teaching researchers about specific abuses or cases that motivated the regulations; research ethics education should also expose researchers to both good or virtuous and bad moments in the history of research, so that through their models, researchers can learn which characteristics they need to cultivate in themselves, and which they must work to protect themselves from developing.

The professionalization of research would create an ethos of professional responsibility and expectations of conduct according to which researchers could hold themselves and their colleagues. Without this kind of ethos, sanctioning an individual researcher for violating research ethics loses its impact. For example, in 1965, the New York State Board of Regents voted to censure and reprimand Southam for his conduct during the JCDH experiment; the Board also voted to suspend Southam’s license for one year but never actually suspended him, placing him on a one-year probation instead.\textsuperscript{223} In 1968, Southam’s peers elected him president of the

\textsuperscript{222} See MacIntyre, 194.
\textsuperscript{223} Arras, 78.
American Association for Cancer Research\textsuperscript{224}—effectively sending the message that his fellow researchers supported his JCDH experiment and disagreed with the Board of Regents’ sanctions against him.\textsuperscript{225} In contrast, two of the three residents who refused to assist with the study and resigned over Southam’s experiment were excluded from the American College of Physicians for their “‘[i]rresponsible’ resignations from…JCDH.”\textsuperscript{226} As John Arras poignantly noted, “These all-too-rare profiles in courage were…trivialized…[and] reduced to the status of merely exculpatory psychological pathology:”\textsuperscript{227} the residents’ “exclusion was eventually reversed on the ground that their ‘overreaction’ to Southam’s experiment was excusable in light of their families’ ‘Holocaust situations.’”\textsuperscript{228}

A virtue ethic for researchers that valued respect for research subjects might have produced dramatically different outcomes for Southam and his resistant residents. If the research community takes dignitary harms seriously, then researchers would not undermine sanctions against their misbehaving peers by voting them into positions of professional honor. Instead, researchers might refuse to collaborate or co-author with individuals in their profession who have proven their disregard of research subjects’ humanity, or vote to exclude these individuals from membership—or at the very least, leadership—in professional organizations.

\textsuperscript{224} Ibid.
\textsuperscript{225} Ibid. “Indeed, the fact that Southam could muster so many distinguished physicians and researchers in his defense, and that he was subsequently given high honors by his peers in the cancer research establishment, suggests that the verdict in his case had a certain ex post facto quality about it. Many years later his daughter reported that Southam viewed his election to the presidency of the American Association of Cancer Research as vindication for his having been unfairly singled out by the Board of Regents.”
\textsuperscript{226} Ibid.
\textsuperscript{227} Ibid.
\textsuperscript{228} Ibid.
CONCLUSION

The ethical lessons to be learned from JCDH are more complex than just the importance of getting a signed consent form, and we must resist the temptation to write off JCDH as a minor wrong just because none of the subjects suffered harmful physical consequences. One way to resist this temptation is by considering the case side by side with the Akedah narrative, in which Isaac, like the JCDH subjects, survives his ordeal without lasting physical harm but is also unquestionably wronged. As contemporary interpretations like Frymer Kensky’s suggest, part of our task as inheritors of the Akedah narrative is to work to maintain our sense of horror at the story, no matter how many times we hear it and no matter that we know how the story will end. The reasons for horror can be found by examining why the text was problematic for the early rabbis. Rabbinic efforts to alleviate their discomfort and re-establish Isaac’s humanity (or dignity) by presenting him as a willing participant in the Akedah highlights the ethical underpinnings of informed consent that are sometimes overlooked. Through the lens of the Akedah, we can more clearly problematize Southam’s actions at JCDH: by choosing not to seek subjects’ consent, Southam denied their humanity; he prioritized the expected social gains of his scientific inquiry above his individual subjects’ right to refuse to participate in the study. In this way, Southam failed to respect his patients’ dignity.

Informed consent procedures help mitigate these abusive actions, but regulations cannot, on their own, bring about the kind of cultural change in research that promotes respect for subjects as human beings. Inculcating researchers with attitudes of respect for their subjects’ dignity can be accomplished through new approaches to research ethics education and training. This new educational model would “professionalize” research as a practice with its own history. In a professionalized research practice, knowing norms or regulations would be necessary but not
sufficient. Researchers would also learn the case histories behind the regulations and see themselves as part of that history. Part of that history includes research abuses like JCDH which must be taught with a focus on respect for subjects and the ethical significance of dignitary harm. Drawing analogies between JCDH and the Akedah is one way to accomplish this goal.

The unexpected framework of a familiar religious narrative can create discursive space to reinvigorate old case studies and make it possible to open up research ethics discourse to consider broader themes about research ethics training/education and significance of dignitary harms. Taking a step back, this chapter demonstrates just one of the ways Jewish sources can contribute to research ethics discourse. In the next chapter, we will consider how another familiar narrative—the book of Job—can help us think through the ethics of compensating research subjects for physical injury, both in the presence and absence of informed consent.

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229 See MacIntyre, 194.
CHAPTER FOUR: JOB AND COMPENSATION FOR INJURED RESEARCH SUBJECTS

INTRODUCTION

In February 1948, a woman now known only as Berta was a patient in a Guatemalan psychiatric hospital:

Berta was injected in her left arm with syphilis. A month later, she developed scabies (an itchy skin infection caused by a mite). Several weeks later, Dr. Cutler [a physician-researcher with the United States Public Health Service] noted that she had also developed red bumps where he had injected her arm, lesions on her arms and legs, and her skin was beginning to waste away from her body. Berta was not treated for syphilis until three months after her injection.

Soon after, on August 23, Dr. Cutler wrote that Berta appeared as if she was going to die, but he did not specify why. That same day he put gonorrheal pus from another male subject into both of Berta’s eyes, as well as in her urethra and rectum. He also re-infected her with syphilis. Several days later, Berta’s eyes were filled with pus from the gonorrhea, and she was bleeding from her urethra.

On August 27, Berta died.230

Berta was just one of the subjects in a series of unethical medical experiments funded and performed by the U.S. government from 1946 to 1948 in Guatemala. “Some of the research involved deliberate infection of people with sexually transmitted diseases…without their consent. Subjects were exposed to syphilis, gonorrhea, and chancroid, and included prisoners, soldiers from several parts of the [Guatemalan] army, patients in a state-run psychiatric hospital, and commercial sex workers.”231 Records from the “intentional exposure experiments” include a

231 Ibid., 2.
total of 1,308 research subjects but only document approximately half of the subjects receiving some form of treatment.\textsuperscript{232}

The details of the Guatemala studies remained hidden, largely unpublished,\textsuperscript{233} for decades, only coming to light in 2009.\textsuperscript{234} When they did, President Obama personally called President Álvaro Colom of Guatemala to apologize to the Guatemalan people.\textsuperscript{235} U.S. Secretary of State Hilary Clinton and U.S. Secretary of the Department of Health and Human Services Kathleen Sebelius promptly issued a joint statement of apology to “the government of Guatemala and the survivors and descendants of those affected.”\textsuperscript{236} The Presidential Commission for the Study of Bioethical Issues, a government bioethics commission appointed by President Barack Obama, concluded, at the end of its fact-finding investigation, that the studies in Guatemala “involved unconscionable violations of ethics,” even when judged by research ethics standards of the 1940s.\textsuperscript{237} In 2011, some of the study survivors and their descendants filed a lawsuit against the United States in U.S. federal court, seeking compensation. The case was dismissed on legal

\textsuperscript{232} Ibid., 41. It’s impossible to know why only some research subjects received treatment for STDs. It is possible that only approximately half of the subjects exposed to STDs developed an infection—only those infected would require treatment. However, this scenario seems unlikely because Cutler and the other researchers worked diligently to increase rates of infection in the study population. For example, he abandoned inoculation by “normal exposure” (sexual intercourse with infected paid sex workers) because infection rates were unsatisfactorily low. Instead, “the foreskin was retracted and the glans placed on a stretch over the forefinger of the left hand of the physician. Using the long end of a 20 gauge, long-bevel hypodermic needle held in the right hand, the dorsal surface of the glans just distal to the coronal sulcus was lightly abraded over an area of about 2 x 5 mm. We tried to stop the abrasion short of drawing blood or serum, barely removing the surface layer, but not infrequently small bleeding points could be noted. The abraded area was covered with…[a] cotton pledget [soaked in \textit{Treponema palladium}]” (65).

\textsuperscript{233} Presidential Commission for the Study of Bioethical Issues, \textit{Ethically Impossible}, 86.

\textsuperscript{234} Susan Reverby, “Reflections on Apologies and the Studies in Tuskegee and Guatemala,” \textit{Ethics & Behavior} 22, no. 6 (2012): 494. Historian Susan Reverby initially found the records of the study in an archive in 2003 while conducting research for a book about the Tuskegee Syphilis Study. In 2009, she shared a paper she wrote about the Guatemala study records with a former director of the Center for Disease Control, who in turn shared it with current CDC leadership. The paper, and the details of the Guatemala studies, eventually made their way to the White House.


\textsuperscript{236} Ibid.

\textsuperscript{237} Ibid., 92.
technicalities. In a striking acknowledgment of the law’s failure to enact ethical norms even as it recognizes them, the court noted,

As the plaintiffs assert, and the defendants acknowledge, the Guatemala Study is a deeply troubling chapter in our Nation's history. Yet...this Court is powerless to provide any redress to the plaintiffs. Their pleas are more appropriately directed to the political branches of our government, who, if they choose, have the ability to grant some modicum of relief to those affected by the Guatemala Study.

Four years later, the U.S. government still has not offered any form of compensation to the study survivors. The Guatemala Study represents an extreme instance of a much wider problem in research ethics, especially research conducted by the United States: research subjects who are injured by their participation in an experiment often personally bear the costs of treating and rehabilitating their bodies.

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238 Garcia v. Sebelius, 867 F.Supp.2d 125 (D.D.C., 2012), 137. The Federal Tort Claims Act, which waives the U.S. government’s sovereign immunity in many cases, does not apply to actions that took place outside of the U.S. Since the experiments took place in Guatemala, the U.S. was able to invoke sovereign immunity and the court therefore had no jurisdiction to consider the survivors’ claims; thus, the survivors’ case was dismissed.

239 Garcia v. Sebelius, 144 (italics mine).

240 The CDC pledged $775,000 to help Guatemala’s government monitor and control the spread of H.I.V., but as Harvard Law Professors I. Glenn Cohen and Holly Fernandez Lynch noted in their 2012 op-ed, “Those efforts...are laudable, but not enough. By focusing exclusively on the future, they leave those Guatemalans who were directly affected by past American research uncompensated.” I. Glenn Cohen and Holly Fernandez Lynch, “Guatemalans Used in Experiments Deserve Compensation,” New York Times, July 4, 2012 (available at http://www.nytimes.com/2012/07/05/opinion/guatemalans-used-in-experiments-deserve-compensation.html?_r=0; last accessed June 13, 2015). In 2015, the survivors’ attorney filed a lawsuit seeking compensation from Johns Hopkins University, the Rockefeller Institute, and Bristol-Meyers Squibb; the lawsuit alleges that Johns Hopkins University is responsible for the study subjects’ injuries because doctors from Hopkins held prominent positions on boards that reviewed and approved funding for the Guatemala Study. Scott Dance, “Hopkins Faces $1B Lawsuit over Role in Government Study that Gave Subjects STDs,” Baltimore Sun, April 1, 2015 (available at http://www.baltimoresun.com/health/bs-hs-hopkins-guatemala-lawsuit-20150401-story.html?page=1; last accessed June 13, 2015).

241 Pike, 24.

242 Leslie Meltzer Henry, “Moral Gridlock: Conceptual Barriers to No-Fault Compensation for Injured Research Subjects,” Journal of Law, Medicine & Ethics 41, no. 2 (2013): 411; Pike, 25. Pike also noted that the experimental nature of a study also means that research subjects’ health insurance companies may not cover the cost of treating research-related injuries.
Scientific research is designed to be a controlled process in which a hypothesis is tested in order to develop generalizable knowledge.\textsuperscript{243} When medical research trials involve human subjects, the stakes are high: the human cost of research can be injury, illness, disability, or even death. In the shadow of horrific harms caused not only by the Nazis’ torturous experiments, but also domestic research scandals, including and especially the Tuskegee syphilis study,\textsuperscript{244} the last half of the 20\textsuperscript{th} Century saw increased, albeit limited, regulation of experimentation with human subjects.\textsuperscript{245}


\textsuperscript{244} For a detailed summary and analysis of the Tuskegee Syphilis Study, see James H. Jones, “The Tuskegee Syphilis Experiment,” in The Oxford Textbook of Clinical Research Ethics, eds. Ezekiel Emanuel, Christine Grady, Robert A. Crouch, Reidar K. Lie, Franklin G. Miller and David Wendler (New York: Oxford University Press, 2008): 86-96. “From 1932 until 1972, the U.S. Public Health Service (PHS), aided and abetted by a number of partners, conducted a nontherapeutic study of the effects of untreated syphilis on more than 400 black men in Macon County, Alabama, in and around the county seat of Tuskegee. Although PHS officers and other participating physicians performed a variety of tests and medical examinations on the men over the years, the Tuskegee Study in essence was a 40-year deathwatch. Only men with advanced cases of syphilis were selected for study, and the men were left largely untreated” (86). None of the men gave their informed consent to participate in the study, and the men likely thought they were receiving treatment. When the study began in 1932, PHS officials “told local residents and the men who were selected for study that PHS had returned to Macon County to resume the treatment program” that had been previously discontinued (90). Additionally, PHS officials “started handing out pink-colored aspirin tablets,” dubbed “pink medicine,” to the men after their examinations (90). “Most of the men had never taken aspirin before and they marveled at how quickly it relieved their aches and pains” (90). Even after penicillin was discovered and proven to be successful treatment for syphilis, the study continued and PHS officials and physicians involved in the Tuskegee Study actively tried to prevent the men from receiving penicillin. For example, many of the subjects were “1-A” draft registrants, and would have been among the first group called up to fight in World War II; “[o]nce their physical examinations revealed syphilis, the men in the study started receiving letters from their local draft boards ordering them to take treatment” (93). “PHS intervened with the local drafts and obtained deferments for all of the men in the study” so they would not be called to fight in World War II and would not receive treatment for their syphilis (91, 93).

Nearly half of the 1947 Nuremberg Code’s provisions aim to minimize the human cost of research. For example, the Code states that “no experiment should be conducted, where there is an *apriori* [sic] reason to believe that death or disabling injury will occur.” Moreover, “the experiment should be so conducted as to avoid all unnecessary physical and mental suffering and injury,” and “proper preparations should be made and adequate facilities provided to protect the experimental subject against even remote possibilities of injury, disability, or death.” Finally, to ensure that these protections are carried out effectively, the Code states that “the experiment should be conducted only by scientifically qualified persons” with “the highest degree of skill and care,” who “must be prepared to terminate the experiment at any stage, if [they] ha[ve] probable cause to believe, in the exercise of the good faith, superior skill and careful judgment required of [them], that a continuation of the experiment is likely to result in injury, disability, or death to the experimental subject.”

The Nuremberg Code’s guiding principles, though non-binding under U.S. law, suffuse the background of U.S. federal regulations known as the “Common Rule.” The Common Rule aims to protect human subjects in research that is either funded or performed by U.S. government employees. Study protocols subject to the Common Rule must be reviewed and

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246 The Nuremberg Code lists ten guiding principles for research with human subjects, promulgated in 1949 after the 1947 U.S. military trial of Nazi doctors.
248 Ibid., provision 4.
249 Ibid., provision 7.
251 Ibid., provision 10.
253 Code of Federal Regulations, Title 45, Part 46, Subpart A (2009). Subparts B, C, and D provide additional protections/restrictions for research with “pregnant women, fetuses, and neonates;” prisoners; and children, respectively.
approved by an Institutional Review Board (IRB).\textsuperscript{254} The IRB is a committee of “at least five members, with varying backgrounds to promote complete and adequate review of research activities commonly conducted by the institution.”\textsuperscript{255} IRBs are only supposed to approve studies where “risks to subjects are minimized”\textsuperscript{256} and there is a proportionate balance of risks of harm and potential for benefit.\textsuperscript{257}

Inevitably, the experimental nature of studies means that subjects can face unforeseen and, in some cases, unforeseeable risks; subjects may suffer injury, illness, or disability in even the most meticulously designed studies.\textsuperscript{258} A prevention-focused approach to research-related injuries has, unsurprisingly, offered little guidance for responding to research-related injuries when they do occur. According to the Common Rule, “for research involving more than minimal risk,” researchers must provide potential subjects with “an explanation as to whether any compensation and an explanation as to whether any medical treatments are available if injury occurs and, if so, what they consist of, or where further information may be obtained.”\textsuperscript{259} However, as bioethicist and lawyer Alexander Capron noted, “this is plainly a very limited requirement: researchers are not required to provide any compensation or medical care, but merely to announce clearly what they will and will not provide.”\textsuperscript{260} This “buyer beware”

\textsuperscript{254} Ibid. IRBs are local committees tied to specific institutions where research will take place, such as a hospital or university.
\textsuperscript{255} Ibid., §46.107(a).
\textsuperscript{256} Ibid., §46.111(a)(1).
\textsuperscript{257} Ibid., §46.111(a)(2). As discussed above in Chapter Two, IRBs sometimes downplay their directive to balance risks and benefits as long as proposed studies have appropriate informed consent procedures and disclosures in place.
\textsuperscript{260} Capron, 27.
approach is another (side) effect of a contract-based understanding of informed consent and the doctrine’s dominance in research ethics practice, and there is no guarantee that injured subjects will be compensated.

Government commissions began recommending assurances of compensation for injured research subjects as early as 1973.261 To date, nine government commissions have expressed the importance of ensuring compensation for injured research subjects,262 yet the government still has not acted on these recommendations. Bioethicist Leslie Meltzer Henry describes this impasse as “moral gridlock:” she argues that enacting any no-fault compensation system has stalled due to disagreements over how the ideal no-fault compensation system should look.263

Nevertheless, the U.S. needs to implement a no-fault compensation system for injured research subjects, as the available fault-based legal avenues continue to leave many injured research subjects without support for shouldering even the financial cost of treating an injury. In this chapter, I will summarize secular arguments for compensating injured research subjects and explain the current law’s inability to adequately respond to cases about research-related injuries. I argue that given the history of moral gridlock, new language and approaches are needed to frame the compensation conversation. I propose religious narrative as a means of reorienting the conversation surrounding ethical duties to compensate research subjects. Specifically, I turn to

261 Henry, 411 (1973 was the Tuskegee Syphilis Study Ad Hoc Advisory Panel, developed in response to public outcry over the Tuskegee study).
262 Ibid., 411-12. These commissions are: (1) the Tuskegee Syphilis Study Ad Hoc Advisory Panel [1973]; (2) the Department of Health, Education, and Welfare’s Medical Malpractice Committee [1973]; (3) the Department of Health, Education, and Welfare Secretary’s Task Force on the Compensation of Research Subjects [1977]; (4) the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research [1978]; (5) the Presidential Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research [1982]; (6) the Advisory Committee on Human Radiation Subjects [1995]; (7) the National Bioethics Advisory Commission [2001]; (8) the Institute of Medicine’s Committee on Assessing the System for Protecting Human Research Participants [2002]; and (9) the Presidential Commission for the Study of Bioethical Issues [2011].
263 Henry, 411-12.
the book of Job. The story of Job is particularly useful, because it offers a familiar narrative touchstone for thinking about how to respond to unearned or undeserved suffering. Paying particular attention to the story’s final chapter and post-Holocaust Jewish interpretations of Job, I use this familiar narrative to imagine how ethical compensation for research-related injuries ought to look. Before turning to Job, let me turn to the secular arguments for compensating subjects with research-related injuries.

SECULAR ARGUMENTS IN FAVOR OF COMPENSATION

Because “compensation for research injuries is not systematically available in the United States,” research subjects are often personally responsible for the cost of treating their injuries. As early as 1973, the Tuskegee Syphilis Study Ad Hoc Advisory Panel, which was formed by the U.S. government in 1969 to investigate the Tuskegee Syphilis Study and determine whether the study ought to continue, recommended that the federal government “assure compensation for subjects harmed as a result of their participation in research.” To date, a total of nine government commissions have expressed the importance of ensuring compensation for injured research subjects.

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265 Henry, 411; Pike, 24.


268 Ibid., 411-412.
Nevertheless, Elizabeth Pike, an attorney and staff member for the Presidential Commission for the Study of Bioethical Issues, lamented,

For four decades, U.S. advisory committees have considered and reconsidered whether there is an obligation to compensate research participants who become injured as a result of participating in research. Despite repeated recognition of such an obligation, U.S. advisory committees have made no concrete proposals and have taken no steps to implement systematic compensation.\

Leslie Meltzer Henry, a bioethicist at the Johns Hopkins Berman Institute for Bioethics, attributes this inertia to “moral gridlock,”\(^\text{270}\) or the failure to find a common moral justification for compensation,\(^\text{271}\) especially when different principles lead to mutually exclusive compensation systems. For example, U.S. tort law, which will be discussed in more detail below and which is currently most injured subjects’ only venue for recovering their associated costs,\(^\text{272}\) is grounded in notions of reparative justice, “a special duty...that arises from one’s previous wrongful acts.”\(^\text{273}\) Reparative justice focuses on identifying fault and assigning blame to an individual; this approach is unable to address situations where no one is at fault for the subject’s injury.\(^\text{274}\) On the other hand, compensatory justice, understood as “a concrete application of the principle of fairness in the imposition of risks for the benefit of society,”\(^\text{275}\) can sustain a no-fault compensation system. Research subjects already expose themselves to risk for the benefit of others—both the researchers and society benefit from subjects’ participation. Expecting

\(^{269}\) Pike, 11.
\(^{270}\) Henry, 412.
\(^{271}\) Ibid.
\(^{272}\) Henry, 413.
\(^{276}\) Ibid. “The subject who incurs a research-related injury is not just another person who has ‘needs.’ Rather he or she has taken certain risks for the benefit of society through the advancement of medical knowledge. In such a
research subjects to bear the financial costs of treating research-related injuries, costs which they bear in addition to the injury itself, is unfair. The same societal benefit that warrants spending taxpayers’ dollars to fund experiments with human subjects also warrants budgeting public money to compensate for injuries arising from these experiments, even when no one acted unethically to cause the injury.

WHY RESEARCH SUBJECTS ARE GENERALLY UNCOMPENSATED

There are two main reasons that injured research subjects in experiments conducted in or by the U.S. do not receive compensation for their injuries: first, researchers or sponsors lack incentives to assure compensation outside of litigation, and second, injured research subjects are unlikely to succeed in a lawsuit for compensation due to a cluster of idiosyncrasies in the U.S. legal system. Each of these reasons will be considered in turn.

Researchers Lack Incentives to Provide Compensation

The first reason that injured subjects in U.S. trials are rarely compensated for research-related injuries is that researchers and sponsors have no legal or economic incentive to automatically provide compensation for injuries. As discussed above, the Common Rule, which

setting, where there is no negligence, recovery ‘is premised on the assumption that the injured party exposed himself to risk in the public interest’” (quoting “Medical Experiment Insurance,” Columbia Law Review 70, no. 5 (1970): 974).

278 Childress, “Compensating Injured Research Subjects: I. The Moral Argument,” 22. “But subjects…should be able to make claims on the society which is the beneficiary of the risk taken. Indeed, society benefits from the increased medical knowledge in unsuccessful as well as successful experiments. Not only is society either as a whole or as a sum of its members the beneficiary of advances in medical knowledge, but through the federal government it conducts, sponsors, or mandates most of the research involving human subjects in the United States.”
applies to experiments funded or performed by U.S. government employees and governs all NIH-funded experiments with human subjects, does not require researchers or sponsors to compensate subjects for research-related injuries. Though researchers may incorporate some form of compensation for injuries into their budget or study design, there is no legal or economic incentive for them to do so. This lack of incentive is further reinforced by potential subjects’ limited choices when deciding whether to participate in an experiment: individual subjects may not negotiate additional provisions in the consent form, potential subjects are deciding whether to participate in a study, not selecting among possible studies in which to participate.

In contrast, an increasing number of countries require researchers to provide—and prepare financially to provide—compensation for subjects who suffer research-related injuries. The European Union requires any clinical trial conducted in a member state to provide “insurance or indemnity to cover the liability of the investigator and sponsor.” The amount of insurance required for each study is assessed by research ethics committees that assess the risk of harm involved in each study. In some European Union countries, such as Germany, injured subjects must prove that their injuries were caused by their participation in the study; in others, such as Spain, research subjects are eligible for no-fault compensation (i.e., they do not have to

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279 Code of Federal Regulations, Title 45, Part 46, Subpart A. Subparts B, C, and D provide additional protections/restrictions for research with “pregnant women, fetuses, and neonates;” prisoners; and children, respectively.

280 See Capron, 26-27.

281 One possible exception here would be the case of healthy individuals serving as a type of control subject, also known as “healthy volunteers.” Since healthy volunteers may be needed for many studies, these volunteers, though unable to negotiate the specific compensation for a study, may feel like they have less to lose by declining to participate in an experiment. For more on healthy volunteers, see “NIH Clinical Research Trials and You: The Basics,” National Institutes of Health, June 12, 2015, http://www.nih.gov/health/clinicaltrials/basics.htm#3.

282 EU Council Directive 2001/20 O.J. (L 121) 34 (EC) at arts. 3.2(f), 6.3(h). The directive had to be implemented by 2004; each member state was able to implement their own specific compensation requirements within the broader guidelines of the EU Council Directive.

283 Ibid.
prove causation) for physical injury and economic loss.\textsuperscript{284} India, Mali, Uganda, and Brazil are only some of the other countries that require researchers to provide compensation for research-related injuries for experiments conducted within their borders.\textsuperscript{285} In some cases, other countries have refused to permit U.S.-sponsored studies to take place within their borders unless and until investigators agreed to follow the host country’s laws about compensation.\textsuperscript{286} For example, in 2004, a monitor from the World Health Organization temporarily halted a U.S.-sponsored malaria experiment in Mali, until the sponsor purchased a clinical trial insurance policy with which to compensate injured research subjects, as was required by Malian law.\textsuperscript{287} But in 2008, the NIH refused to continue as a sponsor\textsuperscript{288} for a multi-site experiment after learning it would have to compensate subjects with research-related injuries.\textsuperscript{289} There are a few possible explanations for the NIH’s inconsistent stances, and these explanations are not necessarily mutually exclusive. One possibility is that the NIH may have acquiesced in the earlier study because the study had already begun, whereas the latter study was still in the planning stages.\textsuperscript{290} Another possibility is that after purchasing clinical trial insurance for the 2004 trial, the NIH decided it would no longer sponsor studies requiring them to compensate subjects for research-related injuries. Finally, the NIH may have been willing to make a finite expenditure to purchase

\textsuperscript{284} Pike, 40-41.
\textsuperscript{285} Ibid., 41-43.
\textsuperscript{286} Ibid., 43 (discussing a 2004 malaria study in Mali; a World Health Organization monitor required the NIAID (within the NIH) to purchase clinical trial insurance after the study began).
\textsuperscript{287} Ibid. Also see James D. Neaton, Abdel Babiker, Mark Bohnhorst, Janet Darbyshire, Eileen Denning, Arnie Frishman, Jesper Grarup, Gregg Larson, and Jens Lundgren, “Regulatory Impediments Jeopardizing the Conduct of Clinical Trials in Europe Funded by the National Institutes of Health,” \textit{Clinical Trials} 7, no. 6 (2010): 713.
\textsuperscript{288} “Sponsoring” the research, in this case, involved registering as a sponsor with the E.U.; the NIH’s refusal to serve as a sponsor did not affect the availability of NIH funding. See James D. Neaton et al., 708.
\textsuperscript{289} Pike, 42-43. (This study took place in 2008, four years after the Mali malaria trial in which the US was required to purchase clinical research insurance. In this more recent case, he NIH’s refusal to serve as a sponsor arose late in the trial’s planning, but before the trial began; in Mali, by contrast, the trial was already underway, which may have contributed to the U.S. sponsor’s agreement to purchase insurance.)
\textsuperscript{290} See ibid.
insurance in the 2004 study but unwilling to write a blank check, so to speak, for research-related injuries in the 2008 study. This final possibility is borne out by the NIH’s claim that agreeing to compensate injured subjects would put the NIH in violation of the U.S. Antideficiency Act.\textsuperscript{291} The Antideficiency Act prohibits federal agencies from promising or expending funds beyond what has already been appropriated to them in the federal budget,\textsuperscript{292} such that the NIH could not agree to provide open-ended compensation for injuries. However, taken together, these two cases suggest that, at the very least, the NIH could purchase insurance policies with which to compensate injured subjects, but that the NIH is only willing to do so when required by law.

**Tort Law Is Stacked Against Plaintiffs**

In the absence of a systematic no-fault compensation program for research-related injuries, injured subjects seeking compensation must file lawsuits against researchers, research sponsors, or institutions. Unfortunately, a cluster of legal technicalities make it unlikely that their cases will be successful.\textsuperscript{293}

Most lawsuits involving research-related injuries would be framed as negligence claims\textsuperscript{294}—i.e., claims that the researcher, research sponsor, or institution failed to exercise reasonable care. To be successful, negligence claims must prove: (1) that the defendant had a duty to protect the plaintiff, (2) that the defendant “breached the duty” by failing to exercise due care; (3) that the plaintiff suffered an injury; and (4) that the breach of duty caused the injury.\textsuperscript{295}

\begin{itemize}
    \item \textsuperscript{291} See Neaton et al., 712.
    \item \textsuperscript{292} United States Code, Title 31 §§1341-1342.
    \item \textsuperscript{293} Pike, 26 (“The tort system is uniquely difficult for injured research participants, even as compared with injured medical patients…..”); also see Beh, 12; Morreim, 474-75.
    \item \textsuperscript{294} Pike, 27.
    \item \textsuperscript{295} Mariner, 686. (She goes on to state that “Proximate causation ordinarily requires proof that a reasonable person would not have enrolled (or continued) in the trial if the information had been disclosed.”)
\end{itemize}
Proving the cause of an injury can be especially difficult in the context of a medical experiment when subjects are enrolled precisely because they are already sick (and sometimes seriously sick). But the first two elements—duty and breach of duty— actually present the greatest obstacles for injured subjects suing for negligence.

The researcher’s duty to research subjects is less robust than a physician’s duty to his or her patients. In U.S. courts, as in bioethics literature, the physician-patient relationship is described as fiduciary, meaning that the physician is required to act for the patient’s benefit. By contrast, the researcher-subject relationship is not fiduciary, because clinical research “does not aim to benefit any specific individual, but rather to advance generalizable knowledge and thereby to benefit broader populations.” Thus, clinical researchers owe their primary duty to the research protocol; the duty they owe to their subjects is narrower in scope than the duties that doctors owe their patients, even if the researcher is also a doctor. It is not that researchers are indifferent to their subjects, but that their duties call them to consider other obligations. Researchers’ duties to their subjects include: ensuring that researchers have minimized risks of harm to the subjects; disclosing all material information so potential subjects can make informed, voluntary decisions about whether or not to participate in the experiment; and stopping the study as soon as it becomes apparent that the risks to research subjects outweigh the potential benefits that might be gleaned from continuing the study.

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296 Capron, 25.
297 This relationship is also complicated by the fact that the researchers are also physicians.
298 See Forell and Sortun, 558.
299 Morreim, 475.
300 Ibid.
301 Morreim, 476.
302 See ibid., 477 (describing researchers’ duty of care).
Injured research subjects may also have difficulty proving that researchers breached their (limited) duty to the subjects. IRB approval of a study protocol creates a presumption that the experimental design fulfilled the researchers’ duty of care. The event of a research-related injury is hardly sufficient evidence that there was a breach of such a duty. If the risk of the injury was disclosed to potential subjects on consent forms, then the injured subject’s signature indicates that the subject “assumed the risk” of the injury. Assumption of risk is a legal defense that precludes a research subject from recovering for a negligence-related injury. And even if the risk of that injury was not disclosed on the consent form, the injured research subject would have to prove that the researchers “knew or should have known” about the risk of that particular kind of injury in order to successfully argue that there was a breach of duty. The inherent uncertainty of scientific experiments makes it difficult for injured subjects to successfully argue that researchers should have known about a risk.

When injured research subjects sue the federal government, the doctrine of sovereign immunity presents an additional obstacle to receiving compensation for injuries. According to the doctrine of sovereign immunity, no one may sue the U.S. government unless the government explicitly agrees to be sued (thereby waiving sovereign immunity). Absent the federal government’s agreement to be sued in a particular case, there are limited situations that fall under statutory waivers of sovereign immunity. Most relevant for injured research subjects is the

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303 Additionally, studies that involve greater risk to human subjects may be intermittently reviewed by an independent Data and Safety Monitoring Board (DSMB). The DSMB reviews non-anonymized study data and has the authority to halt a study if the risk of harm to subjects is too great. In cases where subjects were injured due to participation in a study protocol that was both approved by an IRB and allowed to continue by a DSMB, there would be an even stronger presumption that the researchers met their duty of care.

304 American Law Institute, Restatement of the Law, Second, Torts §496A.

305 Ibid.

306 But see Beh, 12 (arguing that “the tort system’s scrutiny of research with the advantage of 20-20 hindsight can make litigation based on fault appear unfair to the researcher”).
Federal Tort Claims Act (FTCA), a statute that waives sovereign immunity in certain instances where a federal employee’s behavior causes an injury, but the FTCA does not waive immunity for “any claim arising in a foreign country.” This is the legal technicality that prevented the court from reviewing the claims made by the survivors of the Guatemala Study, and it may prove a more frequent legal obstacle for injured research subjects as medical experiments increasingly move overseas to developing countries. Even injured subjects who are able to sue under the FTCA still have to prove that the government employee’s actions caused their injuries, thus facing the difficulties proving causation in a research context discussed above.

The common law’s shortcomings as a guarantor of justice, coupled with the moral imperative not to abandon research subjects when they are injured and vulnerable, make it important to implement a systematic no-fault compensation scheme for research-related injuries. Since strictly philosophical approaches to the problem of compensation have resulted in moral (and political) gridlock, we need a new framework to guide this endeavor and new sources for considering possible moral appeals.

In the next section of this chapter, I propose turning to narrative ethics and thinking with the book of Job, a biblical text about unjust (or unjustified) suffering, as a framework for considering what is owed, and by whom, to injured research subjects.

**TURNING TO RELIGIOUS NARRATIVE: THE BOOK OF JOB**

This is the story of Job:

There was a man in the land of Uz named Job. That man was blameless and upright; he feared God and shunned evil. Seven sons

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308 Ibid., §2680(k)
309 Particularly narrative ethics as employed in Nussbaum, *Love’s Knowledge*.
310 See Morris, 55; Frank, 23-25.
and three daughters were born to him; his possessions were seven thousand sheep, three thousand camels, five hundred yoke of oxen and five hundred she-asses, and a very large household. That man was wealthier than anyone in the East. It was the custom of his sons to hold feasts, each on his set day in his own home….When a round of feast days was over, Job would send word to them to sanctify themselves, and, rising early in the morning, he would make burnt offerings, one for each of them; for Job thought, “Perhaps my children have sinned and blasphemed God in their thoughts.” This is what Job always used to do.  

One day God praises Job to Satan, “There is no one like him on earth, a blameless and upright man who fears God and shuns evil!” Satan is unimpressed and challenges God, “…lay your hand upon all that he has and he will surely blaspheme You to Your face.” God accepts Satan’s challenge, responding, “See, all that he has is in your power; only do not lay a hand on him.”

Satan takes everything from Job:

…a messenger came to Job and said, “The oxen were plowing and the she-asses were grazing alongside them when Sabeans attacked them and carried them off, and put the boys to the sword…. This one was still speaking when another came and said, “A Chaldean formation of three columns made a raid on the camels and carried them off and put the boys to the sword…. This one was still speaking when another came and said, “Your sons and daughters were eating and drinking wine in the house of their eldest brother when suddenly a mighty wind came from the wilderness. It struck the four corners of the house so that it collapsed upon the young people and they died…."

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311 Job 1:1-5.  
312 Ibid., 1:8.  
313 Ibid., 1:11.  
314 Ibid., 1:12.  
315 Job 1:13-19. Though the text does not explicitly say that Satan was responsible for these losses, the narrative structure, with the verses describing Job’s losses immediately following God’s permission for Satan to do anything short of laying a hand on Job, suggests that the losses and the heavenly “wager” are related.  
316 Ibid.
Despite his many losses, “Job did not sin nor did he cast reproach on God.” Job passes Satan’s test; God wins the heavenly wager. But Satan refuses to accept defeat, telling God, “…all that a man has he will give up for his life. But lay a hand on his bones and his flesh, and he will surely blaspheme You to Your face.” With God’s permission to do anything short of taking Job’s life, “[Satan] inflicted a severe inflammation on Job from the sole of his foot to the crown of his head.” Despite tremendous suffering—Job’s friends cannot even recognize him from a distance—“Job said nothing sinful.” But after Job’s friends sat with him in silence for seven days and nights, “Job began to speak and cursed the day of his birth.”

At this point, most of the book of Job consists of a series of speeches between Job and his friends. Job’s lamentations express utter frustration: either God is punishing him despite his blamelessness, or God is unwilling to let Job know what he did wrong so that Job may repent and seek amends. Neither option is compatible with notions of a just God. Finally, God addresses Job from a whirlwind, but God does not answer Job’s questions. Instead, God challenges Job: “Who is this who darkens counsel, speaking without knowledge? Gird your loins like a man; I will ask and you will inform Me. Where were you when I laid the earth’s foundations? Speak if you have understanding….Have you ever commanded the day to break,

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317 Ibid., 1:22.
318 Ibid., 2:3.
319 Job 2:4; there’s an interesting resonance here with the distinction between bodily harm and damage to property drawn in m. Bava Kama 8:7, discussed above in Chapter Two.
320 Ibid., 2:7. (The Hebrew for Job’s affliction—“שחין רע”—can also be translated as “sore boils.” See, e.g., the 1917 JPS English translation of the Tanakh.)
321 Ibid., 2:12.
322 Ibid., 2:10. (The Hebrew—“חטא איוב בשפתיו”—translates more literally as “Job did not sin with his lips.”)
323 Ibid., 2:13.
324 Ibid., 3:1.
325 Job 3:3-31:40. Job 32:6-37:24 consists of speeches by Elihu, a fourth character not among the three friends who first sat silently in mourning with Job.
326 See, e.g., Job 10:2.
327 Ibid., 38:1.
assigned the dawn its place…”? After this display of power, God insists on an answer from Job: “He who arraigns God must respond.”

Job eventually relents, “…I spoke without understanding of things beyond me, which I did not know….I had heard You with my ears, but now I see You with my eyes; therefore, I recant and relent, being but dust and ashes.” These words cause a change of heart for God, whose favor returns to Job. In fact, God “restored Job’s fortunes…and…gave Job twice what he had before.” God also give’s job seven sons and three daughters to replace the children who died during Satan’s first trial of Job. Job finally received support from his community, too. His brothers, sisters, and friends rally around him, consoling him, sharing a meal, and each giving him a kesitah and a gold ring.

Job lives a hundred and forty years, long enough “to see four generations of sons and gandsons.” When Job dies, he is “old and contented” despite the awful ordeal with which God and Satan tested him.

**Job in Jewish Thought**

Historical-critical biblical scholars maintain that the book of Job comes from at least two sources that have been woven together. There is a series of poetic speeches about theodicy

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328 Ibid., 38:2-12.
329 Ibid., 40:2.
330 Job 42:3-6.
331 See ibid., 42:8.
332 Ibid., 42:10.
333 Ibid., 42:13.
334 Ibid., 42:11.
335 Job 42:16.
336 Ibid., 42:17.
that makes up the majority of the book, and there is a prose narrative, comprised of Job 1-2 and Job 42:7-17, that frames the speeches.\textsuperscript{338,339} The frame narrative, read alone, offers a coherent tale about obedience to God that is very much compatible with traditional covenantal views of justice: Job is subjected to a trial, he does not blaspheme God, and so God rewards Job for his obedience and faithfulness.\textsuperscript{340} Splitting the prose narrative to frame the poetic speeches provides a context for the speeches, but creates a dilemma: the frame narrative presents a patient, obedient Job, while the poetic speeches present a Job who protests the events that have befallen him.\textsuperscript{341} By the time readers come to the latter half of the frame narrative, Job is no longer a consistent character, and it is unclear why he is rewarded. As inheritors of this more complex, redacted text, Jews and Christians have employed varied creative tactics in an effort to read Job as a coherent theological whole. This sometimes involves emphasizing one depiction of Job—patient or protesting—over the other. In his overview of Jewish interpretations of Job throughout history, Jewish philosopher Alan Mittleman observed that, “Ancient Jewish interpretations of Job praise Job the patient and condemn, or at least do not praise, Job the rebel. Modern Jewish interpretations, by contrast, praise Job the rebel and scant the patient, pious Job of the frame story. Job the rebel becomes a model of sincerity or authenticity, a chief value of modernity. Job

\textsuperscript{338} Ibid.

\textsuperscript{339} Job scholars further divide the poetry section into more, smaller sections. For example, Carol Newsom divides the poetry section into: “the dialogue” (Job 3-27); “the poem on wisdom” (Job 28); “Job’s closing speech” (Job 29-31); “the Elihu speeches,” (Job 32-37); “the divine speeches,” (Job 38-41); and “Job’s reply” (Job 42:1-6). Carol Newsom, “Reconsidering Job,” \textit{Currents in Biblical Research} 5, no. 2 (2007): 155-182. In his extended close reading of Job, David Burell divides the poetry into the Prologue (Job 1-2), “three rounds of multifaceted dialogue” between Job and his friends (Job 3-11, Job 12-20, and Job 21-31), and the Denouement (Job 32-42, which includes Job 42:7-17 as Epilogue). David Burell, \textit{Deconstructing Theodicy: Why Job Has Nothing to Say to the Puzzle of Suffering}, (Grand Rapids, MI: Brazos Press, 2008), 21-22.

\textsuperscript{340} Job 1-2; Job 42:7-17.

the patient and pious sufferer so celebrated by antiquity is at best an ambivalent figure [for
modern interpreters].”

The most extensive discussion of Job in rabbinic literature takes place in tractate Bava Bathra of the Babylonian Talmud. Job is introduced in the midst of rabbinic attempts to determine who wrote specific portions of the Tanakh, but the conversation quickly shifts to rabbinic disagreement over whether Job was an actual person and, if so, when he lived. Within the discussion of when Job lived, the Talmudic text also conveys rabbinic ambivalence about Job. On the one hand, Job is described as having “prophesied to the heathen,” and a tradition attributed to R. Johanan states that “[g]reater praise is accorded to Job than to Abraham.” Moreover, a tradition attributed to R. Abba b. Samuel describes Job’s generosity as an employer. On the other hand, the rabbis’ concern for making sense of Job’s doubled

342 Mittleman, 25.
343 BT Bava Bathra 15a-16b. With some overlap, there is also extensive discussion of Job in Gen. Rabbah 57 and Seder Olam Rabbah 21.
344 BT Bava Bathra 15a. The rabbis are trying to figure out which portions of the Tanakh were written by Moses. In the midst of this debate, we learn that someone among the rabbis says “that Moses wrote his book [i.e., through Deuteronomy] and the section of Balaam and Job.”
345 Ibid. “A certain Rabbi was sitting before R. Samuel b. Nahmani and in the course of his expositions remarked, ‘Job never was and never existed, but is only a[n archetypical figure. He replied, ‘To confute such as you the text says, “There was a man in the land of Uz, Job was his name.”’ ‘But,’ he retorted, ‘if that is so, what of the verse, “The poor man had nothing save one poor ewe lamb, which he had bought and nourished up etc.” Is that anything but a parable? So this too is a parable.’ ‘If so,’ said the other, ‘why are his name and the name of his town mentioned?’”
346 Ibid. The rabbis riff midrashically on the word “אָפָו,” “now,” which appears in Job 19:23. The rabbis suggest that the appearance of this same word appears in Exod. 33:16, wherein Moses is speaking with God, supports R. Joshua b. Levi b. Lahma’s opinion that Job and Moses lived contemporaneously. Since “אָפָו” also appears in Gen. 27:33 and Gen. 43:11, the Talmudic discussion moves on to consider whether Job was rather a contemporary of Isaac or Jacob instead.
347 See Mittleman, 27.
348 BT Bava Bathra 15b. The other six prophets to the heathens are Balaam, Eliphaz the Temanite, Bildad the Shuhite, Zophar the Naamathite, and Elihu the son of Barachel the Buzite.
349 Ibid.
350 Ibid. “Job was liberal with his money. Ordinarily, if a man owes half a prutah [to a workman], he spends it in a shop [because a prutah cannot be divided, it was common practice to purchase an item for one prutah in a shop and split the item with the worker], but Job used to make a present of [the whole prutah] to the workman.”
Wealth belies an understanding that Job failed God’s test. For example, an interpretation of the biblical verse “For all this, Job did not sin with his lips,” picking up on the textual idiosyncrasy of the words “with his lips” and attributed to Raba, suggests that “With his lips Job did not sin, but he did sin with his heart.” If Job sinned, and, by extension, failed God’s test, then the rabbis must make sense of why Job’s wealth doubled at the end of the biblical story. The following passage from Bava Bathra not only confirms that at least some rabbinic interpreters believed Job failed his test, but indicates that Job’s supposed reward is actually a form of punishment:

There was a certain pious man among the heathen named Job, but he [thought he had] come into this world only to receive [here] his reward, and when the Holy One, Blessed be He, brought chastisements upon him, he began to curse and blaspheme, so the Holy One, Blessed be He, doubled his reward in this world so as to expel him from the world to come.

Interestingly, the rabbis do not seem especially concerned by the idea that God would subject a pious individual to such extensive, unearned suffering.

Job has long been a way for Jewish thinkers to discuss the problem of unwarranted suffering. The book of Job gained increasing prominence in Jewish Thought in the latter half of

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351 Ibid.
352 Ibid, 16a.
353 Job 2:10.
354 In other words, the hermeneutic invitation to interpret the verse derives from the fact that “For all this, Job did not sin,” would have been a complete, clear sentence. Based on the rabbinic assumption that all words in the biblical text are there for a reason, the otherwise unnecessary words “with his lips” invite some form of rabbinic interpretation.
355 BT Bava Bathra 16a. The page goes on to explain how Job blasphemed God.
356 Job 42:10.
357 BT Bava Bathra 15b.
358 The text expresses some concern that God appears to be “persuaded against his better judgment” by ha-Satan (BT Bava Bathra 16a), but this concern has more to do with God’s being persuaded by ha-Satan than with the actions God has been persuaded to perform (i.e., the suffering he will allow Job to endure).
the 20th Century, especially in theological efforts to make sense of and/or respond to the
Holocaust. Job has been particularly relevant for Jewish theologies that resist a standard
covenantal reading according to which the Holocaust was some form of divine punishment
imposed upon the Jews. Within this body of Jewish thought, a recurring trope, perhaps most
famously found in the writing of Elie Wiesel, equates Job with Holocaust survivors.359 Wiesel’s
interpretation of Job is especially relevant because he is the figure through whom so many Jews
and non-Jews alike encounter and engage with the Holocaust.360 In his book of biblical
commentaries, Messengers of God: Biblical Portraits and Legends, Wiesel wrote, “I was
preoccupied with Job, especially in the early years after the war. In those days he could be seen
on every road in Europe.”361 For Wiesel, Job is the Holocaust survivor. This metaphor is apt, not
only because Holocaust survivors suffered immensely, losing everything—homes, families,
health, and wealth—from their lives before the camps, but also because they, like Job, suffered
through no fault of their own. And more specifically, Job is an apt metaphor for the Holocaust
survivor who must live with the memories and effects of his traumatic experiences.

More generally speaking, post-Holocaust Jewish Thought about Job is more helpful than
Talmudic discussions of Job for addressing a blameless victim’s unethical suffering. There are
narrative features of the biblical text that also make Job an apt comparison for injured research
subjects. We know, as readers of the frame narrative, that Job is not to blame for his suffering.

Schuster, 2005), 211-36; Joseph Freeman, Job: The Story of a Holocaust Survivor (Westport, CT: Praeger
Glatzer (New York: Schocken Books, 1972): 224 (comparing Job to Holocaust victims by mentioning “the Job of
the gas chambers”).
360 i.e., through his book, Night (1972, reprint New York: Hill and Wang, 2006), which describes his experiences in
the Holocaust and is part of the reading curriculum for so many public school systems.
361 Wiesel, Messengers of God, 233.
and that he feels as though God has abandoned him when he is most vulnerable. Similarly, the injured research subject, though injured through no fault of his own, is “abandoned” by researchers, research sponsors, and society when he is at his most vulnerable if left to pay for needed medical treatment or therapy out of his own pocket.

Just as post-Holocaust Jewish theological readings of Job are primarily interested, not in assigning blame for the Holocaust, but in making sense of a world in which the Holocaust occurred, I also turn to the book of Job not to assign blame for research-related injuries, but to chart a course for moving forward in a world where these injuries happen. Thus, I use the book of Job to engage the ethical obligations that fall upon investigators, research sponsors, and society when research subjects suffer research-related injuries, even if no one is at fault for the injuries.

The Book of Job as Framework: Relevant Narrative Features

Using the story of Job as a framework for thinking about compensating research-related injuries begins by considering certain narrative features of the biblical text. Job is described as a righteous, “God-fearing” man and a wealthy man—his fortune includes “seven sons and three daughters,” “seven thousand sheep,” “three thousand camels,” “five hundred yoke of oxen,” “five hundred she-asses,” and “a very great household.” Job is also a careful man—according to the text, Job “rose up early in the morning [and] offered burnt-offerings” after his children had a feast, reasoning, “It may be that my sons have sinned, and blasphemed God in their hearts.” One day, God holds Job out as an exemplar to Satan. Satan “wagers” that Job is only righteous

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362 Job 1:1.
363 Ibid., 1:1-3.
364 Job 1:5.
because God has been so kind to him—indeed, Satan suggests that if Job lost his fortune, he would blaspheme God. God accepts Satan’s wager, and Job loses his children, flocks, home, and wealth, after which Job simply says, “God gave, and God took away. Blessed is God’s name.”

Unconvinced, Satan suggests that Job would surely blaspheme God if Job’s own body (rather than just his possessions) were affected. With God’s permission to do anything short of killing Job, Satan afflicts Job with “boils” or “inflammation” covering his entire body. Nevertheless, the biblical text notes that “for all this, Job did not sin with his lips.”

Though the biblical text presents Job as the unknowing subject of a heavenly wager, we may, for the purposes of seeking moral frameworks outside of the legal system to think about the ethics of compensation, see Job as the unwitting subject of an experiment. The experiment, designed to test competing hypotheses about whether Job will blaspheme God, is not completely unregulated—God’s limits on Satan act much like research regulations designed to protect research subjects. In the course of the experiment, Job is injured—he suffers from boils or inflammation all over his body; his “flesh is covered with maggots and clods of earth;” his “skin is broken and festering;” and he has become so emaciated that “the neck of [his] tunic fits [his] waist.” Ultimately, God compensates Job for his injuries. Close attention to how God compensates Job, discussed later in this chapter, offers a narrative touchstone for discussions about what is owed, ethically, as compensation to injured research subjects today.

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365 Ibid., 1:21.
366 This distinction between loss of property and loss of health corresponds to m. Bava Kama 8:7’s assertion that one may preemptively release someone from liability for damaging one’s property but not one’s body.
367 Job 2:7.
368 Ibid., 2:10.
369 Ibid., 7:5.
370 Ibid.
371 Ibid., 30:18.
Compensating Injuries in the Book of Job

For the purpose of this chapter and the aim of considering how injured research subjects ought to be compensated for research-related injuries, the most interesting piece of the book of Job is the compensation Job receives at the end of the narrative. The biblical text states,

And the LORD restored Job’s fortune when he prayed for his friends, and the LORD gave Job twice as much as he had before….So the LORD blessed the latter end of Job more than his beginning: and he had fourteen thousand sheep, and six thousand camels, and a thousand yoke of oxen, and a thousand she-asses. He also had seven sons and three daughters….And after this Job lived a hundred and forty years, and saw his sons, and his sons’ sons, even four generations. And so Job died, old and full of days. 372

Four aspects of Job’s compensation are especially helpful for thinking about the ethics of compensating research-related injuries: (1) the biblical text is ambiguous about whether God heals Job; (2) God compensated Job even though Satan inflicted the injuries; (3) compensation from God is supplemented by Job’s community; (4) modern readers often find Job’s compensation inadequate, or unresponsive. The implications of each of these aspects will be discussed in turn.

1. The Biblical Text is Ambiguous About Whether God Heals Job

One aspect of the end of Job that is fruitful for thinking about compensation for research injuries is the text’s ambiguity about whether God heals Job’s boils. The text’s ambiguity is actually advantageous: the process of comparing possible interpretations offers a point of entry for thinking creatively with the narrative of Job in order to consider what kinds of compensation are owed to injured research subjects. Job 42:10 states, “And the LORD restored Job’s fortune…and the LORD gave Job twice as much as he had before.” While the second half of the

372 Job 42:10-17.
verse, “and the LORD gave Job twice as much as he had before,” clearly applies to Job’s wealth, the meaning of the first half of the verse, “restoring Job’s fortune,” is less clear. “Fortune” might refer only to Job’s wealth, or it might encompass his health, too. Job 42:16-17 notes that Job “lived a hundred and forty years” and “died old and full of days,” details that suggest Job was healthy. Additionally, the narrative’s conclusion—Job’s reward—aims to return Job to the status and lifestyle he enjoyed before the wager. Thus, along with his replenished flocks and “replacement children,” it would make sense for God to return Job to health, too. Surely Job is not left to live a hundred and forty years with the sores that caused him so much suffering! And yet, if Job were healed, wouldn’t the text say so? The biblical text is specific enough to include the numbers of animals within Job’s new flocks and the names of his new daughters; perhaps the text never states that Job’s health was restored because he did, in fact, live the remainder of his hundred and forty years afflicted by those painful sores. Whether reading the text as suggesting that God healed Job, or as suggesting that God did not heal him, the story still offers important insights into how injured research subjects ought to be compensated.

Both interpretations of the text indicate an obligation to try to heal the injured subject—indeed, a modern reader’s dissatisfaction with the idea that God did not heal Job is just one indication of the moral importance of attempting to heal injuries arising from experiments. And the possibility that Job was not healed by God alerts us to the limits of modern medicine and the possibility that paying for an injured subject’s medical treatment may be a minimal but insufficient form of compensation: the medical treatment may not fully heal the injury.

Perhaps Job lived to one hundred and forty years of age with the boils. Perhaps Job received a doubled fortune precisely because his health was not restored—perhaps the additional wealth was a means of alleviating the monetary burden of living with an injury. Perhaps God
was unable to heal Job. This possibility is somewhat shocking given that the biblical text describes God as the One who “laid the earth’s foundations,”⁶³⁷³ “closed the sea behind doors…[and]…clothed it in clouds,”⁶³⁷⁴ and is the only one who “can draw the sword against [behemoth].”⁶³⁷⁵ God’s inability to heal Job, even as God doubles his wealth and provides him ten new children and a long life, can serve as an important reminder that complete compensation for research-related injuries is never really possible. For example, monetary compensation can offset the cost of treating an injury or reduce lost wages when injuries make it impossible for a subject to continue working, but money cannot eliminate the injured person’s pain. Additionally, medical treatment, even if it comes at no financial cost to an injured subject, may not be able to return the subject to pre-injury functioning. Researchers in particular must continue to weigh these realities seriously when they recruit and enlist human subjects in their experiments.

2. *God Compensates Job Even Though Satan Inflicted the Injuries*

Even though Satan directly inflicts Job’s injuries,⁶³⁷⁶ God, not Satan, steps in to provide Job’s compensation.⁶³⁷⁷ Job’s compensation side-steps the direct line of causation, focusing more on making sure Job is compensated than on who provides the compensation. This particular aspect of the narrative offers a useful entry to considering why a no-fault compensation system for research injuries is important and preferable. The challenges that research subjects face when trying to prove that researchers are at fault for an injury have been discussed at length above; a no-fault system would both make it easier for injured research subjects to obtain compensation.

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⁶³⁷³ Job 38:4.
⁶³⁷⁴ Ibid., 38:8-9.
⁶³⁷⁵ Ibid., 40:19.
⁶³⁷⁶ Job 2:7
⁶³⁷⁷ Ibid., 42:10, 42:12.
and enable them to receive compensation more quickly by eliminating the potentially tedious process of demonstrating causation. The greater efficiency of a no-fault system would also save money for whichever party takes on the financial responsibility of compensation. Resources that would normally be spent rebutting a claim that researchers were at fault for an injury could instead be spent on the costs of injured subjects’ medical treatment.

One could argue that God is implicated in Job’s injuries by agreeing to the wager and giving Satan permission to impose any trials on Job as long as he does not kill Job. Following this line of reasoning might suggest that IRBs or their institutions ought to be held accountable for compensating research-related injuries in studies they approved—or perhaps God’s role in compensating Job suggests going to the top of the power structure and requiring the NIH or U.S. government to bear the costs and responsibility of compensation. The biblical text focuses more on Job’s outcome than on determining who ought to be responsible for ensuring that outcome; breaking through moral gridlock to systematically compensate injured research subjects will also require attending to the injured subjects and desired outcomes as the primary focus of concern.

3. Compensation from God is Supplemented by Job’s Community

A third aspect of Job’s compensation with interesting implications for compensating research injuries is that after God doubles Job’s wealth, Job’s community rallies around him:

Then came there unto him all his brethren, and all his sisters, and all they that had been of his acquaintance before, and did eat bread with him in his house; and they bemoaned him, and comforted him concerning all the evil that the LORD had brought upon him; every man also gave him a piece of money, and every one a ring of gold.  

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379 Ibid., 42:11.
In the context of research-related injuries, this passage is especially helpful for thinking about individual citizens’ responsibilities for fulfilling societal obligations to compensate injured research subjects. Job’s community is not to blame for his injuries, yet they contribute to his compensation. Job’s community responds to him in two ways: first, they support him emotionally, “bemoaning” and “comforting” him—they finally, publicly acknowledge that Job suffered, and that his suffering was not punishment for sin. This aspect of the community’s actions toward Job can be compared to establishing a no-fault system for compensating injured research subjects. Rather than leaving injured research subjects alone to bear the frustration and trauma of “shouting into the whirlwind” of the tort system trying to prove that a specific party is at fault for their suffering, a no-fault system lowers the threshold for acknowledging the subject’s injuries and emphasizes supporting the subject in his or her suffering over finding someone to blame for that suffering. Second, Job’s community also compensates him financially, by giving him money and gold rings. The financial compensation, in particular, speaks to taxpayers’ obligations to fund whatever compensation is implemented.380

380 There is precedent for taxpayers funding no-fault compensation systems for people who are injured by actions aimed at the public good. For example, the National Childhood Vaccine Injury Act established a no-fault compensation system for individuals who suffer serious adverse reactions to any of seventeen classes of vaccines. Code of Federal Regulations, Title 42, § 100.3 (2015). Monetary compensation for these injuries is paid from a trust that is funded by a seventy-five cent tax on vaccines covered by the act. United States Code, Title 26, § 4131(b)(1) (2015). The Act came about, in part, because of the public interest in widespread vaccination, which would require both that citizens get vaccinated in large numbers and that vaccine manufacturers supply large numbers of vaccine doses. Increased vaccination led to a low but inevitable incidence of vaccine injuries, and lawsuits over these injuries proved cost-prohibitive for both injured parties and vaccine manufacturers. See Bruesewitz v. Wyeth, 131 S.Ct. 1068 (2011), 1073. The U.S. has a similar societal interest in continued medical research with human subjects, and both injured subjects and researchers/sponsors can face prohibitive costs in litigation over research-related injuries. Implementing a no-fault compensation system for handling serious research-related injuries would remove the risks and burdens of litigation from subjects, researchers, and sponsors; it could also provide the government a means of enticing more research to abide by the ethical guidelines of the Common Rule if doing so were required for a sponsor’s study to be governed by the no-fault scheme.
Based on the biblical text, Job’s community also appears to compensate him of their own will, without being told to do so (e.g., by God). The community’s un-commanded compensation recalls the practice of acting lifnim mishurat hadin, or more generously than the law requires. The example of the community can help open conversation about what it would mean to approach compensation for research injuries through the lens of lifnim mishurat hadin. Research sponsors might volunteer to purchase insurance policies to cover the costs of treating research-related injuries, even if not required to do so by law. For example, Pike noted that the University of Washington has reimbursed subjects for the cost of treating research related injuries since 1979.

4. Modern Readers Often Find Job’s Compensation Inadequate or Unresponsive

A final aspect of Job’s compensation that is useful for thinking about compensating research subjects actually has more to do with readers and the reception of Job than the biblical text itself. Modern readers may find Job’s compensation inadequate or frustrating in two ways. First, they may be frustrated that God answer to Job does not respond to Job’s questions. Job never learns why he suffered: God never tells him what sin he committed to warrant losing everything (because, paradoxically, there is no sin to reveal), and Job never comes to know about the heavenly wager. On the one hand, this frustration might suggest the importance of making sure the compensation responds to the injury in some way. For example, giving all injured researchers some nominal amount of money that cannot cover the cost of treating their injury, or requiring researchers to provide treatment for research-related injuries but allowing them to bill

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381 Job 42:11.
382 A more in-depth discussion of lifnim mishurat hadin can be found in Chapter Two.
383 Pike, 24.
the subjects for that treatment, would be similarly non-responsive and, consequently, unacceptable forms of compensation. On the other hand, this frustration may also indicate a frustrating reality that cannot be avoided: in some cases, it may be impossible to know what precise action caused an injury, and as the shift to a no-fault compensation scheme means setting aside fact-finding missions to determine causation, it may be necessary for injured subjects to give up on the idea of learning what caused their injuries.

A second way in which modern readers may be frustrated by Job’s compensation is that it seems insufficient. For example, God gives Job ten new children—seven sons and three daughters—in an effort to return Job to what he had before Satan’s first test. But when we read this verse through modern eyes, we cannot help note that children are not fungible. The new children do not remove or undo the loss Job feels about the death of his first ten children; they do not bring his first ten children back to life. In the context of compensating injured research subjects, this particular frustration may be channeled both to ensure that compensation amounts are sufficient to cover all or most treatment costs as well as to rein in excessive amounts of compensation.

CONCLUSION

Current law is unable to assure compensation for research injuries, and this state of affairs is unacceptable for both practical and moral reasons. As a practical matter, the absence of mechanisms for compensating injured research subjects has already presented obstacles to NIH sponsorship of collaborative, international studies and may only continue to interfere with

385 Neaton et al., 711-716. Although Neaton’s article focused only on NIH co-sponsorship of clinical trials conducted in Europe, particularly EU member states, Pike mentions India, Mali, Uganda, and Brazil as other countries who insist researchers compensate subjects for research-related injuries. See Pike, 41-43.
NIH or other U.S. sponsors’ international research. Additionally, trying to litigate research injuries—currently the predominant avenue available for injured subjects—costs both subjects and researchers or sponsors extensive time and money. Morally, leaving injured research subjects to bear the costs of treating their research-related injuries perpetuates unfairness.

Regardless of his or her personal intentions when agreeing to participate in a study, a research subject acts for the benefit of society when he or she takes on the risk of harm to his or her body that study participation entails.\textsuperscript{386} As bioethicist Jim Childress argued, “[a] primary concern should be to keep faith and faithfulness with those who act on behalf of and at the behest of society.”\textsuperscript{387} In the context of research subjects, keeping faith and faithfulness mean refusing, as a society, to leave research subjects with the costs of treating research-related injuries.

Reading Job, with special attention to how Job is compensated at the end of the narrative, offered a framework for considering what an ethical compensation system would look like. Four aspects of Job’s compensation that guided this consideration were: (1) the biblical text is ambiguous about whether God heals Job; (2) God compensated Job even though Satan directly inflicted the injuries; (3) Job’s community supplemented the compensation Job received from God; and (4) modern readers may be frustrated by the specific compensation Job received. Each of these aspects of Job’s compensation offered a means of thinking with the story of Job to open up conversation that could sidestep some of the moral gridlock that has prevented the U.S. from implementing systematic compensation for research injuries.

\textsuperscript{387} Ibid., 23.
A predictable, no-fault approach is needed for compensating research injuries. Either U.S. researchers or sponsors must incorporate a clinical trial insurance policy into their research budgets, or the U.S. must create some sort of alternative court with a lower burden of proof and a common compensation fund for handling research injury claims. In order to take an important step forward, compensation policies should initially focus on making sure research subjects do not suffer the financial burden of seeking treatment for research-related injuries and should leave aside questions about compensating for lost wages or other kinds of compensation.

388 E.g., like the no-fault vaccine court established under the National Childhood Vaccine Injury Act.
CONCLUSION

This manuscript addressed two interrelated problems in research with human subjects: (1) over-dependence on informed consent to guarantee ethical research conduct, and (2) the conflation of ethics with regulatory compliance—especially regulations about informed consent procedures. A consequence of this overarching, legalistic emphasis is that research ethics practice lacks sufficient tools or language for addressing ethical considerations that fall between or beyond the reach of regulations and law. For instance, Chapter Three demonstrated that the regnant approach to research ethics is poorly equipped to address the significance of dignitary harms—harmsthat occur despite the absence of physical injury. Because the tort system does not award significant damages for dignitary harms without attending physical injuries, the threat of legal action acts as an insufficient deterrent to the abuse of research subjects that results in dignitary harm. Moreover, I argued that overcoming the challenge of articulating the ethical significance of dignitary harms under a legalistic framework requires thinking about the conduct of clinical research as a profession or practice with internal, ethical goods that include respect for research subjects and their dignity. Chapter Four noted that federal regulations and nuances of the tort system leave many subjects who are injured by their participation in an experiment to personally pay to treat their research-related injuries. After explaining why this scenario is unethical, I argued for a more aspirational approach to compensating research injuries—an approach that assures compensation or treatment for research-related injuries even though the law does not require its provision.

My proposed intervention for improving the ethics of research with human subjects uses religious narratives to reframe and refocus research ethics discourse. Religious perspectives have
typically been absent from research ethics discourse, but I have argued that many religions’ “prophetic voice”—which resists the power of market-based arguments and expresses concern for society’s vulnerable members—can play an important role in shifting research ethics discourse beyond consent and compliance to better address concerns about dignity, exploitation and fairness. Religious concepts and narratives help shift attention beyond obtaining informed consent without undermining the importance of consent for research ethics. Religious narratives thus offer a way to highlight that informed consent is necessary but not sufficient for ensuring research is performed ethically. This approach to consent is intertwined with approaching regulatory compliance as also necessary but not sufficient for conducting ethical research. In using Jewish sources as a framework, the Talmudic concept of lifnim mishurat hadin is especially helpful for analyzing highly regulated practices like research with human subjects because acting lifnim mishurat hadin involves doing more than the letter of the law requires without violating the law.389

I have utilized Jewish sources, particularly Jewish narratives, to enrich research ethics discourse. My approach differs from other appeals to narrative in Jewish bioethics by starting with biblical stories rather than stories found in the Talmud. Though I begin with biblical narratives, which are not unique to Judaism, I develop distinctively Jewish contributions to research ethics discourse by building upon the biblical foundation with the long tradition of rabbinic and later Jewish commentaries on these narratives.

Biblical narratives are useful mechanisms for introducing religious sources into research ethics discourse for two reasons. First, biblical narratives are part of a common scriptural

tradition shared by Judaism, Christianity, and Islam. Thus, building a Jewish research ethic from biblical narratives helps to ensure the ability expand religious research ethics discourse to involve scholars working on other Abrahamic traditions. Second, biblical narratives pervade American culture, particularly literature and film; starting with familiar biblical narratives thus facilitates the incorporation of religious perspectives into current, secular research ethics discourses. My method also prioritizes biblical narratives that are ethically fraught and problematic. These “troublesome” texts have inspired an abundance of commentaries and interpretations, rendering the biblical text’s meaning indeterminate. This indeterminacy creates a safe space for conversation, debate, and creative meaning-making, all of which are necessary for developing a more robust research ethics discourse and practice.

The Akedah and the book of Job proved especially useful for discussing ethical concerns that currently fall beyond law’s reach, because these narratives and the Jewish interpretive traditions surrounding them tap into the same sense of horror or frustration elicited by unethical experiments such as the Jewish Chronic Disease Hospital case and the U.S. Public Health Service’s STD studies in Guatemala.

What About Law?

Despite its limits, law retains an important role in clinical research ethics. To reiterate Robert Cover, “[l]aw may be viewed as a…bridge linking a concept of a reality to an imagined alternative—that is, as a connection between two states of affairs, both of which can be

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represented in their normative significance only through the devices of narrative.”  

Thus, the narratives of the Akedah and Job may alter the way we understand the status quo or open our imaginations to new alternatives, but law is an important means of turning imagined alternatives into reality. Cover continued, “‘[b]y themselves the alternative worlds of our visions…dictate no particular set of transformations or efforts at transformation. But law gives a vision depth of field….”  

As nice as it would be if the insights gained from thinking with religious narratives automatically produced changed behavior—for example, if thinking with the story of Job prompted researchers to proactively purchase clinical trial insurance so subjects would not bear the cost of treating their own research-related injuries—law can be instrumental in bringing about behavioral change not just through regulation but also by encouraging certain desirable practices (without necessarily mandating them). I will conclude this section by discussing some of the ways law may be channeled to promote some of the changes recommended in previous chapters.

The Professionalization of Research: Researcher Character and the Virtue of Respect  

Chapter Three’s discussion of the Akedah and the Jewish Chronic Disease Hospital case addressed the importance of cultivating researchers’ respect for their human subjects. The chapter proposed changing the way clinical researchers learn research ethics by emphasizing the history of research with human subjects to develop a sense of research as a profession—or, in MacIntyre’s terminology, a practice.  

According to MacIntyre, “[t]o enter into a practice is to enter into a relationship not only with its contemporary practitioners, but also with those who

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392 Ibid.  
393 See MacIntyre, 190.
have preceded us in the practice, particularly those whose achievements extended the reach of the practice to its present point.” To this I would add that entering a practice also means entering into a relationship with individuals whose actions betrayed or set back the practice, and taking on the responsibility to avoid repeating their mistakes or abuses. In the context of research with human subjects, this means it is not enough to familiarize researchers with relevant regulations; rather, researchers should also be familiar with the research scandals that contributed to the regulations’ adoption.

Law, specifically the current federal regulatory system, could be used to encourage the professionalization of research with human subjects. For example, the NIH already requires all individuals involved in designing and conducting a trial with human subjects to fulfill an education module on research regulations and subject safety before NIH funds are disbursed for a study. While individual institutions may develop their own curricula to fulfill the education requirement, the NIH Office of Extramural Research developed its own course, available online, which fulfills this requirement. The NIH could amend its education requirement to include a historical component focusing on descriptions and ethical analyses of past research abuses in the curriculum. Alternatively, as an initial step forward, the NIH could revise its own course curriculum without amending the education requirement. Since researchers can confidently expect the NIH-designed course to meet regulatory requirements, researchers and/or their institutions may choose to utilize the NIH-designed course rather than develop their own

394 MacIntyre, 194.
curriculum. The NIH could facilitate the development of research as a practice merely by expanding the course’s content to include a historical component and making the course easily available for researchers.

No-Fault Compensation for Injured Research Subjects

Moral gridlock has prevented lawmakers from designing and implementing a national no-fault compensation system for research injuries. Although some institutions, such as the University of Washington, have established programs to cover the medical costs of treating subjects’ research-related injuries, laws must change to create any national or state-level alternative compensation schemes. The first step forward may be passing new laws or regulations that encourage researchers or institutions to compensate injured research subjects without requiring them to do so. Perhaps the NIH could offer expedited or prioritized review of grant proposals to those that include provisions for compensating research-related injuries. Additionally, the NIH could maintain a list of study sponsors who carry clinical trial insurance to cover subjects’ research-related injuries on the ClinicalTrials.gov website; if making this information available for potential research subjects affects study recruitment, more research sponsors might consider carrying clinical trial insurance, especially for studies that involve higher levels of risk.

397 See Henry, 412; also see discussion of moral gridlock in Chapter Four of this dissertation.
399 ClinicalTrials.gov is an NIH website that contains a searchable database of clinical trials with human subjects.
Adding More Voices from Religious Ethics

This dissertation is a first step toward including religious ethics’ missing voice in discussions about the ethics of using human subjects for medical research—but there is still more work to be done. I selected the Akedah and Job in part for their accessibility and familiarity across Abrahamic religions, to begin laying the foundation for a multivocal religious discourse on clinical research ethics. I hope scholars of Christian and Muslim ethics bring their own traditions’ interpretations of these texts, as well as additional texts from their canons, to bear on the ethical questions raised throughout this manuscript: the limits of informed consent, the significance of dignitary harms, and what is owed to injured research subjects. For instance, although the biblical text describes Job as an exceedingly wealthy man from Uz,400 the Job of Christian liberation theology is equated with the oppressed and the poor in Latin America.401 The Job who suffers is not a wealthy man who has fallen on hard times, but a poor man who is made even poorer as the casualty of a struggle or challenge between more powerful entities (God and Satan). Thus, interpretations of Job found in works of liberation theology may further draw our attention to the plight of subjects who are injured by their participation in U.S.-sponsored research taking place in the developing world: subjects who are already poor and often already sick; who may bear an even greater burden if they are injured by their participation in an experiment without the guarantee of free treatment or rehabilitation; and whose communities may, in many cases, be too poor to afford treatments proven effective by their own risk-taking in experiments but intended for the markets of wealthier countries.

400 Job 1:2-3.
Another reason I turned to the Akedah and Job as framing narratives for this inquiry is that they are disturbing texts. It is not just the text, but the reader’s struggle with the text, that produces the rich engagement with ethical problems that religion offers to bioethics more broadly. As Zoloth noted, “Biblical texts, with their unsettled questions and the dark lacunae and the flawed heroes are a template for the lacunae of medicine and allow for a midrashic, interpretive, and contextual analysis of the medical narratives that we are called on to reflect upon.” In the context of clinical research ethics, these “unsettled” and unsettling texts help to see the ethical questions presented by research with human subjects as questions emerging from the lived narratives of subjects and researchers, not just from the application of rules or regulations. It is the struggle with problematic passages in religious narratives, and engagement with the struggles of earlier generations of readers with these passages, that cultivates the prophetic voice of resistance and critique of current research practices and the prophetic warning of consequences that may result if practices do not change. Growing the presence and contributions of religious voices within research ethics discourse, across traditions and locations, will require a commitment to struggling with problematic texts in order to propose creative policy solutions that advance research ethics beyond compliance and over-reliance on informed consent.

402 See Zoloth, “Faith and Reasoning(s),” 261.
403 Ibid. For more general discussion of the role of lacunae in the interpretation of biblical narrative, see Auerbach, 3-23.
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