

Duquesne University

Duquesne Scholarship Collection

Electronic Theses and Dissertations

Spring 5-10-2021

Clash of Titans: An Ethical Framework Towards Limitations In Religious Accommodation Within Healthcare

Yoelit Lipinsky

Follow this and additional works at: <https://dsc.duq.edu/etd>



Part of the [Bioethics and Medical Ethics Commons](#)

Recommended Citation

Lipinsky, Y. (2021). Clash of Titans: An Ethical Framework Towards Limitations In Religious Accommodation Within Healthcare (Doctoral dissertation, Duquesne University). Retrieved from <https://dsc.duq.edu/etd/1983>

This One-year Embargo is brought to you for free and open access by Duquesne Scholarship Collection. It has been accepted for inclusion in Electronic Theses and Dissertations by an authorized administrator of Duquesne Scholarship Collection.

CLASH OF TITANS: AN ETHICAL FRAMEWORK TOWARDS LIMITATIONS IN
RELIGIOUS ACCOMMODATION WITHIN HEALTHCARE

A Dissertation

Submitted to the McAnulty Graduate School of Liberal Arts

Duquesne University

In partial fulfillment of the requirements for
the degree of Doctor of Philosophy

By

Yoelit Tikvah Lipinsky

May 2021

Copyright by
Yoelit Tikvah Lipinsky

2021

CLASH OF TITANS: AN ETHICAL FRAMEWORK TOWARDS LIMITATIONS IN
RELIGIOUS ACCOMMODATION WITHIN HEALTHCARE

By

Yoelit Tikvah Lipinsky

Approved December 18th, 2020

Joris Gielen, PhD
Director, Center for Healthcare Ethics
Associate Professor of Healthcare Ethics
(Dissertation Director)

Gerard Magill, PhD
The Vernon F. Gallagher Chair
Professor of Healthcare Ethics
(Committee Member)

Joris Gielen, PhD
Director, Center for Healthcare Ethics
Associate Professor of Healthcare Ethics

Peter Osuji, C.S.Sp., PhD
Associate Professor of Healthcare Ethics
(Committee Member)

Kristine Blair, PhD
Dean, McNulty College and
Graduate School of Liberal Arts

ABSTRACT

CLASH OF TITANS: AN ETHICAL FRAMEWORK TOWARDS LIMITATIONS IN RELIGIOUS ACCOMMODATION WITHIN HEALTHCARE

By

Yoelit Tikvah Lipinsky

May 2021

Dissertation supervised by Dr. Joris Gielen

In late October 2017, a young Canadian Jewish man was at the center of a storm that involved ethics, religion, law and policy. He had been unconscious for a month and doctors deemed him brain dead. The Jewish community, and his family, wished to keep him on life support, since their religion did not consider brain death to be ‘death.’ This clash between medical and religious perspectives poignantly illustrates the unique and growing challenges posed by religious observance in Canada’s secular healthcare system. A similar story is found in America. In December 2019, a story was published demonstrating fears that if a Catholic hospital merged with its rural secular peer, women requiring (or requesting) abortions would no longer receive them. Often, Catholic hospitals are in rural areas and the only healthcare institutions for miles. Both health professionals and religious adherents share the belief in the primacy of their mandated point of view in decision making in critical care and end of life

situations. A multicultural society boasts a polyglot of religions, which enjoy an entrenched legal guarantee of religious freedom; subsequently, there is a call to ground bioethics within secularism. This dissertation explores various cases and scenarios in medicine where Jewish and Catholic ethics clash with secular bioethics. This dissertation does three things: promote a ‘dual approach’ towards accommodation; create a concrete definition for ethical undue hardship and; create a framework for ethical limitations on religious accommodations at both the individual and institutional level.

ACKNOWLEDGEMENT

B'H

I have been lucky in friends and family. I have also been lucky in professors and mentors.

Remarkable thanks and gratitude must be extended to Dr Joris Gielen, my dissertation supervisor. Your guidance, wit and keen edits helped to bring this paper to fruition. It is very difficult to do a thesis amid the pandemic; even more so from a distance! You have made it easy and enjoyable. Thank you. Further thanks for the professors at the Center for Healthcare Ethics, in particular to Dr Magill, a wonderful teacher and scholar.. A huge thank you and hug to Glory Smith who championed me from the beginning and buoyed me throughout the entirety of the program.

I also am grateful for the mentorship and friendship of Dr Jonathan Weinkle. It is truly physicians like him who embody the *art* of medicine. His smile, good humour, intelligence and passion for patient care is truly a wonder to witness. He taught me how to truly listen to patients and allowed me to experience the wonderful diversity of cultures at Squirrel Hill Health Center. Another thank you goes to some professors from my past—Maria McDonald and Tirzah Meacham who offered guidance, coffee, and enthusiasm for my progress. Thank you also to my Pittsburgh friends who enabled me to make Squirrel Hill my home. My Shabbatot were less lonely, my living room was filled with laughter and I always had someone to talk to and depend upon.

Huge thank you to my Toronto contingency of cheerleaders and supporters. I appreciate the love and support. Your check-ins, phone calls, virtual dinner sessions and visits have kept me going. I value your making time for me, despite your very busy lives.

Words cannot express the extent of my appreciation for my family, who who make up the foundation of my successes and my character. To my darling Mommy and Daddy, you have always encouraged me to succeed and have empowered me to do so. Your emotional guidance and safety net of love have allowed me to weather to weather any storms. Thank you—this dissertation is as much yours as it is mine. I respect you and love you deeply. To my brothers Baruch and Yehezkel, who have also supported me, encouraged me and provided me lots of laughter, coffee and love. I love you both.

And finally, to Ariel. You came around when I wasn't looking and was everything that I needed and more. Your acceptance, love, kindness and support is so appreciated and valued. You have made these final few months of hard work sweeter with your presence. Love you.

ברוך אתה ה' אלוהינו מלך העולם שהחינו וקימנו והגיענו לזמן הזה.

TABLE OF CONTENTS

<u>Abstract</u>	i
<u>Acknowledgement</u>	ii
<u>1. Introduction</u>	1
1.A. Secularism and Religious Pluralism: A Tale of Two Ethics?	5
1.B. Defining Undue Hardship in Accommodation in Healthcare	8
1.C. Religious Barriers at the End of Life	12
1.D. Religious Barriers in Clinical Care: Specific Cases and Circumstances and the Confines of Cultural Competency	17
I.E. Religious Evaluation and Accommodation during Secular Ethics Consultation: Towards a New Evaluative Scale	36
<u>2. Secularism and Religious pluralism: A Tale of Two Ethics?</u>	43
2.A. Secularism and Secular bioethics	46
2.A.i . ‘Secular bioethics’ and religion	49
2.B. Private Practice within Public Spheres	55
2.B.i. Rawls ‘Public Good’ and religion	58
2.B. ii. Public Good, public schools and religion	61
2.B. iii. Applying Rawls and ‘public good’ to religion and bioethics	62
<u>3. Defining Undue Hardship in Accommodation in Healthcare</u>	66
3.A. Understanding Undue Hardship and Reasonable Accommodation in Canadian and American Legal Contexts	67
3.A.i. Individual Moral Agency and Undue Hardship	70
3.A ii. Religious and Personal Ethics	73
3.B. Organizational Moral Agency and Undue Hardship	75
3.B. i. Institutional Moral Agency and Faith	76

3.B.ii. Case Study: Undue Hardship and Organ Donation	81
3.B. iii Case Study: Undue Hardship and Abortion	89
<u>4. Religious Barriers at the End of Life</u>	99
4A. Pain Palliation, Pikuach Nefesh and Double Effect	108
4.A.i Double Effect in Catholicism	113
4.A.ii Pikuach Nefesh in Judaism	118
4.B. Pediatric Palliative Care	128
4.B.i Religious and Educational Barriers to Pediatric Palliative Care	135
<u>5. Religious Barriers in Clinical Care: Specific Cases and Circumstances and the Confines of Cultural Competency</u>	148
5A. Religiously Triggered: Background to the Hasidic Community and Their Nuanced Mental Illness	151
5.A. i. Hasidic Men: ‘Social Deviance, ‘and complex mood disorders	156
5.A.ii. Postpartum depression, Fertility OCD, and eating disorders among Hasidic women	159
5.A. iii Hardship and religious accommodations in healthcare: whither cultural competency?	167
5 B. Public Health or Personal Interest: Vaccines, and Genetic Editing/CRISPR	171
5 B.i. Religious right? HPV vaccination opposition in Judaism and Catholicism: Flipped hardship?	175
5.B.ii Jewish approaches towards CRISPR: Flipped hardship?	181
5.B. iii. Catholic approaches towards CRISPR: Flipped hardship?	195
5C. Foresight: Onco-fertility Religious Accommodation in Clinical Care	197
5.C.i. The process of preserving fertility in pediatric patients	198
5.C.ii. Fertility and Reproductive Technology in Judaism	199
5.C.iii. Fertility and Reproductive Technology in Catholicism	201
5.C. iiiii. Secular Ethical Concerns	202

5.C. v. Pediatric decision making and fertility preservation	203
5.C. vi. Religion, Oncofertility and Undue Hardship?	206
<u>6. Religious Evaluation and Accommodation during Secular Ethics Consultation: Towards a New Evaluative Scale</u>	209
6 A i: The current scope of measuring religion in clinical ethics consultations	211
6 A ii: Clinical ethics consultations: does religion even matter?	213
6 A iii Medicine and miracles: autonomous choices?	216
6 B: Children, religion and clinical consultations: the outliers	219
6.B i. Assent and the limitations of ‘mature minor’ assessment tools within religion	225
6.B. ii. Catholic and Jewish approaches to child assent, maturity, & miracles	231
6.B. iii. Applying Undue Hardship: voluntary participation in clinical research and religious accommodation	234
6 B iiiii Finding the balance and applying the new theory : balancing religion and medicine within a clinical consultation	236
<u>7. Conclusion</u>	251
END NOTES	252
BIBLOGRAPHY	276

Introduction

In late October 2017, a young Jewish man was at the center of a storm that involved ethics, religion, law and policy. He had been unconscious for a month and doctors deemed him brain dead due to a cardiac arrest after a severe asthma attack. The ICU team wished to remove him from life support and the family refused outright, citing their Jewish Orthodox faith not recognizing brain death. Subsequently, the case made its way through the court systems, with the Hospital maintaining its decision and the family asserting their religious rights. The patient's family was insistent that their actions were fulfilling the ultimate Jewish commandment of *pikuach nefesh*—saving a life, since to them, he was still alive.¹ This clash between medical and religious perspectives poignantly illustrates the unique and growing challenges posed by religious observance in Canada's secular healthcare system. It is vital to address these issues for demography shows these they will become increasingly prevalent.

Often, medical workers and religious adherents share the belief in the primacy of their point of view in decision making in critical care and end of life situations.² At critical moments differing views between religious families and medical professionals often lead to awkward conversations or a complete lack of understanding as time ticks by and illness demands responses. These tensions will be brought to a head by two demographic trends. First, rising immigration rates produce an increasingly multicultural society. This development brings with it a polyglot of religions, which enjoy a safe, legal guarantee of religious freedom, and an appreciation of varied religions and cultures, particularly in Canada and the United States of America. Second, the population is ageing and end-of-life decision making will be at the forefront.³ However, religion permeates all medical decision making. It is not isolated to the end of life.

This thesis will explore the limits of both individual religious accommodation and institutional moral culture. Religion colours medical decision making at both the individual and institutional levels.⁴ Thus, the question is whether and how to accommodate religion when 'best medical practice' is at risk. This communication schism still holds in a religious healthcare institution as a religious-moral culture dictates medicine. Religion influences attitudes in medicine and medical decision making. The problem is complex and interdisciplinary, involving theology, law, medicine and policy. Thus, this thesis is equally interdisciplinary in an attempt to fully unpack and analyze the situation at hand. This results in a myriad of literature from several distinct disciplines. Further, while Canada and the United States are comparable in terms of medical protocols and progress, the individual structure of each healthcare system provides its unique challenges. This thesis will draw from all this literature, which, despite its vast subject scope, lacks a defined framework that limits religious accommodation. While religion and religious expression is thriving in North America, there is a paradoxical, subsequent, call within the field of clinical ethics literature to ground bioethics within secularism.⁵ To wit, the current discourse posits that religious accommodation should be limited in healthcare; part and parcel of living within a secular liberal democracy. As this dissertation shall discuss in detail, secular ethics cannot strip itself wholly from religious underpinnings. This thesis will explore whether and how there can be an ethical limit to religious accommodation at both individual and institutional jurisdictions when 'best medical practice' is at risk. Mainly, these are clashes between two codes of ethics. The thesis will utilize both Catholic and Judaic medical ethics traditions and look at bioethics in both America and Canada.

Law literature from Canada analyzes previous court cases that involve a clash of religious and medical ethics, usually involving life support systems. Ultimately, the law literature evolves

into a lengthy discussion of the *Charter of Rights and Freedoms*, which is legislative protection of individual religious rights, and whether and how to balance individual rights within a pluralistic healthcare system.⁶ Courts have yet to rule in these cases since the patient often passes away during the legal process. While the patient's death may stall or even satisfy the legal dispute, it does not resolve the ethical dilemmas. Whereas legal literature continues to call for distinct definitions and accommodation limits, they do not currently exist. Moreover, placing these disputes within the court system fails to recognize that the clashes between religion and medicine is an ethical dilemma over and above a legal one. The courtroom is truly no place for these disputes since it ultimately avoids understanding the foundation of ethics that creates this disagreements.

Subtle allusions to differing ethics can be teased out within the discussions in policy literature. In fact, Canadian policy literature often notes the secular nature of the Canadian shared healthcare system and resource allocation issues.⁷ A definition of what 'reasonable' accommodation entails lacks in law, as observed via court cases that present the idea/concept of 'undue hardship.' Undue hardship is roughly definable and determined on a case by case basis, with the onus being placed mainly on an institution to prove hardship. In legal arguments, undue hardship is used mainly in cases involving addiction, education, and employment.⁸

In the United States, religious accommodations exist on a state-by-state or institutional basis. Thus, creating a universal framework for ethical accommodation becomes more difficult. Further, the law is different according to which State a family resides in. Further, many insurance companies offer stumbling blocks as well, since many will not pay for life support once a patient is declared brain dead (again, most clashes between religious and medical ethics arise at the end of life.) Policy again attempts to mediate a discussion of ethics, particularly when classifying

death. This is most apparent in the state of New Jersey, which has a large population of Orthodox Jews and which allows families to get a second opinion on the patient's diagnosis and permits them to move a patient to a private facility even if they are declared brain dead.⁹

The theological component of this thesis is detailed and complex. This thesis works upon a strong foundation in Judaic theology. In Judaism, this means a close reading of *halakha* (Jewish legal/religious laws) sources itself alongside interpretations from rabbinic sources. Further, this thesis is fluent in the application of the religious-legal sources to newer medical technology that rabbis have yet to explore. The thesis also places itself on the shoulders of Jewish rabbinical scholars in medical ethics. Further, most modern *Jewish legal* decisions can be found within Israeli health policy, since the *Rabbanut* (A collective of Jewish rabbis learned in religious law,) oversees the health ministry. Thus, innovative Israeli technology (such as an automated life support withdrawal machine,) attempts to fulfill the ethics of both *halakha* (literally, the Law or 'the Way' = Jewish legal and religious Law) and 'best practices' in medicine. However, some rabbis who write on medical ethics are ignorant of these innovations, or else, are not fluent enough in the realm of medicine. Importantly, this thesis is not a theological exegesis and must be cautious about falling into that chasm. However, the literature within Jewish bioethics is divergent with 'majority' and 'minority' opinions. Jewish ethics is often 'behind' medical progress. Thus, the thesis attempts to create possible and distinctive Judaic approaches towards technology like CRISPR. Additionally, there are often oversights and over-generalizations in Jewish ethics, most notably with the concept of *pikuach nefesh*, which will be explained later in this dissertation. Moreover, as with any religious tradition, overgeneralizations of believers can be made. This thesis attempts to align the principles of secular medical ethics with the principles of Jewish ethics, causing them to speak *with* each

other, as opposed to at each other. This dissertation also discusses Catholic circumstances and institutions. Specifically, this thesis also presents an analysis of Catholic hospitals, who exercise Catholic moral traditions in their approach to healthcare. To compliment this, there is a large body of literature exploring conscientious objection within healthcare in Catholic institutions. Ultimately, this dissertation will be creating an argument towards limits of accommodation even within religiously based, rural hospitals. As such, there is no literature or policy which attempts such clear demarcations .

Finally, bioethical literature on the limits of religion is almost impossible to find, outside of discussing Jehovah's Witnesses. Instead, the importance of cultural competency and the integration of religion/spirituality is encouraged.. Some ethical literature is written by physicians who analyze a case or situation they have personally attended. These articles are biased towards paternalism or else, insistent upon the physician decision being the 'correct' approach. Some articles state the importance of coming to a team decision or calling in an ethicist to help negotiate severe clashes.¹⁰ Nevertheless, there is a lack of definable frameworks or modalities of assistance. It is not enough to state there is a problem; this thesis actually attempts to create a viable solution.

1.A. Secularism and Religious Pluralism: A Tale of Two Ethics?

The first chapter will lay the philosophical foundation for the application of this unique ethical limitation framework. In America, public schools are legally obliged to limit religious expression that becomes either dangerous or considered the antithesis to best education principles. Discussions of several cases indicate how court systems have applied limits to religious accommodation or expression.¹¹ This borrows directly from the Rawls' ideal of public good and religion in the public sphere. While American public schools exemplify this, the same

theory can and should apply to medical practice. This thesis will neatly relate these parallels; the subsequent chapters will elucidate and build upon the equivalences. For some physicians, religion and ethics are dissimilar. Ethics is logical reasoning whereas religion is faith.¹² Nonetheless, ethics and religion are bedfellows in medicine, certainly within North America. A neat paradox is readily apparent. Whereas the forbearers of bioethics may have been theologians, the new generations of ethicists are endeavoring towards a shared [secular] morality.¹³ In a multicultural world, the philosophical notion of ‘indigenous pluralism’ can aptly describe the current environment in hospitals. Further, this philosophy can assist in coping with issues that may arise when different religions hold different views on death and dying.¹⁴ Thus, indigenous pluralism can offer some guidance. While a conscience clause acknowledges the belief system of various groups, indigenous pluralism forces the religious group to consider the beliefs of *others* as well. While this is a strong philosophy independently, it strengthens the purpose of conscience clauses. Indigenous pluralism is at its core a two-way mirror. It gives various religions and cultures the right to their beliefs so long as they respect the religion and cultures of others. Respect is merely tolerance. It does not necessarily mean acceptance.¹⁵ Indeed, religious beliefs should be upheld but only when considering the cost to the greater society. Together, these create a balanced system: while the State recognizes the religious objection to brain death, the ultimate cost to society cannot be ignored. This further allows for gradations in interpretation of religious law and ethics since not all Jews, Muslims or even Christians practice alike. A conscience clause, via indigenous pluralism, allows for hermeneutic diversity.¹⁶ It may also lead to policies and laws being changed to reflect this multiculturalism. Hence, religion does have feasible impact on laws and policies. Whether indigenous pluralism serves as a setback for secularism however, remains to be seen. Additionally, indigenous pluralism can be interpreted

as simple but it is far from an easy fit. It may not be a truly practical solution to already existing policies and law.

Public schools are free of religion and meant to serve the public; offering education that is free and fair for all.¹⁷ Children are free to form extracurricular religious groups that may engage in prayer, activities and the like. These are not sanctioned by the public school per se, but offered on a voluntary basis. Students who self-identity as religious and wish to participate in these groups may do so voluntarily.¹⁸ The public school thus acts as a passive observer and will intervene if there is a concern of student safety.¹⁹ While public schools must accommodate religion, they are responsible for generalized education and must step in when religious accommodation jeopardizes this objective. Further, public schools specialize in children and their ‘best interests’ in education. When voluntary religious groups are contrary to this interest, public schools are within their right to sanction the group.²⁰ Education is a public good. Since the religious groups are formed under the public good, it has to conform to the rules and expectations of that good. Once the religious group imposed on public values, the school was within its ethical imperative to ban it. Legal arguments for accommodation are unfounded since the establishment of the group itself was voluntary. By forming the group, it was silently understood that they would conform to the notions of the public good.

The notion of public good is ascribed to philosopher John Rawls. His theory provides an excellent structure for the limitations of religious accommodations. Rawls describes a more nuanced theorem, whereby the social contract is “rights-based.”²¹ In order to subscribe to this social contact theory, there are basic assumptions made about what is considered a ‘right.’ To that end, Rawls institutes the notion of ‘original position;’ whereby there is an agreement that there is “...something essential to the activity of moral reasoning...” but also conceived (and

decided upon,) socially, as a collective.²² Presumably, the collective has similar views and moral reasoning which allows them to reach fair justice. This is the understanding of simple social contract theory and therein lays the essential problem. Socialized health care systems may be considered micro social contracts. Social contract theory, particularly Rawls' assumes that all individuals possess the same moral core when stripped of all circumstances.

Just like public schools, public healthcare institutions can accommodate religion. This is limited to the realm of required medical services. Rawl's Veil of Ignorance fits neatly into this conversation as well. For Rawls, justice is equated to fairness; personal decisions and judgments are made in (optimistically) total impartiality. Behind one's 'Veil of Ignorance' the adjudicator is shrouded from personal circumstances and can thus focus on the decision to an equitable and fair judgment, unbiased by other factors.²³ However, this is not the case in a multicultural society. "The right and the good" of society is applicable only to those who can don this veil and I shall attempt to prove that religious believers don a veil of belief instead. Yet, the veil of belief cannot exist in a voluntary setting. As such, to participate in medical research, religious individuals must remove their veil of belief. Within a healthcare system, they are being provided public goods. The burden of undue hardship cannot be placed on the healthcare institution.

1.B. Defining Undue Hardship in Accommodation in Healthcare

The next chapter will explore a legal term called 'undue hardship' and how it can apply to individuals (or institutions) that are experiencing an ethics conflict. Undue hardship further adds to the foundation laid in the previous chapter. The application of undue hardship will be via two case studies: institutional (abortion) and individual (organ donation.) Moral agency and moral culture often betray tensions within a healthcare institution. In a religious hospital, the tension is a permanent undercurrent. Religion is a binding community with individual moral codes.²⁴ In a

religious hospital, a physician is a dual agent representing best medical practice alongside the religious moral culture of his institution.²⁵ Under a religious healthcare lens, there are difficulties surmounting the concepts of moral agency, moral complicity and moral cooperation.

In a secular healthcare setting, there is equal tension. Conflict between an individual's moral agency and an institution's moral culture can undermine an organization's mission. Moreover, a religious individual's moral agency may be counterpoint to medical treatment. Thus, the crux of the argument becomes this important juncture. Indeed, at what point does an individual's moral agency elicit undue hardship? Counterpoint to this is the concern of religious organizational moral culture which may elicit undue hardship on individual patients. Individual moral agency and organization moral culture are part of the same coin. These can best be illustrated via the themes of status, sexuality, fertility and abortion. Status within religion, including paradoxes between religious and personal ethics, are indicators of individual moral agency. Indeed, exploring these illustrative examples showcase how religious traditions can create hardship for moral agency.

A telling aspect of organizational moral agency is whether and how abortions are considered. According to Catholicism, both mother and fetus share equal right to life.²⁶ Judaism places responsibility of maintaining the mother's health above the fetus.²⁷ As a result, whereas abortion is allowable within Judaic law, a religious and medical committee nonetheless supervises it in Israel.²⁸ For Catholicism, the sanctity of an unborn life has no parallel. The fetus is respected person, from the point of gestation.²⁹ Indeed, while right to religious freedom is sacrosanct, it may compromise best medical judgement; rigidity in religious healthcare may be risking patient care. The construct of moral agency within a healthcare setting is significant. Indeed, for a secular hospital, the ethical definition of undue hardship rests on providing the best

standard of medical care. For religiously-mandated hospitals however, greater weight is placed upon faith. Abortion is a contentious issue in both Judaism and Catholicism. Yet, each religious tradition contextualizes the onus of undue hardship differently.

Abortion was legalized in Israel in 1977.³⁰ The Israeli Abortion Law has four categories that permit abortions. These categorizations are based on careful analysis and interpretation of source-texts. Upon close analysis, all four categories place the desires of the mother tantamount to the fetus.³¹ The physicians' value a patient's autonomy over and above the fetus.³² The 'abortion committee' anecdotally professes the significance of this Jewish law places the importance of having children upon the man. Childbirth is life threatening. Thus, the Law does not oblige her to take risky ventures.³³ While Judaism does not encourage abortion, it is a viable option, especially for the health of the mother. While the fetus does have value its value is lesser than the mother's.³⁴ Whereas all religious hospitals refers patients to the committee, not all abortions are permitted.³⁵

Conversely, Catholicism considers undue hardship staunchly on the fetus. Anecdotes refer to non-Catholic physicians who are unsure about whether they can refer a patient to safe place to have an abortion.³⁶ While religious physicians must refer a patient in a timely manner, physicians working in a Catholic hospital are barred from doing so.³⁷ For Catholicism, the sanctity of an unborn life has no parallel. The fetus is a respected person, from the point of gestation.³⁸ Thus, the burden of undue hardship is placed upon the fetus, except for a Double Effect cases. Physicians who deem abortions medically necessary are denied the right to perform them, due to the Catholic Directives, with the exception of situations that are allowable under the Principle of Double Effect.³⁹ Some Catholic theologians wish to extend the allowance of abortions to mothers who show mental or physical objection to carrying the fetus.⁴⁰ Some fear

the loss of autonomy, specifically if the pregnancy was due to rape or otherwise unwanted.⁴¹

Abortion within a Catholic context is differently complex. Some healthcare providers working within the Catholic system may find difficulty with abortions being generally prohibited. Some physicians who find themselves medically opposing the *Directives* in certain cases ultimately resign from the Catholic healthcare system.⁴² According to a recent study, physicians at some Catholic hospitals had difficulty managing ectopic pregnancies as per best medical practice.⁴³ Catholic ethicists advise treatment without taking ‘direct’ action towards the embryo. According to the study, these patients lacked full choice of options and were exposed to unnecessary risk.⁴⁴

Scarcity and religious traditions complicate matters of organ donation. While some hospitals or even countries are considering a pay-for-donation scheme, most healthcare institutions rely on altruism.⁴⁵ Religious patients complicate matters at both the donor and recipient level in a secular hospital. Judaism and Catholicism stand on the religious obligations towards charity, justice and saving lives. Thus, it would be the ultimate good deed for a Jewish or Catholic person to donate their organs. Judaism presents a problematic approach towards organ donations. According to the Talmud, deriving benefit from the dead, or mutilating the dead is strictly forbidden. Further complicating the situation is Judaism’s traditional lack of acceptance of brain death. In North America, most Orthodox Jews are ‘living donors’ due to *halakhic* considerations.⁴⁶ This limits donation to organs like livers or kidneys. Perhaps then unsurprisingly, Israel ranks as among the lowest in organ donation. Generally, Catholic teachings, through the Pope, capitalize on the altruistic nature of organ donation. Catholicism does permit organ donation, however with understood ethical barriers. These include mistaken diagnosis of death; a prohibition surrounding removing vital organs from the living and; a fear of progressing towards removing organs from severely disabled persons.⁴⁷ Judaism and

Catholicism share trepidation surrounding a brain-death diagnosis, which is imperative for heart donation.⁴⁸ The Vatican affirmed brain death to be permitted within Catholicism; Judaism recognizes brain death however certain communities within Judaism do not.⁴⁹ Organ donation after cardiac death is supported by the Vatican.⁵⁰ While Orthodox Israelis often do not donate organs, they are willing recipients of organs. Consequentially, Israeli hospitals must acquire organs from around the globe, at great financial cost.⁵¹ To mitigate this, Israel enacted the *Organ Transplantation Law* in 2008.⁵² The primary concern with donations rests again on the concept of *goses* (a person actively dying cannot be touched or hurried towards death.) . Shortening a *goses* ' life is murder within Judaism. The Talmud bluntly illustrates this by terming the person who closes a *goses* ' eyes as he is dying as a murderer. Modern Talmud scholars have attempted to re-interpret *goses* towards 21st century bioethical concerns.⁵³ Part of the religious-legal difficulty surrounding the *goses* is the ambiguity surrounding a *goses* ' classification within modern medicine.⁵⁴ While a *goses* is traditionally dead within “three days time”, this timeframe is refuted in other notable texts.⁵⁵ Rabbi Feinstein rules that if there is no longer an ability to cure a patient (and only the ability to extend his life for a short while), the physician may not treat the patient.⁵⁶ The Israeli government is thus caught betwixt and between. *Halakhic* protections of *goses* are strong; the lack of donations stronger still.

1.C. Religious Barriers at the End of Life

The fourth chapter will delve into a theological-ethics discussion of common barriers that religion poses to modern medicine. It is tracing these barriers through the ethics of end-of-life decisions since this is ultimately where most conflict can arise. This is demonstrated vis-à-vis the concept of Double Effect and *pikuach nefesh*. The chapter will briefly survey the end -of- life for pediatric patients as well and how they are affected by religious ethics. This chapter will also

introduce the notion that accommodation is very much a dual-approach. Religious context may taint how to approach the end of life. Indeed, religious patients may impose barriers that impede ‘best practice’ in healthcare. These barriers may also contribute to the institution encountering undue hardship; a balance between accommodation and medicine must be found.

Both Orthodox Judaism and Catholicism have parameters around the preservation of life.⁵⁷ This is complicated by attempts to palliate pain. As such, both traditions caution physicians to walk a fine line between treating pain without hastening the death of a patient. While the intention of a physician may be to erase pain, the medical reality is that the pain treatment may bring about death.⁵⁸ Catholic theology uses a principle called Double Effect to determine whether a medical intervention can proceed, even with moral risk.⁵⁹ Orthodox Judaism has an overarching principle of ‘*pikuach nefesh*’, which literally translates into saving or guarding a life. Traditionally, all other Judaic tenets are pushed aside in favor of saving a life.⁶⁰ The definition, and subsequent limitations, of ‘saving a life’ are contested.

The Double Effect guides difficult end of life decision making. For example, while the intention of palliating pain is indeed good, ‘bad’ effects (such as respiratory distress,) still resonate and must be given weight in assessing whether the treatment is viable under Catholic moral teaching.⁶¹ Indeed, a palliative patient requires compassion—a tenet of Christianity and Christian healthcare ethics.⁶² Whereas analgesics belong in compassionate care, it can shorten a life span.⁶³ Intentionality is the most important component of the Double Effect principle for pain management. Although all four components of Double Effect work in tandem, intentionality is what ultimately determines the permissibility of relieving pain. Many Catholic ethicists permit opioids to be dispensed to patients since the intention behind the action is ‘good.’⁶⁴ In the case of palliative pain management, the intention of the act—to relieve a patient’s suffering—outweighs

the ‘bad’ effect of potentially hastening death. Further, it is assumed the physician is choosing the best alternative with the least harm.⁶⁵ Consequently, intention is certainly knowable in Double Effect. While sanctity of life is integral to Catholicism, there is no requirement to prolong life if quality of life is compromised.⁶⁶

Pain palliation and *pikuach nefesh* are in tandem. The *pikuach nefesh* principle requires all lifesaving medical interventions to occur if a life can be sustained for even a short amount of time.⁶⁷ Indeed, the importance of *pikuach nefesh* does not permit individuality or leniency within palliative care situations. According to the Talmud, saving a life trumps everything; saving one life is akin to saving an entire world.⁶⁸ Life is sacred in Judaism; hence there is no concept of ‘forgoing treatment.’ Further, there are no delineations of ‘extraordinary’ treatments or quality of life concerns. Instead, there is theological discourse based on preserving and guarding a life, despite futility of treatment.⁶⁹ Further, there is a mandate to relieve pain.⁷⁰ Together, this creates a strong case towards not merely pain management but further attempts to stabilize a dying patient (such as through feeding tubes). The risk involved with pain palliation is not an ethical concern in Judaism. Since pain causes bodily stress, it is permitted to palliate pain to purposefully extend a life, albeit however briefly.⁷¹ Judaism recognizes that the intention of a patient in pain is simple: they wish to be pain free.

These aforementioned discussed factors are further complicated within a pediatric context. Specifically, pediatric hospitals focus on ‘family centred’ care and thus, religious and cultural considerations may add conflict. There is added complexity of balancing the autonomy of the pediatric patient with their parent-decision makers. Traditionally palliative care was only a consideration for cancer patients. Now, it is being embraced as a crucial treatment for symptom management for all patients during an end of life trajectory.⁷² Due to palliative care being a more

recent specialty, children's palliative care is thus evolving. Pediatric palliative care is considered a "total approach to care" involving emotional, spiritual, social aspects of life and offers support to family. There is a 'fear of death' specific to pediatric palliative care. Family barriers include social, cultural/religious issues. This may be imparted in 'truth-telling' or withholding of the truth from pediatric patients.⁷³ Indeed, in a time of heightened emotions and stress, a religious family may find it difficult to render a medical decision completely divorced from religion. As such, religious families may align with religious beliefs, irrespective of best medical practice. Trying to overcome these barriers would serve as reasonable religious accommodation.

Technological interventions have shielded modern patients to the realities of death. Indeed, in the medical world, stopping medical intervention can be viewed as 'causing' death.⁷⁴ Dying children is both philosophically and emotionally disarming. Further, physicians are traditionally more aggressive in their care of pediatric patients, to give them a full chance of survival. However, it is a physician's duty to lead patients towards a compassionate understanding of death and dying.⁷⁵ The emotional hardship—and fear-- of children facing death is exacerbated at a pediatric level. Thus, physician aggressiveness is compounded. Non-palliative care physicians are hesitant to bring palliative care into discussions with families.⁷⁶ A study conducted with pediatric oncologists displayed this claim. Through collected survey quotes, there is significant mistrust and fear towards the palliative care team. Several physicians noted 'failure' if they needed to include the palliative team. Further, some remarked on the additional burden this would place on the family.⁷⁷ An additional medical barrier is enacting end of life treatment plans for children. Arguably, to enact such conversations is the ultimate act of compassion. Compassion is a different philosophical notion than sympathy or empathy. Thus, 'compassion' is defined via three variables: recognition of suffering; benevolence; being "personally addressed" by the

suffering and; a desire to relieve the suffering.⁷⁸ Together with their physician, a family can create a plan towards a peaceful death for their child.⁷⁹

Religious/cultural considerations merely compound fears of death and end of life but as sociological studies indicate, it may bring peace to the dying. Thus, understanding possible religious/cultural barriers is imperative. Doing otherwise may erect a barrier to palliative treatment.⁸⁰ Some religious/cultural traditions may be ably accommodated. Clergy may be called in to mediate between cultural concerns and medical judgment. However, some families find that a clergy visitation is a harbinger of death.⁸¹ A further, often overlooked cultural barrier is language. This barrier too can be adequately broached. Some languages do not have adequate words to describe what is occurring.⁸² Withdrawing treatment from a child is a difficult decision. Religion may affect a family's decision. Some religious traditions will allow a patient/family to forgo treatment. Catholic Law takes notice of the emotional toll on the family; and will forgo a life sustaining treatment if the family appears troubled by it during proceedings.⁸³ Jewish families stand in juxtaposition to Catholic thought; instead, there is theological discourse based on preserving and guarding a life, despite futility of treatment.⁸⁴ Judaism's zeal towards aggressive treatment and prolonging life is particularly true with pediatric patients.

Normally, autonomous consent is granted by the patient. In pediatric medicine, a child may not yet be cognitively capable of granting consent. Thus, parents are utilized to make medical decisions while keeping the pediatric patient informed. Decision making rests solely on the parents, regardless of the child's age or ability to comprehend their situation. Yet, not all families are agreeable to this. The cultural conviction is that the prognosis will upset the child so much, he or she will cease to 'fight' the illness.⁸⁵ Further, these families may be hostile towards consideration of palliative care as it would stymie 'hope' and thus, the chance for a miraculous

cure.⁸⁶ While the idea of hope is important and perhaps even fundamental to maintaining internal strength, the ethical importance of mitigating hope must be addressed. While hope and miracles may be associated with religious or cultural beliefs, it is imperative to gain a complete understanding of the influence this may have on parental decisions. To wit, foundational belief in hope may lead to poor medical decision making.⁸⁷

1. D. Religious Barriers in Clinical Care: Specific Cases and Circumstances and the Confines of Cultural Competency

The fifth chapter will provide in-depth insight into how religion can have a profound influence on medical decision making. Further, a novel term called ‘flipped [undue] hardship’ will be defined and analyzed via several distinct scenarios in both Jewish and Catholic medical ethics. Additionally, this chapter will further illustrate how cultural competency alone is often not sufficient. The insular Hasidic community's experiences with mental illness serves as an excellent case study for a re-evaluation of cultural competency methodologies.

Surveys of vaccine refusal and the rise of CRISPR demonstrates how Jewish medical ethics may stand in opposition to what is considered 'best medical practice' in secular ethics. Catholicism's approaches towards CRISPR will serve as a foil to Judaism. For Catholic schools in Canada, a public health campaign bringing the Human Papilloma Virus vaccine (HPV) into schools was a further exemplar of the conflict of religious values versus public health. This conflict will be explored, balancing the similarities and contrasts of the response, through the similar vaccine rollout to the Orthodox Jewish community in Israel. Pediatric oncofertility will also be analyzed within this chapter as a further complication illustrating whether and how children compound the notions of religion, decision making and accommodation. When it comes to ultra-Orthodox Jews (hereafter referred to as *Hasidic s. Hasidim p.*) specific religious

knowledge may influence the pathology of their mental illness.⁸⁸ Whereas Hasidim are included in the umbrella term of *Haredim* (ultra-Orthodox,) Hasidim are distinctive since each community follows a specific *Rebbe*, a spiritual teacher-leader and rabbi. This important difference is often absent in the literature. As such, treatment options must be exclusively bespoke to the community since *Hasidim* hold contempt for both the secular world and psychiatry.⁸⁹ Many, if not most *Haredi* families speak little English, are patriarchal and do not make medical decisions without rabbinical consultation. Further, the notion of mental illness is still taboo in this insular society. Rather, it is the result of the *yatzar ha-rah* or ‘bad spirit’ that can be exorcised via prayer, study and repentance.⁹⁰ Indeed, religious ritual governs every minute of life. Additionally, some *Haredi* communities encourage midnight graveyard visits and religious visions; actions which a secular physician may find aligns with mental illness.⁹¹ Some rabbinical leaders attempt to mediate an ill community member via prayer and supplication.⁹² A Hasidic patient is thus isolated dually: by his illness and by his community’s resistance to secular, Western medical intervention.

Mental illness is not restricted to one gender. Unsurprisingly, there is a lack of literature surrounding Hasidic women. This demonstrates a notion beyond gender bias. Hasidic women dominate the public sphere and are the backbone of familial piety. They are expected to stay within the shrouded community. Hence, their health issues are cloaked even more than Hasidic males. However, Israeli and New York based researchers have been successful in identifying mental illness within this population. *Hasidic* women are predisposed to eating disorders (ED) and OCD, the trigger of which is unique to the religious world. To adequately treat these patients, secular physicians must be knowledgeable of the ‘menstrual purity laws’ and the dietary laws.⁹³ Thus, for mental health interventions to be impactful on this community, a clinician

would have to be well versed and comfortable with these tenets of Hasidic Judaism. Most hospitals understand and accommodate the need for same-sex therapists or kosher food. The esoteric philosophy of *Hasidim* however adds further complexity to both diagnosis and treatment.

Hospitals in both New York and Jerusalem have wrestled with providing cultural and religious accommodation. However, doing so may create a point of undue hardship. The concept of ‘reasonable accommodation’ is generally assumed to be the medical institution accommodating the religious patient. To truly determine undue hardship within mental health care, it is essential for the Hasidic community to accommodate mental healthcare. By ‘meeting in the middle’ the Hasidic community can receive culturally sensitive care that is respectful of their religion up until the point of undue hardship. Hasidic *Rebbes* must permit leniencies to accommodate treatment; this would fall under the foundational notion of *pikuach nefesh* (saving a life).⁹⁴ Once the Hasidic community accommodates *pikuach nefesh* for mental health, undue hardship for religious accommodations may be applied. The application of undue hardship will, in turn, create a template ethical best practices that assures adherence to treatment and hopefully, a path to recovery. If a Hasidic community does not recognize mental health as *pikuach nefesh*, a limit on religious accommodations may be best for practical and effective patient care.

When a Rebbe or family decides to utilize Western mental health services, it is orchestrated in a manner that still ensures spiritual purity and rabbinic permission. In Israel specifically, this community utilizes a rabbinical letter of introduction to refer a patient to a mental health professional or institution.⁹⁵ These letters offer a unique window into this insular world. Several themes from these letters emerge. The first is discomfort. Most rabbis are pained leaving their students under secular care. Subsequently, they require regular reports or send a

mashgiach (s. supervisor, or in this case a supervisor of the patient's *neshama* or Jewish soul.)

Another theme is spirituality/mysticism. The rabbis often allude to the treatments they recommended to the patient which may include praying, learning *Torah* or being “more social” in the community. The rabbis’ express disbelief at the failure of spirituality and belief to help. A final theme is reluctance/acquiesce. Even some years ago, *Hasidim* would never seek out secular assistance. Each rabbinical letter alludes in some way to hospitals and physicians serving as the last choice. They also require updates on the patient via telephone or letters.⁹⁶ The *Hasidic* community has a stereotypical view of psychiatrists and psychiatry. They believe all practitioners to be atheist—even those who are Jewish. Further, they expect that the doctor will ‘prescribe’ leaving *Hasidic* Judaism to be cured. Finally, there is general worry about leaving a *Hasidic* Jew inside a secular hospital where women, magazines, televisions and general secular society can harm or entice.⁹⁷ Moreover, Hasidic society likes to keep its ‘dirty laundry’ within itself. Going outside the community for assistance may be acceptable when necessary so long as it is done quietly.

Several case studies illustrate common elements to Hasidic men displaying “social deviance;” often the first sign of acute mental illness.⁹⁸ This deviance includes no longer waking up on time to study, withdrawing from study partners or social events and being antagonistic towards others. Importantly, social deviance can be an umbrella term to describe all actions that do not adhere strictly to religious life. Hasidic life is demanding for men. They are required to study full-time in *yeshivot* (houses of study.)⁹⁹ They are required to be fluent in Jewish law and prayer. Men who have learning disabilities or ADD find themselves isolated and appear ‘deviant.’ Further still, men who are not capable of understanding the logic games of Talmudic

literature may find themselves ‘passed along’ rather than assessed for more suitable occupations.¹⁰⁰

Common themes within mental health treatment centers include: fervent adherence to religion, hostility to those outside the *Hasidic* community, and an interwoven relationship between psychiatric symptoms and religious observance. The latter theme is also apparent with women. Very often, religion is the trigger of a mental health crisis. This is illustrated through numerous case studies. Indeed, articles concerning male patients often have these individual stories. With Hasidic men, the greatest challenge becomes separating expressions of religious belief with expression of possible psychosis.¹⁰¹ Also, many patients are hostile towards their physicians, Jewish or not. Further accusations of atheism, being a ‘non -Hasid’ or being accused of homosexuality are common. Hostile attitudes further delay proper diagnosis and treatment. The literature notes that lingering hostility prevents successful treatment.¹⁰² Additionally, Hasidic patients are difficult to follow-up after initial hospitalization.¹⁰³ This may be due to a reluctance to be continuously ‘labelled’ as mentally ill inside the community.

The role of a Hasidic wife cannot be understated. Her adherence to the laws of *kashrut* (Hebrew; kosher) and menstrual purity create a spiritually pure Jewish foundation for her family. Failure is not an option. Perhaps not unsurprisingly, women’s mental illnesses do not deviate from her domestic sphere.¹⁰⁴ Obsessive Compulsive Disorder (OCD) is exceptionally linked to the complicated laws of menstrual purity.

Procreation is holy and the main objective for marriage.¹⁰⁵ A Hasidic woman should be content with having children and raising them in the Hasidic way. Just like their male counterparts, Hasidic women think they are being spiritually tested when they encounter postpartum depression.¹⁰⁶ They may view themselves as failures in spirituality and as mothers.

They too believe in God's intervention and seek it as a cure. Women only seek out secular care services when advised to by a rabbinic authority and/or their family members notice that something is wrong. However, women prefer to seek help further from their homes, for fear of being observed.¹⁰⁷ Obviously, the stigma of mental health does not erode once married. This is a direct result of stigma and a closed society. Living within a sheltered community compounds the issue; friends and family think that a postpartum woman should focus on other things and put her trust in God as a curative.¹⁰⁸

Eating disorders (ED) such as anorexia or bulimia are present across all ages in the Hasidic world. Girls as young as 15 demonstrate early experimentation with, to full-blown eating disorders.¹⁰⁹ Interestingly, one study claims that more observant girls have lower tendencies towards eating disorders. Several other studies note the opposite.¹¹⁰ It is clear however that fears related to matchmaking is often what triggers the disorder initially. Religious men want thin women. Additionally, Judaism revolves around feast festivals and Shabbat meals; designed to be rich and multi-coursed in observance of the holy days.¹¹¹ Talmudic law prescribes how much is to be eaten during some feast-days. Some researchers couple anxiety over ritually mandated food consumption with anxiety over finding a good match, triggering eating disorders.¹¹² Disordered eating is a control mechanism. A Hasidic woman leads a proscribed existence; eating may be a way to demonstrate individual governance.

Religious accommodation and cultural competency in healthcare is considered best practice.¹¹³ However, several barriers in secular healthcare prevent complete cultural competency for the Hasidic patient. Treating Hasidic patients requires more than a passing understanding of their religious beliefs. Hasidic patients encounter structural barriers.¹¹⁴ Most only speak Yiddish, and would feel more comfortable with a same-gendered care provider. The

density of their religious and cultural reality make understanding their illness difficult. This is apparent vis-à-vis clinical barriers.¹¹⁵ The prognosis for most Hasidic sufferers of mental health is poor since they fail to continue therapeutic protocols. To solve this, a mere understanding of Judaism would not be sufficient. Clinicians who regularly encounter Hasidic patients must understand the religious philosophies and culture.¹¹⁶ Some clinicians find greater success when they approach rabbinic leaders of the Hasidic sect they serve.¹¹⁷ This has a twofold purpose. It trains providers in cultural norms that are essential to treatment.¹¹⁸ By the same token, it demonstrates keen cultural competence of the inner workings of the Hasidic community. Indeed, gaining the trust and blessing of the *Rebbe* makes seeking mental health services acceptable.¹¹⁹ Hasidic Jews are wary of psychiatry and psychology. The adversity is already present. Traditional application of mental health theories and practice is not sufficient. Moreover, the sociocultural components of competency must change dependent on the Hasidic group.¹²⁰ An outsider would find this daunting. However, recognition of all the cultural and societal values within Hasidic observance is tantamount to diagnosis and prognosis.¹²¹

There are clinicians who practice the art of cultural competency yet find difficulties within an in-patient treatment setting. Treatment and therapy activities that prohibit (or delay) a Hasidic patient from observing his rituals could be interpreted as a hostile attempt to ‘secularize’ him.¹²² Some patients refuse to participate in mix-sex group therapy workshops or continue treatment on the Sabbath. Clinicians have a discussion with their patients, pressing the importance of continued treatment.¹²³ This amplifies the hostility. For Hasidim, delaying or doing a ritual sub-optimally creates tension and anxiety, more significant since most in the Hasidic community view mental illness as a moral/spiritual failure.¹²⁴ Finding the balance towards acceptable

accommodation and participation in treatment is difficult and not explored fully within the literature.

Some professionals who work almost exclusively within the ultra-Orthodox and Hasidic milieu adopt the patient's belief system.¹²⁵ Doing so eases tension and hostility and creates a more fluid conversation for patient and therapist. The therapist even suggested asking the *Rebbe* for permission to take medication.¹²⁶ This approach gave the patient a sense of legitimacy in his religious rationale and set the course of treatment within the religious sphere. Some therapists even utilize Jewish mystical notions as a furthering of their therapy. For example, creating a *beit din* (Hebrew =house of law) to urge a 'demon' to stop his pursuit of a patient and allow him to carry on in his religious life. Or, inspiring a patient to create his own protective *Golem* against his hallucinations.¹²⁷ This requires a vast knowledge of Hasidic beliefs and therapeutic application thereof. These examples are taken from Israel-based articles; it may be a hardship to expect a clinician to immerse himself so deeply in Hasidic ideology. While the approach is successful, it may be limited by place of execution. For successful intervention, mental health diagnosis must be made quickly. Mastering Hasidic theology and culture may take time and be unreasonable for the average mental health professional.

Religious traditions can also make accommodations for better healthcare outcomes. Patients who suffer from mental illness also suffer a lower quality of life. They may no longer feel joy or wish to socialize or preform religious rituals.¹²⁸ Prolonged suffering may lead to death or attempted suicide.¹²⁹ Cultural competency can ease the journey of *Hasidic* patients but it does not mitigate all obstacles. Cultural competency dictates that Western ethical values (specifically those embracing individual and autonomous choices) do not always fit within all cultures.¹³⁰ This is specifically true for the *Hasidic* movement. However, cultural competency does not exist

in a healthcare silo Greater understanding of culture would exist if clinicians reached out to the community. While it drives for understanding and acceptance of cultural differences, it is in danger of promoting generalizations and also does not profess to have limitations. While understanding religious/cultural practices holds value for a physician, this dissertation will analyze the shortcomings of cultural competency within a healthcare environment. However, the notion of working with a particular community to gain greater understanding will be explored via the National Health Services' *Hasidic*-centered psychiatric service and the new hospital in B'nai Brak.¹³¹ These services bridge the divide using the best practices of cultural competency. They seek community approval through rabbinical endorsement, they attempt to hire mostly observant or observantly-aware Jewish staff, they try to create Sabbath-friendly therapy modules.¹³² In return, participants agree to continue their treatment and follow-ups as required or else, lose the valued services. Britain's NHS is publicly funded; crucial since most *Hasidic* Jews are below the poverty line.¹³³ The B'nai Brak hospital also employs rabbis who ensure males continue their religious studies. This is considered a privilege and can be revoked or modified if treatment is not being adhered to.¹³⁴ Yet, these are tremendous undertakings. They require financial backing and training in *Hasidic* thought and religious practices.¹³⁵ They are also the result of dense populations of *Hasidic* communities within the UK and Jerusalem. This may not be feasible, even in the UK, for an extended period of time. Thus, it is perhaps even more essential that *Rebbanim* redefine and reduce the stigma of mental illness. Change is not foreign; even to *Hasidic* Judaism. Within this spirit, a re-interpretation of traditional texts can be assumed.¹³⁶ Further, there is a precedent within Jewish methodology that allows for other cultures to influence the practice and *Halakha* (Jewish law) of Judaism. For example, to accurately dedicate a new Jewish month, rabbis turned to astronomy to calculate the new lunar month¹³⁷. Doing so

would permit secular assistance to be rationalized as acceptable; as it is for physical illness. Incorporating mental illness into the umbrella of *pikuach nefesh* creates a new vocabulary that creates acceptance of mental illness and reduces stigma.

There is strong stigma within the confines of the ultra Orthodox community surrounding vaccinations. Previously, these concerns were isolated to HPV vaccine. Recently, it has bled into routine vaccinations as well. Religious reasons is often given as why a parent chooses to forgo a vaccination. Religion is perhaps understood as a reason considering the HPV vaccine. The HPV (human papilloma virus) vaccine is a recent addition to youth immunizations. The HPV vaccine is available to females between the ages of 9-26 to guard against sexually transmitted HPV virus which can lead to cervical cancer.¹³⁸ It is recommended the vaccine be taken first prior to sexual activity, with an optional ‘top-up’ dose taken in mid-twenties.¹³⁹ Unlike other childhood vaccinations, participant usage of the HPV vaccine is sub- optional; surprising since cervical cancer is often recognized too late.¹⁴⁰ Researches have concluded that religious sexual ethics is to blame for this phenomenon. Indeed, acceptance of the vaccine *ipso facto* is acceptance of non-marital sexual activity. For both Catholic and Jewish ethics, sexual activity is normative within marriage. However, whereas some Jewish ethicists may point towards the possibility of the vaccination saving a life, some Catholic ethicists view the vaccine as condoning sexual promiscuity.¹⁴¹ Ultra-Orthodox Jews refusing childhood vaccines such as measles or MMR is more concerning. Rabbis often cite that scientific progress is God’s own hand in Creation. Thus, the ‘public good’ argument may pervade religious ethics if discussed in line with Judaism’s law citing adhering to the country in which one lives.

Stigma will never truly disappear from an endogamous society. Hence, the advent of CRISPR proves very exciting for Jewish ethicists as a further assist to future generations.

Indeed, . If sickness, disease or ailment can be prevented or cured, a Jewish person has an *obligation* to seek out health.¹⁴² Jews heavily promote genetic testing due to endogamy. Orthodox dating services request its members to get tested for common illness like Tay-Sachs and cystic fibrosis. The potential to possibly eradicate these illnesses thus is promising with the community. Naturally, there are fears of eugenics, more relevant after the Holocaust. Only in the past decade has the Orthodox community been open towards and accepting of children with mental or physical limitations. Hence, conversations surrounding the future of genetic engineering is done with some trepidation and care. In contrast to Catholic ethics, while Judaism notes that embryos have potential for life, there is no *right* to life. A fetus does not hold the weight and rights of personhood until it is separate from its mother. It is assumed that this separation occurs during natural birth, when the head and shoulders are exposed.¹⁴³ An embryo is thus not given the status of personhood. The Talmud refers to fetus and embryos as *mayim b'alma* or, mere water. [Aramaic]¹⁴⁴ Thus, experimentation done by harvesting cells from embryos is of no major ethical concern for Judaism.

The fears of genetic enhancement or even generational disease eradication that CRISPR could provide is dependent on the ‘domino effect.’ While CRISPR can potentially eliminate ‘unwanted’ traits like schizophrenia, it is unknown whether and how ‘unwanted’ traits may be related to ‘desirable’ ones. For example, many artists and musicians suffered from poor mental health. However, their genius too was apparent.¹⁴⁵ Rabbinical scholars however appear to focus on the ‘unwanted’ traits; indeed, Jewish bioethics would tend to allow advances such as CRISPR.¹⁴⁶

The application of unique precedents or narratives is now commonplace to modern Jewish bioethics. Whereas the concept of *pikuach nefesh* (safeguarding life) is certainly

applicable in genetics, it does not fully explain why some *poskeim* allow for genetic enhancement. For Jews, physicians and scientific progress is the hand of G-d on Earth. G-d created the universe, but human beings, with creativity and intellect are tasked with perfecting it.¹⁴⁷ There is perhaps no better example of perfecting G-d world than genetic intervention. The concept of perfection can very well be extended towards non-therapeutic genetic engineering. Indeed, this position is well represented within the Orthodox *poskim*.¹⁴⁸ CRISPR is a risky venture and risk within Judaism is a complex notion. It is true that Jews are prohibited from taking non-required medical risk, however, Orthodox rabbis permit cosmetic surgery, despite the associated risks.¹⁴⁹

Traditional Judaic textual sources are silent on genetic engineering. Thus, being able to understand the Jewish Orthodox approach of genetic intervention from drawing a parallel to the Jewish approach to plastic surgery is a typical exemplar of creating modern Jewish bioethics. It may also serve to offer boundaries towards genetic enhancements. The genetic future of medicine is no longer speculative. It is thus essential that religious traditions create a viable foundation towards approaching them. However, Judaism's pro-natalist ethos may conflict with anticipated secular ethical guidelines.

In Judaism however, risk is calculated using different equations. Low risk procedures are considered 'normative' and 'accepted by society' and can be undertaken with little concern. Some procedures have greater risk and can only be undertaken for 'good' reason. The most high risk procedures should be avoided at all cost; except for the purpose of saving one's life.¹⁵⁰ Indeed, one is permitted to desecrate the Sabbath in order to save someone who is trapped, even if they are not expected to survive for much longer. Although, if great risk is the cost for even a short period of longevity, the patient can choose to accept or refuse treatment.¹⁵¹ This is an

important paradox. Whereas great risk must be avoided, it can be embraced for even short term gain. However, a patient is permitted to fear high risk and even refuse care.

It is not incorrect to understand CRISPR's potential to save lives. Arguably, that is its purpose: to stop genetic diseases that impinge upon quality or duration of life. Therefore, CRISPR must be classified under *halakhic* terms of risk. As CRISPR develops and continues to be tested it would be classified as high risk since the impact and side effects of germline modification is not yet realized. However, for Jews who suffer from CF or other life limiting illnesses, this risk, however high, is permitted for even a moment of additional life. There is a tremendous caveat: a patient is able to refuse treatment if the risk is too high. Germline modification affects all future *patients*; can one individual decide for his future generations? Moreover, the modifications made on the 'defective' gene may have implications on healthy ones. Or, what one person considers to be life limiting, another may be able to adapt to. Consequently, what value does Judaism place upon autonomous choices, when an individual choice affects the collective. There are two ethical parallels that may be applied here: not requiring permission to save a life and destroying a pursuer.

According to the Talmud, permission is not required to save someone. Indeed, if someone expresses not wanting to be saved, one is obligated to ignore his wishes and save him regardless.¹⁵² Additionally, there is a famous responsibility to stop or even kill a pursuer to save someone else. Even minors are obligated in this commandment.¹⁵³ Anecdotally, an individual's actions has impact on the collective. In the Talmud, if one person refuses to join a prayer quorum, all men present lose the merit of his prayers.¹⁵⁴ Together, these create a powerful argument towards accepting CRISPR. A person with a genetic mutation does not need to ask permission of all his (potentially) affected kin; the mutation is a 'pursuer' and must be

eradicated. In fact, if a person did not wish to utilize CRISPR, his progeny would lose the merit of the technology, from his ‘selfish’ decision. While this creates a tidy case enabling Judaism’s embrace of CRISPR, the problem of enhancement—or improving God’s own work—remains. Hence, analyzing Judaism’s approach towards cosmetic surgery which literally ‘perfects’ God’s work is a novel parallel.

Many experts in Jewish law limit the scope of medical practice to healing and reducing harm. Therefore, surgeries that restore health, such as tumor removal or skin grafting after a burn are acceptable. Moreover, they can be interpreted to be obligatory¹⁵⁵. The patient’s autonomous choice towards pursuing healing is consequently directed by religious obligation. However, a paradox exists within Judaism. Whereas a patient is religiously obliged to seek out treatment, they are also commanded to mitigate risk. Medical interventions which are considered ‘high risk’ with little benefit are to be avoided. Additionally, enhancement is considered to be against the integrity and beauty of God’s own creation.¹⁵⁶ Further, according to Rabbi Walenberg, a doctor is not *licensed* to perform these procedures, since there is no reduction of harm or pain.¹⁵⁷ Rabbi Walenberg’s position goes against other *posekim* who permit plastic surgery. His approach is creationist and serves to ‘protect’ the sacrosanct nature of G-d as knowledgeable and formidable creator. Further, he attempts a literal interpretation of the physician’s obligation to ‘do no harm.’¹⁵⁸ This reiterates Mackler’s important yet difficult distinction that it is difficult to demarcate between therapy and enhancement.¹⁵⁹

However, most rabbinical decisions encompass the aforementioned socio-cultural ideologies. Much like abortions are considered based on the mental/emotional anguish of the mother, the desire for a person to improve or change their appearance is measured in terms of emotional duress.¹⁶⁰ Indeed, if a person seeks physical changes in order to get a better spouse,

this is approved. Further, if one's appearance always caused them emotional harm, they are permitted to use a surgical corrective approach.¹⁶¹ However, the literature often utilizes the example of a person desiring rhinoplasty. This is sanctioned for the aforementioned reasons. Yet, there is almost a purposeful silence about whether this allowance would extend to 'vanity' procedures such as breast augmentation. To properly extend this logic to genetics and CRISPR, defining 'vanity' cosmetic procedures is integral. That definition would enable Judaic scholars to truly encapsulate whether certain diseases fall under the scope of 'vanity' (and thus, should not be mitigated with CRISPR) or medically, emotionally or socio-culturally necessary to mitigate. The academic literature is silent on such definitions. A rabbi may condone a rhinoplasty, but is less likely to permit breast augmentation. A nose is in the 'public' domain and is easy to observe whereas breasts are sexualized and in the 'private' domain. However, this may be merely an exercise in semantics. Whereas a larger nose may cause emotional harm from bullying, the argument may be made that a woman unhappy with her breasts may suffer from reduced self-esteem.

However, parallels may still be drawn from cosmetic surgery. Surgery is permitted if it will alter one's prospects. Indeed, in this sense, we are assistant to God's creation; moreover, we are obliged to perfect our lives.¹⁶² While self-mutilation is prohibited, there is a Talmudic duty to fix what is broken.¹⁶³ CRISPR then can be seen as a co-creator, a fixer of what is broken. Yet, this does not solve the dilemma of classifying what genes are considered 'broken.' Using the Talmud as a foundation, however, Judaism may be able to create classifications. Talmudic Judaism had a rudimentary understanding of disease, particularly hereditary diseases. It cites that a person should not marry into "...a family of lepers..." and that "...an albino man should not marry an albino woman..." so the children are 'sheltered' from the illnesses of their parents.¹⁶⁴

This undeveloped logic is the basis for endogamous genetic mutations. In a direct correlation, CRISPR should only be utilized to correct inheritable, life limiting or terminal illness that has an excessive likelihood of being passed on. Talmudic precedents create ample permission for Jewish patients to fully embrace CRISPR technologies. This is an issue of accommodation very different from those analyzed previously. Secular bioethics is more weary of CRISPR technologies. The question is more expressly whether and how Jewish patients can utilize CRISPR technologies within a secular world. Simply: does religious ethics' permissiveness undermine the concerns of secular ethics in a pluralistic milieu? What may be beneficial to the Jewish community may be questionable in secular ethics. Moreover, genes that particularly affect the Jewish community may not be considered first in CRISPR's initial usage. Some scholars caution against using the technology in a eugenic sweep.¹⁶⁵ The line between 'therapeutic' and 'enhancement' would become more blurred. Further, the impact to society must be considered. While Jews would consider even high risk beneficial for a modicum of life, secular ethics is concerned with the risk of changing society itself.

Finally, religious ethics offers differing opinions on the usage of reproductive technologies. The joy of children cannot be underestimated within Judaism. However, does this obligation apply to children who are undergoing chemotherapy and may lose their future ability to reproduce? This is recently considered best medical practice within pediatric chemotherapy treatment and dubbed onco-fertility. Medically, the method to harvest sperm or preserve ova may be considered invasive and inappropriate, due to a patient's age and the emotions involved with a cancer diagnosis.¹⁶⁶ Religious ethics have additional concerns. Both Judaism and Catholicism place prohibitions on masturbating to procure sperm. The technique used to procure adolescent or prepubescent sperm remains like techniques utilized on adult males. Simply, the male must

ejaculate into a medical container and the ejaculate is then put into freezer storage.¹⁶⁷ However, when the patient is not yet physically mature, this method is ethically questionable and may even be deemed inappropriate. Some studies counter this ‘natural’ approach in favour of electro-ejaculation which forces ejaculation while the patient is under mild anesthesia.¹⁶⁸ While quick and devoid of any sexual paraphernalia, this method is too, not without concerns. Various studies have shown that sperm collected via surgery or assisted ejaculation is not ideal—whereas sperm harvested through traditional means of self-procurement is stronger and more vital specimen.¹⁶⁹

Whereas sperm procurement is less evasive, ova harvesting is far more complex since it involves undergoing surgery, often coupled with hormone therapies to facilitate easier collection.¹⁷⁰ These cryopreservation techniques have a low success rate. Further, there are concerns as to whether procuring oocytes prior to fertilization is scientifically responsible, as freezing has been known to cause permanent damage to the delicate tissues.¹⁷¹ Females who choose to freeze their eggs are scientifically advised to freeze an embryo as it can survive in a prolonged frozen state, compared to mere ova.¹⁷² Yet, to create an embryo, one requires a donor.

Although Judaism is focused distinctly upon reproduction and is progressive in terms of embracing reproductive technologies, the usage is restricted by *halakha*. Sexual intercourse in Judaism is designed primarily for reproduction—masturbatory emissions are prohibited. Rabbi Waldenberg, one of the foremost *posekim* in the field of Jewish medical *halakha* admonishes those who use artificial insemination, even as a husband, as it “ruins the tents of Israel...” The act of sexual intercourse is pure and sacred, necessary to preserve Jewish homes.¹⁷³ Hence, it must be performed in its original (traditional) intended manner. The onus for procreation rests directly on the male. Females cannot be obligated in the *mitzvah* of procreation due to its life-

risking tendencies. Whereas she may be religiously unobligated, she is *socially obligated* due to status and traditional domestic sphere roles. As it is stated in *Genesis Rabbah 71*. Whereas procreation is not the sole purpose of marriage, it is considered part and parcel of it. This idea can be easily traced throughout the *Torah*. Genesis 1:28 observes that, "G-d blessed [man and woman] and said unto them, 'Be fruitful and multiply and replenish the earth and subdue it.'" After the Flood destroyed the world and its populace, Noah's family was blessed with fertility (Genesis, 9:1). Certainly, the various trials of infertility experienced by the matriarchs—and their desperation to have children, which leads them to offer up maidservants to their husbands—establishes a strong case for children being a pillar of a Jewish marriage. According to Rashi, even as a child, Miriam encouraged her parents to copulate again, resulting in the birth of Moses and, subsequently, ensuring a Jewish future.¹⁷⁴ Fertility is thus foundational for the continuity of Jewish faith.

Harvesting ova is not as *halakhically* complex. With a youth or child, there is no concern of ritual menstrual purity (*niddah*) which is usually observed in a marital relationship. However, these laws pertain to normative and married couples. What is of concern, however is the possibility of frozen embryos. Normally, eggs are not frozen exclusively as they are built of delicate tissues. It is the preference of medical experts that an egg be frozen with a sperm inhabitant—creating an embryo—which has a better chance of long-term survival. Thus, a female patient must consider sperm donation. Most *posekim* assume donor sperm to be adulterous. Similarly, donated eggs are frowned upon for lineage issues.¹⁷⁵ Rather than feticide being a concern, the Jewish fear rests in labs accidentally dispensing the incorrect sperm specimen.¹⁷⁶ These concerns are established even with a married couple utilizing reproductive technologies.

Catholic ethical thought shares the same Old Testament narrative of fertility. Leaving aside the difficulties of masturbation, Catholicism has concerns with ova preservation and transplantation.¹⁷⁷ Thus, the ethical implications of preserving fertility at present is dictated by ethical implications in the future. As with Judaism, Catholicism prefers procreation to be wholly within the confines of a marriage bed. Removing the physical act and transferring it to a lab setting is disconcerting.¹⁷⁸ Cryo-preservation of ova alone is experimental; the tissues are often too delicate to survive past five years. Thus, to provide the best outcome for a pediatric patient, embryos are preferred for long-term freezing.¹⁷⁹ Catholicism thus struggles with a unique ethical concern. Ova preservation is not sustainable and yet, potential embryos have a right to life.

Some ethicists would permit pediatric patients to preserve their ova, if the experimental treatment is offered. Being aware of the limitations of current procedures, the end-result allows for marriage-based natural conception. Further, technology rapidly evolves. It is not unwarranted to believe ova preservation can be advanced.¹⁸⁰ Indeed, science could compliment the notion of Catholic marriage and conception as ova preservation simply restores the ability to procreate.¹⁸¹ Much like Judaism, the importance of coitus is thus not disrupted by science. Further, the patient would not be *obligated* to make use of her restored fertility. If embryos were frozen, there is an ethical assertion towards life. Embryo creation offers additional obstructions. Catholicism rejects the usage of donor sperm; since it taints the marriage relationship.¹⁸² Perhaps leniency can be learnt in Catholicism, based on the notion of *intent*. *Donum Vitae* cites that utilization of donor materials would “offend” the call to parenthood.¹⁸³ Yet, the *intent* of onco-fertility is just that: to preserve the possibility of parenthood. Moreover, becoming biological parents may strengthen a marriage.

1.E. Religious Evaluation and Accommodation during Secular Ethics Consultation:

Towards a New Evaluative Scale

Finally, the last chapter will establish a new evaluative scale to inaugurate ethical limitations and better communication within clinical settings, demonstrated via a step-wise format for both Catholic and Jewish patients. Creating and applying the notion of bioethical undue hardship in clinical ethics will lead into a detailed application of balancing both medical and religious ethics during a clinical consultation. A helpful chart and questions will serve as a visual toolkit for which hospitals and other health institutions can devise their own ethical policies surrounding accommodation.

Clinicians cannot deny the impact of religion to patients, and even to believing health care providers. Subsequently, care providers want an inherent way to discuss and know the religious beliefs of patients. There have been several attempts at crafting a spiritual assessment tool which is used to quantify the weight of religion. In response to the increasingly powerful voice of religious patients, the British National Health Services created a ‘spiritual assessment’ sheet to be filled out with both medical caregivers and patient to assess the spiritual/religious beliefs of patients.¹⁸⁴ The NHS requires its healthcare providers to be “...competent in providing care to patients of differing cultures, religions and beliefs...”¹⁸⁵ Versions of a similar ‘spirituality checklist’ exist throughout the UK, Canada and the United States. Organizations such as the Institute of Medicine and The George Washington Institute for Spirituality and Health have devised their own versions of spiritual assessment tools designed to assist physicians and end of life care providers to correctly value spirituality. The latter organization’s FICA Spiritual History Tool assesses the strength of a patient’s religious values determined through several categories. These include: Faith and belief, Importance, Community and Address

in care. The study urges that spiritual histories be taken alongside medical history, which indicates the significance the Institute places on spirituality. Further, FICA also offers ethical guidelines towards incorporating spiritual care. FICA is designed onto small plastic cards, designed to fit in a pocket, for at hand spiritual assessments.¹⁸⁶ Just as staff wear IDs noting the various hospital codes, FICA is just as important to clinical care and must be at hand.

In the sphere of clinical ethics consultations, there is a dichotomy between acknowledging religious influences in survey takers but refusing to isolate religion in the output data. Some surveys even inquire about the religious leanings of the survey-taker.¹⁸⁷ But, none insulate religion as an outright factor to calling a consult. Surveys generally ask takers to grade how proficient they are in several common ethical consult themes; religion/culture is not easily discernable from the data. Arguably, it is classified under ‘moral distress’ situations, such as removing life support mechanisms or even discussing end of life care and practices.¹⁸⁸ One survey focuses exclusively upon common ethical consult themes at end of life. While religion is not discussed bluntly, themes such as ‘patient refuses withdrawal of treatment’ and ‘patient non-compliant with medical regimen’ certainly resonates with religion.¹⁸⁹ Again, these surveys support the notion that religion is an outlier and commonplace with ‘difficult’ patients. Perhaps religion is not directly confronted due to the notion of creating a secular ethics or having a common morality. Yet, this behooves the shadow that religious decision making can cast and the current reality.

Miracles play a large role in Catholic healthcare philosophy. Catholics do heavily believe in healing, compassion and hope.¹⁹⁰ Some Catholics are driven by a fervent belief in miracles and as such, a patient has a moral obligation to use what is deemed “ordinary” means of life preservation. Academic literature supports the importance of engaging with spirituality and

religion within pediatric settings. Some pediatric patients find solace in religion and the constant belief that something miraculous could happen. However, clinical research is another form of treatment and cannot be considered extraordinary care. Indeed, while Catholicism places importance on natural law; human beings are all destined to die.¹⁹¹ While sanctity of life is integral to Catholicism, there is no requirement to prolong life if quality of life is not achieved.¹⁹² Catholics are not morally obliged to seek out extraordinary care.¹⁹³ This belief has been echoed within the *Catholic Directives*, formalizing its authority.¹⁹⁴ Ensuring uniformity in complex decisions is the ambition of the *Directives* to assist Catholics and Catholic healthcare institutions. Catholic moral teaching takes notice of the emotional toll on the family; and will forgo a treatment if the family appears troubled by it during proceedings.¹⁹⁵

In ethical situations involving children, whereas most scholars note the importance of integrating a child into decision making, the definition of assent is unclear but it is important. Some scholars take issue with the term. For them, assent does not connote full understanding of a diagnosis and treatment plan he issue and thus, cannot be considered full, informed consent.¹⁹⁶ Moreover, whereas obtaining parental consent is primary, assent may be viewed as secondary. However, if a child dissents to be a participant, his concerns cannot be taken lightly.¹⁹⁷ The very notion of ‘assent’ permits the physician or medical researcher more flexibility. Assent allows the consent conversation to be approached based on the personal maturity level of each patient. The child should be spoken to in an age and developmentally appropriate method, so that he comprehends all risks and benefits.¹⁹⁸ They should be encouraged to sign their own form, acknowledging they wish to be included in the research study.¹⁹⁹ Some younger children are encouraged to draw their assent. If there is a language barrier, translators should be brought in and all factors of risks and benefits should be explored. Regardless of language barrier, the

information should be given both through written lay-language and orally to both parent and child.²⁰⁰

Outside of a pediatric hospital, time and attention to spiritual or cultural needs are considered not apposite to decision making. This is a severe oversight. As previously discussed in this paper, often religion is the driving force of a medical decision. Thus, a new assessment tool is required to properly understand the importance and measure the influence of religious dogma on decision making. Clinical ethicists should be educated in theological foundations and skilled at using the language of theology. Doing so creates a ‘shared language’ and decreases the power-inequality that may be prevalent. The notion of ‘us’ versus ‘them’ is apparent throughout the literature; showing comfort with the language of believers blurs the lines of power dynamics. Additionally, this dissertation suggests using a modified sliding scale model perhaps in conjunction with aforementioned spirituality assessment tools.

The traditional sliding scale theory balances level of risk with the level of ability required for competent decision making²⁰¹. Religious belief does not reduce decision making capacity. Rather, for some, it is merely a prism from which to make a decision. The standards for welfare and quality of life are also colored via religion; rather than sole emphasis placed on good medical outcomes.²⁰² However, medical professionals may view this addition to the decision-making equilibrium as ineffectual. While Beauchamp and Childress note the scale imagery connotes a balancing of autonomy and protection, as do others, a religious patient’s scale demands a third arm. Thus, creating a truer sliding scale; one that also encapsulates religion. Using the language of Rawls, religion should be understood and routinized in hospitals. However, while teaching religion is difficult; teaching the language of religion is more difficult. By speaking in the ethical language of a religious tradition, concerns may be clarified and the contradictions between

medicine and religion temporarily bridged. To speak in the language of a religion, an ethicist must be proficient in the *principles* of that tradition.

The bioethical principles of autonomy, beneficence, non-maleficence and justice can shift in importance based on the particulars of a case. They may also move to greater or lesser significance on the hierarchal ladder based on the personal ethics of a physician or patient. Different circumstances may result in individual principles being promoted in the hierarchy.²⁰³ This hierarchy exists within religious ethics as well. Most religions can be reduced to a handful of specific principles that may influence medical decision making. Some religions have principles that permit modification when certain actions or behaviors are normalized in greater society. This allows for progress in religious ethics as medicine evolves.²⁰⁴ An ethicist who is capable in religion would be able to tease out a handful of principles for each religious belief. Understandably, this should be confirmed with clergy, to ensure the accuracy of principles. Whether they admit it or not, ethicists and clinicians all juggle moral principles before rendering a decision. In contrast, believers utilize their religious principals, almost solely, to base their ethical decision. For example, while a clinician may advise to stop life support for a brain-dead patient, a religious decision maker may not perceive the contextual information surrounding the medical decision. Rather, they simply hear that life support is being removed, which lays counter to a religious principle of preserving life. This is why it is so important for a clinical ethicist to speak in the language of religion. This means an ethicist must speak with an understanding of the religious principles that are impacted in medical decision making. The hierarchy of religious principles may shift depending on the specific situation. The hierarchy may then be negotiated utilizing Moral SDM techniques. Now, the ethicist can apply the adapted sliding scale imagery to discuss religious principles with a patient. As previously indicated, Beauchamp and Childress'

scale imagery connotes a balancing of autonomy and protection.²⁰⁵ Yet, this adaptive imagery requires a religious third arm. This does several things. At first blush, this demonstrates understanding and facility with foundational religious values. It also allows a patient to showcase their personal perspective on their religious practice by protecting those moral grounds. It would be incorrect to judge religiously based consent or non-consent as incompetent. The definition of incompetence requires a person being unable to express themselves, understand the situation and unable to give a reason for their decision alongside other criteria. A religious patient's reason for not consenting to a procedure is possibly not considered 'rational' or 'reasonable' by some physicians. However, they are far from incompetent. A believer needs to state which religious principles are integral to them. This can be done alongside the ethicist using the Moral SDM. This would echo a patient's own interpretation of their religious tenants and subsequently, force them to 'rank' the importance of certain principles. Then, the ethicist and patient can work together towards a shared compromise. Used together, a sliding scale and Moral SDM model could potentially be a far more nuanced way of understanding religious principles within clinical consults. Additionally, when an ethicist speaks in a way that is sensitive to religion, or uses religious language, it creates a bridge across a communication chasm and dissolves some of the power dynamic that currently exists. Rather than religion and medicine clashing within hospital corridors, they can live alongside each other. Moral shared decision making (Moral SDM) means that a moral compromise is created. All parties (patients/families and clinicians) negotiate on principles until a solution that is mutually agreeable is found. Collaboration, by definition, means that some moral ground must give way.²⁰⁶ Assuming that an ethicist is fluent in the principles of religions, they can assist patients in determining which values may have flexibility within a

religion. Further, they can help clinicians understand which values are simply non-negotiable to believers.

2. Secularism and Religious Pluralism: A Tale of Two Ethics?

Sociology points towards a correlation between patients' end-of-life experiences and their religious affiliation. To wit, as some patients grapple with chronic or terminal illnesses, their belief in organized religion grows exponentially. Further still, as this thesis hopes to demonstrate, belief transcends the religion itself to influence decision making, attitudes and overall coping mechanisms in healthcare situations. While indeed, some people lose faith entirely when facing health obstacles, when people hold on to—or grow—their faith, it truly governs all aspects of their decision making process.²⁰⁷ Some aspects of the literature point towards Patients, or their families, may request the intervention of clerics to guide their medical decision making. Moreover, some patients view their medical decision-making vis-à-vis the prism of their religious tradition. Religion thus colours autonomous decision making. The literature aptly describes these clashes of culture; of religious and medical philosophies contending for being the ultimate deciding factor in troubling circumstances.²⁰⁸ Whether and how medicine must yield to religious beliefs is not identified within hospital culture. It is at this critical juncture that ethics is called upon to negotiate between these differing values.

Religion is thus one foundational crux of ethical conflict between patients and professionals. There are several sub-themes of note within medicine/religion conflicts. These include a strong belief in miracles; and how religion can assist patients and families in coping with diagnoses. Further, for some, death/dying is a spiritual act rather than medical.²⁰⁹ However, the literature appears biased towards the implied notion that Western medical decisions oppose over and above religious beliefs. 'Western' medicine does not necessarily imply secular values. Western medicine in this thesis defines normative medical interventions that are found within academic hospital environments. Secular values, thus, are differently shaped, as demonstrated

later in this chapter. Indeed, some physicians dub religiously motivated medical requests as 'inappropriate.'²¹⁰ It appears that ethics is called to consult as though they are capable of swaying a religious patient towards consenting to a physicians' treatment plan. Thus, clashes between believers and health providers must be understood as clashes between *two codes of ethics*. Indeed, most religious traditions have codified laws that create these tenets.²¹¹ Just as there are standard medical protocols, similar 'protocols' exist within religious law for believers. Subsequently, there is a call to ground ethics within secularism.²¹² However, the religious underpinnings of 'secular' ethics cannot be nearly stripped. As this chapter will demonstrate, secular ethics are not wholly created outside of religious values. Many of the notions of so called 'secular ethics' are, in fact, ethos that are foundational to the Abrahamic traditions. The definition of secularism, its religious substratum, and secular ethics will be discussed in the next sub-section. As there will probably always be patients who will eschew the notion of secular ethics and prefer their religious ethics to guide their medical decisions. Thus, whether and how medical ethics can ever stand as a complete 'secular' ethos is another interesting question.

There have been attempts to measure the value of religion within medical decision making empirically. Often, patients call upon clerical support due to an inherent understanding that a religious leader has a grasp of medical-faith doctrines. Believers wish to be comforted by religion and guided by it.²¹³ Enabling religion to guide decision making also assists with coping with a diagnosis or difficult prognosis. However, in modernity, dying is a very different notion than demonstrated within traditional religious texts. Indeed, death and dying with all its modern underpinnings (artificial hydrations, life support, etc.,) are commonly unclear in a religious ethics situation.²¹⁴ Judaism, in particular, bases its tenants of modern medical ethics upon the Torah and Talmud; these texts were written at a time where death was part and parcel of life and

medicine interventions were not possible. Subsequently, when a believer attempts to use religion to cope with medical decision making, conflict often erupts trying to trace modern medicine upon ancient ordinances. Currently there are several measuring instruments in place, including a spiritual assessment 'tool' which enable clinicians to ascertain the significance of religion to patients as part and parcel of their quality of life.²¹⁵ However, these tools are lacking. They exist to recognize the place of religion in decision making, however they do not appear to mitigate conflict. To be clear, the current tools used to measure spirituality supports the importance of faith and belief, however does not offer guidance on ethical divergences. For example, the popular FICA tool created at GW Institute for Spirituality and Health offers conversation starters to measure the importance of spirituality, however, stops short at merely that. In 'FICA recommendations' the Institute once again notes the importance of spirituality and advises it be addressed. Chaplaincy should also be considered. However, there is no FICA tool (nor any other module or tool) existing which demonstrate a clearly demarcated guide on what to do during a clash of ethical codes. . The current literature also suggests that religious beliefs can be accommodated so long as it is not antithetical to medical protocols.²¹⁶ Yet, this is not enough. Further, this discourse appears to create a dichotomy between the believers versus the clinicians. While death and dying currently retain the bulk of clashes between secular and religious ethics, religion objectively colours all medical choices. In later chapters, this dissertation will isolate decisions that are more obliquely religiously-minded.

In Canada's shared healthcare environment, courts of law decide the outcome of these cases. Indeed, these cases all follow a similar pattern: a believers' request is divergent from medical counsel or the best medical practice. The law is tasked with finding an equilibrium, which thus far, no court has done. Under Canadian law, the courts appear to be creating a binary

of citizens: those who are secular and those who are not. For example, patients/surrogate decision makers (SDMs,) who disagree with their physician can appeal to the Consent and Capacity Board (CCB) to determine treatment avenues. Often, religiously motivated requests are beyond the scope of the CCB (or remain unresolved,) and passed to the Court system. While non-religiously motivated requests often resolve within the CCB, petitioners who appeal via the Court are often struck down, with judges supporting the decision rendered by the CCB. This is not an accommodation. Very few of these religiously motivated cases reach judgement, as patients die on life support, or upper courts dismiss the claims to lower courts, or the CCB. This binary of citizens then, only serves to bring hospital ethics and policies into a legal environment. Arguably, the legal arena is not the best resource for this type of mediation. Especially, in Canada's resource-scarce system, this compounds the issue.

The Canadian Court system has not yet created sufficient legal limitations surrounding religious accommodations in healthcare. Ironically, the Hospitals who find themselves in Court have yet to create policies or guidelines surrounding religious limitations. Indeed, since all patients have died before Canadian judges could rule, it is indispensable to provide a new avenue to mitigate discourse between two ethical codes. Thus, a new, *ethical* model for measuring, infusing and balancing religious ideals into clinical ethics would be indispensable. This ethical framework would also keep medical decision making at the bedside, rather than in courtrooms.

2.A. Secularism and secular bioethics

Charles Taylor is undoubtedly the most apt philosopher and scholar to effusively rationalize the notion of modern secularism. Robert Veatch is another philosopher who delves into understanding whether and how a pure secular morality exists. Comparing and contrasting

these philosophical giants would allow this dissertation to establish a working definition of secularism and secular bioethics. It is essential to determine if a shared moral code can exist, outside of religious doctrines as it would allow the later scaffolding for undue hardship to be understood and rationalized. Can religious believers exist within a secular age? Can a secular society accommodate religious beliefs at any time? Is there even a definable secular ethics? Taylor will merely be used to offer his scope and understanding of true secularism—and what it means—analogue to religious belief. It is essential to understand what the definition of a ‘secular age’ is in order to ascertain the division between religion ethics and secular ethics in medical decision making.

According to Taylor, the historiological approach to the fading of state and religion is widespread and complex. Indeed, in this modern (20th century onward,) age of secularization, “...God is not present in public space.” Rather, today’s society can be deemed as “...a moral order for mutual benefit...”²¹⁷ Individuality and a variety of moral codes are welcomed. Intolerance is not permitted in this view of Taylor’s secular society. As he dissects the literal separation of Church and State through history, he denotes some important instances which have, in his view, shaped modern secularism. In America in particular, there is a sense of integration to conform to secular mores, which is apparent through most immigrant narratives. Additionally, America lacks the social and class hierarchies apparent throughout Europe. Immigrants could choose Church to identify as American. Being a nation ‘under God’ was not deeply analyzed or explored, save perhaps for election seasons. Taylor does not neatly define secularism. Rather, he extends his argument towards a concept of secularism in modernity which reaches towards a moral code that does not ‘crush’ what is essential to humanity. Further in his conclusion, Taylor notes that society may be grasping for spirituality and ‘higher awakenings’ rather than being

governed by a particular religious doctrine. Thus, it would appear that human beings are not completely isolated in secularism; spirituality is still foundational to our ethical code.²¹⁸ He calls for an ‘open secularism’ which means that society is openly anti religion or anti spirituality. Omitted from Taylor’s manifesto is an understanding of whether there is an understanding of a pure, secular ethics, unrooted from religious codes. This may be due to his own personal Catholic ethos (indeed, his analysis and examples throughout his book depend heavily on Church doctrines.)

Robert Veatch believes that religious and secular morality can be held in tandem under a normative moral theory. His main adversary is the Hippocratic Oath. The Oath is not a code for secular or even professional morality. According to Veatch, the Oath is based upon a non-sophisticated, inadequate Greek cult. Common morality can exist; uniformity based on the Hippocratic Oath cannot. Veatch takes aim with the notion that professional codes can govern ethics. The Oath cannot justifiably exist when a member of it subscribes to a religious metaethics, or even a secular/philosophical metaethics. Veatch systematically goes through both religious and secular ethicists (including the famous Four Principles of Beauchamp and Childress) and analyzes their shortcomings. In conclusion, he views the confluence of secular and religious ethics to be best demonstrated via the United Nations Universal Declaration on Bioethics and Human Rights.²¹⁹ This Declaration validates a consensus of morality which should hold true for ‘reasonable people.’ Importantly, as Veatch mentions, there is no guidance on what happens during a conflict of values—essentially, which principle should trump another. This then is perhaps the art of medicine and essentially all moral choices: balancing values/principles based on circumstance. If there is a ‘secular bioethics’ it would be the UN Declaration, which combines normative moral principles with nods to spirituality and religion.

Each of the 17 principles is inter-dependant on the others, with further *articles* demonstrating the importance of further assessment via ethics committees, risk management and even bioethical education.

Arguably, true secularism is undefinable—so much of our understood morality is based upon religious codes. Even the concept of ‘do not murder’ conceivably would not exist without its Biblical exposure. Thus, Taylor and Veatch’s exploration of what precisely connotes secularism is unfinished. If comparing both Taylor and Veatch, secularism must be ‘open,’ even tolerant of religious explorations of moral codes. Perhaps then, secularism cannot truly be removed from religious thought.

2.A.i . ‘Secular bioethics’ and religion

Indeed, bioethics has always held a strong theological foundation. The earliest scholars of medical ethics trained in religious studies. In fact, 'secular' ethics centers such as The Hastings Center and the Kennedy Center for Ethics were founded by religious ethicists.²²⁰ American religious history, and its influence on bioethics, cannot be ignored. A strong Protestant ethic shapes early bioethical concepts, notably through the concepts of civil rights, anti-paternalism and anti-authority. The 'individualism' so intrinsic to Protestantism created the importance of autonomy, over and above the commonplace paternalism. Jewish ethicists borrowed the concept of humanity from the Old Testament's prophetic dynasty.²²¹ Although many religious ethicists could separate their religious ethics from their notions of ‘secular’ ethics, religion’s influence on bioethics is still evident even today.

While religious underpinnings are still evident within ‘secular’ ethics, the gradual ‘secularization’ of bioethics, and its rising importance in North America, commenced in the 1970s, with a rise in nation-wide bioethics commissions. The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (1974–1978), the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1979–1983), and the National Bioethics Advisory Commission (NBAC), all have specifically chosen theologically -oriented people to populate these secular agencies.²²² Moreover, religious thinkers submit their input to publications that explore a myriad of concepts. These biomedical scenarios are not without religious controversy: covering topics such as children in research, the status of a fetus, stem cell research.²²³ The same holds in Canada. The overarching tones of Catholicism are present throughout Canadian legislation, most specifically, with federal funding for Catholic schools. The future of bioethics is never far from ‘morality’ as defined by various religions. Currently, it appears that religion is acceptable and accessible in hospitals, via chapels or meditation rooms, alongside clinical demonstration of cultural competency.²²⁴

Religion has always understood and even embraced the realities of illness and death. However, religion has its definition of death and proscribes permissions towards a dying person. Whereby religion counsels its believers on the rituals of death, these are stymied by modern technology. Some religious ethics have shaped themselves around this evolving reality. For example, Catholic religious ethicists emphasize 'ordinary' and 'extraordinary' care. Catholics are not morally obliged to seek out extraordinary care. This belief has been echoed within the *Catholic Ethical and Religious Directives for Catholic Healthcare*, formalizing its authority among Catholics in the US.²²⁵ Jewish families stand in juxtaposition to Catholicism, though;

Judaism simply strives to give every patient a chance at life; moreover, some Jewish ethicists do not view 'brain death' as real death. This notion is counterintuitive to the Harvard definition of brain death and serves as a classic case of religious ethics clashing with modern medicine. While medicine acknowledges cultural diversity, in the early 2000s, a shift towards secularism was acknowledged.²²⁶ Thus, creating the culture of a universal, shared morality that reaches beyond differences.

By attempting to mediate religious and secular approaches to death, some states have adopted a conscience clause. For example, the State of New Jersey has a large population of Orthodox and Hasidic Jews. As such, the State has legislated and developed a 'conscience clause' which allows for various interpretations of death.²²⁷ The law states that death is definable in several possible ways per cultural/religious norms. Nevertheless, this is simply not enough. The clause and subsequent policies do not elucidate the next steps if there is a conflict between religion and medicine outside of death and dying.

To fully understand and apply religious accommodation in a secularized sphere, it is imperative to consider the two separate legal realities of Canada and the US. Canada boasts the Canada Health Act (CHA) which mandates universal health care for each and every Canadian citizen. The CHA is a federal health insurance legislation which underlines conditions and criteria that provinces must satisfy in order to receive their health transfer.²²⁸ Federal-provincial relationships lord over health care in Ontario. This dissertation will specifically focus on Ontario, due to the prominence of religiously motivated cases in the province. While the bills are paid for by the Federal government, each province receives a health transfer which allows them to fund procedures and physicians accordingly. As a result, provinces are permitted to interpret the Canada Health Act as they see fit to ensure equality in fund distribution.²²⁹ To wit, most

provinces allocate money to universal health problems in which something is medically wrong with a patient as the Act states “...it is hereby declared that the primary objective of Canadian health care policy is to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers.” Defining what is insured versus what is covered via private funding is outside the scope of this dissertation.

An added complexity to the Canadian healthcare system is the formal legislation of religious rights. The Canadian quotient is a unique entity, due to the recent *Charter of Rights and Freedoms* (1980,) which legislates all clashes between individual religion and public secularism. According to several scholars, most notably Benjamin Berger, there are "limits to tolerance" that delineate within the parameters of law and policy in conflicts between religion within the public sphere.²³⁰ The Canadian Supreme Court emulates the perspectives of Rawls' 'social good' theory; in such solutions for conflicts that emerge between the 'social good' and individual religious beliefs must be determined by the as a case-by-case basis.²³¹ This pattern presents an apparent paradox: although religion is not as documentable or provable as science, it is and must subsequently be viewed as a truth from which believers make every decision.

Additionally, the understanding of the definition of ‘undue hardship’ in a Canadian context of religious accommodation is critical. The literature is mostly silent on considerations of the issue of undue hardship in a healthcare setting. Whereas there is a consideration of religion in Canadian employment law, and educational/disability accommodation, it emerges that as yet, there is a lack of discussion surrounding 'reasonable' religious accommodation within healthcare.²³² This shall be discussed in detail in the next chapter. However, while there are legal precedents that create better access to care for all communities, individual hospitals decide their

parameters for religious accommodations.²³³ The *Charter* appears to leave particular clashes of religion and law in the hands of judges to ascertain individually. Given the pressures mentioned above on the Canadian health system, judicial uniformity might be a desideratum of universally accessible healthcare.

There are some allusions in Canadian law for defining the scope of the limits of religious accommodation within the law and specifically within healthcare scenarios. Previously, precedents have been reached concerning the rights of religious minors, especially Jehovah's Witnesses and the rights of Aboriginal minors to forgo treatment.²³⁴ These cases, while religiously motivated to an extent, cannot serve as legal or ethical precedents since they involve minors and Aboriginal peoples who are in a protected class. Simply, these and other religious families view the physicians as forcing them to violate their religious beliefs to accommodate routine practices in medicine.²³⁵ Living in a liberal democracy brings about important discourses between the rights of secular law and individual religious rights. A more nuanced view of this would be religious *laws* clashing with secular *laws*.²³⁶ Canada currently permits religious law and even religious courts (the Jewish *Beit Din* as an example) to take command in lifecycle events. If Jews are permitted to marry and divorce religiously, are they not permitted to die following these religious traditions? The answer is based on principles of policy and economics: living within a socialized healthcare system permits accessible and equal healthcare for all citizens. Moreover, while some religious scholars have released edicts recognizing 'brain death' as true death—rather than historical, traditional religious understandings of death—not all worshippers know of or adhere to these edicts

Conversely, the United States has a fee-for-service healthcare system where care is parceled via private insurance companies. Hospitals are not federally controlled, but rather,

governed by a Board. The Board is responsible for crafting the budget and financial stewardship of the hospital.²³⁷ These Boards build the expertise and healthcare delivery of a hospital; choosing where the dollars are spent.²³⁸ Commonly, control of finances indicates control of the hospital and its organizational structure. The Board can choose which physicians to hire. As a result, they may choose to specialize in certain fields or research. The *Affordable Care Act*, created during the Obama administration, attempts to radically change the legislation and financial construction of American healthcare. Under the ACA, the shift in organizational structure and finances is transformational. The ACA demands finances to be allocated in a way that requires moral considerations above and beyond the moral agency of a particular hospital. Rather than be financial stewards, the ACA shifts the powers of a Board towards quality management. They will be stewards of more limited financial resources and will be responsible for community care.²³⁹ While ACA strips the Board of most financial responsibility, they are encouraged to show greater transparency in spending, including being paid for performance. The religious versus secular argument in American hospitals is defined as a conflict of conscience or a conscientious objection. Any healthcare practitioner may refuse to perform certain procedures (notably, abortion, assistance in dying,) due to religious beliefs.

Healthcare providers in the US can recuse themselves from treating a patient (or in the case of pharmacists, dispensing medication,) that conflicts with their religious morals. However, some literature indicates that a physician, in particular, cannot object to anything that is medically justified. Doing so would be antithetical to the Hippocratic Oath.²⁴⁰ However, the issue of conscientious objection by medical professionals is not one-sided. Objection and conscience is important. Indeed, the European Convention on Human Rights respects conscience and religious belief. Ethical analysis of conscientious objections have been done by Wicclair

who cites four main reasons to allow such objections. They include: showing respect for autonomous choices, promotes tolerance for diversity, personal views on a subject may be different and; ensuring that anyone can chose a profession of their choice, regardless of their objections.²⁴¹ This analysis falls short and is perhaps simplistic. Certainly, physicians and nurses may see and do things that shake their moral core. However, promoting one's own moral inclinations over and above professionalism would not be tolerated in other professions. How these conflicts are mitigated shall be discussed in detail in Chapter 3.

2.B. Philosophies of Private Practice within Public Spheres

Rawls' ideal of a 'public square' is an apt visual for understanding how religion is at once public and private. For Rawls, a public square consists of institutions based upon basic principles of justice. These would include government, hospitals, and publicly funded schools. A private square (smaller in size) is for personal religious beliefs.²⁴² The two exist harmoniously, each within the other but never influencing each other. Indeed, the very depiction of the separation between church and state. All religions are equal under the government. Someone strolling into the public sphere to express religious principles is simply not tolerated and according to Rawls, such an individual would be guided by the concepts of "civic virtue." For Rawls, there are intrinsic values that everyone simply agrees upon, despite individual religious differences. Just as Taylor and Veatch assert, there are normative, core values which are universal. When entering the public square, one leaves individuality and religion at the (invisible) door. Not doing so shows disrespect for fellow citizens.²⁴³

Another Rawls theory can further illustrate the dichotomy between public and private values. For Rawls, justice is equated to fairness; personal decisions and judgments are made in

(optimistically) total impartiality. To wit, the ‘veil’ and ‘original position’ simply cannot and perhaps do not exist in a religious mindset. Indeed, one cannot be divorced from religious beliefs in medical decision-making, ‘veil’ or no. “The right and the good” of society is applicable only to those who can don this veil. Religious patients however, may only be able to dawn a ‘veil of belief.’ This concern will later be mitigated using the modified sliding scale, discussed later in this section. Rawls promotes appreciation of reciprocity. That is, the private/public spheres sharing and learning from each other. Bringing a religious speech into the public square of a hospital should be supported, as it would educate others. Religion is not merely a list of commandments and prohibitions; it is a livable, malleable form of social commitment.²⁴⁴

The notion of what constitutes a public good is further elucidated by Rawls. According to him, the social contract is “rights-based.”²⁴⁵ In order to subscribe to this social contract theory, there are basic assumptions made about what is considered a ‘right.’ To that end, Rawls institutes the notion of ‘original position’ whereby there is an agreement that there is “...something essential to the activity of moral reasoning...” but also conceived (and decided upon,) socially, as a collective.²⁴⁶ Presumably, the collective has similar views and moral reasoning which allows them to reach fair justice. This is the understanding of simple social contract theory and therein lays the essential problem. Socialized health care systems may be considered micro social contracts. Social contract theory, particularly Rawls,’ assumes that all individuals possess the same moral core when stripped of all circumstances. However, this is not the case in a multicultural society; not all societies and cultures believe in the same hierarchy or code of morals. This understanding is the key to speaking to a religious patient on their terms.

Thus, in an evolving political climate and without a true definition of secularism, the concept of privacy practiced within public spheres is a daily occurrence in hospitals. Indeed, the philosophical notion of ‘indigenous pluralism’ can aptly describe the current environment. Indigenous pluralism is not a Rawlsian concept. However, it can assist with Rawl’s public sphere imagery. Rawls’ concept of public sphere and private spheres are not realistic in modernity. Thus, indigenous pluralism can assist in coping with issues that may arise when different religions hold different views on medical intervention.²⁴⁷ While the aforementioned conscience clause acknowledges the belief system of various groups, indigenous pluralism forces the religious group to consider the beliefs of *others* as well. This also echoes Rawls since a true public citizen would be respectful of what is best for all citizens. Indigenous pluralism is at its core a two-way mirror. It gives various religions and cultures the right to their beliefs so long as they respect the religion and cultures of others. Respect is merely tolerance. It does not necessarily mean acceptance.²⁴⁸ To clarify, while the New Jersey clause technically allows for brain death to be nullified for Jews (albeit, for a pre-allotted time period,) the notion of indigenous pluralism forces the Jewish community to consider the macro population. Indeed, religious beliefs should be upheld but only when considering the cost to the greater society. Together, the concepts of indigenous pluralism creates a balanced system: while the State recognizes the religious objection to brain death, the ultimate cost to society cannot be ignored. This further allows for gradations in interpretation of religious law and ethics, since not all Jews, Muslims or even Christians practice alike. A conscience clause, via indigenous pluralism, allows for hermeneutic diversity.²⁴⁹ It may also lead to policies and laws being changed to reflect this multiculturalism. Hence, religion does have feasible impact on laws and policies. Whether indigenous pluralism serves as a setback for secularism however, remains to be seen.

Additionally, indigenous pluralism can be interpreted as simple but it is far from an easy fit. It may not be a truly practical solution to already existing policies and law.

Rawlsian ethics has been actively applied to healthcare situations²⁵⁰. However, this thesis goes a step further. Whereas Rawls himself did not apply his theories to healthcare, healthcare can learn from how his concepts have fared in the realm of public school education. Rawls' notion of 'public good' as it clashes with religion builds the foundation for the ethical framework of undue hardship. For Rawls (and in some regard, Taylor and Veatch,) society has a unified understanding of what is reasonable. In other words, there is a 'dominant consensus' innate within society.²⁵¹ This so-called unified reason is a rationale useful in demonstrating that public education is a public good and thus, 'reasonable' accommodation is equitable. Applying this 'reasonable' standard to medicine, however, proves more complex.

2.B.i. Rawls 'Public Good' and religion

While some scholars may dismiss Rawls' (and his contemporaries') theories as being idyllic, there is a greater question that begs discussion. Rawls describes a more nuanced theorem, whereby the social contract is "rights-based." In order to subscribe to this social contract theory, there are basic assumptions made about what is considered a 'right.' To that end, Rawls institutes the notion of 'original position;' whereby there is an agreement that there is "...something essential to the activity of moral reasoning..." but also conceived (and decided upon,) socially, as a collective.²⁵² Presumably, the collective has similar views and moral reasoning which allows them to reach fair justice. This is the understanding of simple social contract theory and therein lays the essential problem. Socialized health care systems may be considered micro social contracts.

Barely fifty years ago, Canadians considered free healthcare ‘socialist’ and protested it coming to Canada. Now, governments of all political leanings support it heartily as a pillar of Canadian identity. By virtue of paying tax dollars, the social collective (tax payers) agree to restore *everyone*’s health, since the collective equates free and accessible health care with justice. But, how far does this social contract with health care extend? Social contract theory, particularly Rawls’, assumes that all individuals possess the same moral core when stripped of all circumstances. Thus, bringing Rawl’s theory forward, partaking of the healthcare system assumes a similar level of morality. For Rawls, there would be no religious objections to removal of life support mechanisms and the like. Hence, can a Canadian healthcare system ethically support two finitely different categories of citizens: those who are ‘Rawlsian’ in morality and those who are religious?

A further concept of social contract theory, and one that further complicates the discussion, is Rawls’ Two Principles of Justice. The First Principle is simply understood as attributing equal rights to extensive basic liberties. The Second Principle concerns social and economic inequalities being equalized to promote the best opportunity for all. These Principles are both immediately considered by Canada’s healthcare system. After all, the healthcare system is accessible to all citizens, regardless of social and/or economic inequalities. Free access to healthcare, regardless of whether a patient requires a shoulder reset or a barrage of surgeries and treatments, alleviates the economic stress. Rawls’ former principle concerns equal rights and liberties, which too are subsumed by Canada’s constitution and *Charter*, which guarantee equal and extensive rights for all regardless of gender, creed or religion.

For Rawls, justice is equated to fairness; personal decisions and judgments are made in (optimistically) total impartiality. Behind one’s ‘Veil of Ignorance’ the adjudicator is shrouded

from personal circumstances and can thus focus on the decision to an equitable and fair judgment, unbiased by other factors. Opponents to Rawls comment on the lack of veracity to his 'Veil', particularly in the medical field where diagnosis and treatment is adapted to a degree due to cultural differences (i.e. modest hospital gowns, Jehovah's witness blood transfusions, etc.) Importantly, however, Rawls' theory is perhaps most aware of its own flaws. Indeed, the theory stands to "... 'justify...'" certain principles of rightness as preferable to competing systems or theories of justice .²⁵³

Yet, by assuming a natural predilection towards determining justice, Rawls' theory no longer takes into account today's multi-cultural reality. To wit, the 'veil' and 'original position' simply cannot and perhaps do not exist in a religious mindset. Indeed, one cannot be divorced from religious beliefs in medical decision-making, 'veil' or no. "The right and the good" of society is applicable only to those who can don this veil and I shall attempt to prove that for religious believers, there is simply not compatible since they don a 'veil of belief' instead.

Whereas Rawls' veil serves to create a unanimous decision for the greater good, these decisions do not necessarily harmonize with religious principles. There are several more troubling concerns with social contract theory, particularly when considered in relation to religion and to medically futile situations in particular: Does an individual's 'religious contract' circumvent the social contract? In a socialized health care system, it can be asserted that social contract theory can indeed surpass religious beliefs, particularly in situations deemed 'medically futile.' While becoming a taxpayer allows a citizen to 'opt into' the social health care contract, there is also an implication they will responsibly 'opt-out'. According to the *Canada Health Act*, the government only pays for healthcare that is determined to "restore" health. Thus, if a health care intervention is not restorative, the 'opt-out' clause of the social contract is enacted. This

concept can be solely be determined by the gatekeepers of healthcare and its scarce resources: the doctors. Whereas religious leaders may comfort a patient and offer counsel, the physicians alone have the unique knowledge of both the scarce resources and the value in supplementary medical interventions.

2.B. ii. Public Good, public schools and religion

In a court setting, a hospital is obligated to accommodate a patient's religious belief until the point of undue hardship. In the legal realm, the definition of undue hardship presses onus upon the institution to show that if they accommodate a particular belief, it would "...require[ring] significant difficulty or expense" when considered in light of a number of factors."²⁵⁴ Undue hardship cases are not blanket legal decisions, rather, they are adjudicated on a case-by-case basis.²⁵⁵ Much like Rawls' idea of a social construct, arguably, religion is a binding community with individual moral codes.²⁵⁶ A believer would insist that the hospital is pressing undue hardship on them, since they are unable to fully participate in religious medical decision making. In both the USA and Canada, health care is seen as a public good, and most hospitals are understood to be a secular institution. American Catholic hospitals hold a distinctive place and space and will be addressed elsewhere in this dissertation. Thus, how can bioethics create an ethical understanding of undue hardship? American public schools offer a likely philosophical precedent.

American public schools are free of religion and meant to serve the public; offering education that is free and fair for all.²⁵⁷ Children are free to form extracurricular religious groups that may engage in prayer, religious activities and the like. These are not sanctioned by the public school per se, but offered on a voluntary basis. Students who self-identity as religious and wish to participate in these groups may do so voluntarily.²⁵⁸ The public school thus acts as a

passive observer and will intervene if there is a concern of student safety.²⁵⁹ Some religious groups have been disbanded by public schools due to safety issues (in this Court case, a student Christian group actively encouraged bullying of suspected LGBTQ students.) When taken to court, the ban on being permitted to disperse even religious groups is upheld.²⁶⁰ This is an important and imperative distinction. While public schools must accommodate religion, they are responsible for generalized education and must step in when religious accommodation jeopardizes this objective. Further, public schools specialize in children and their ‘best interests’ in education. When voluntary religious groups are contrary to this interest, public schools are within their right to no longer sanction the group.²⁶¹ Public education is a public good. Since the religious groups are formed under the umbrella of that public good, it has to conform to the rules and expectations of that good. Once the religious group imposed on public values, the school was within its ethical imperative to ban it. By forming the group, it was silently understood that they would conform to the notions of the public good.

2.B. iii. Applying Rawls and ‘public good’ to religion and bioethics

While the literature skims the issue, the ramifications of religious-based healthcare are apparent. Whether and how can religious accommodations be enveloped into patient safety? For instance, there are significant ethical concerns when a patient lacks choice in the case of Catholic healthcare institutions in rural settings. For example, patients who need timely abortions (for medical or personal wishes) may have to travel beyond their home state to find a non-Catholic hospital. There are further ethical concerns when a patient requests care that lies outside the parameters of standard of care because of religious reasons. While Rawls did not live to see the medical/technological age we are now in, nor the court cases brought forth by religious believers,

he did address bioethics via his themes on justice, conscientious objection, and abortion. Using his own arguments as a foundation, this section will demonstrate a deeper need for firm parameters to guide religious accommodation in healthcare settings.

Rawls understood that religious beliefs encompass all decisions. However, unlike Taylor, Rawls does suppose there is a shared, societal rationality. Indeed, the citizen's concern for his neighbor outweighs his personal, religious beliefs. 'Mutual respect' is the guiding principle of a Rawlsian society. Conscientious objection (in the case of this dissertation, religiously-prioritized decision making,) only benefits the individual. It protects them and enshrines them in the sanctity of their tradition, but the greater liberal society cannot benefit. If, however, a decision was made based on true moral concerns, this is beneficial to society since it demonstrates respect for morality.²⁶² For a 'Western-secular' society, 'true moral concerns' is a problematic notion. Indeed, any believer insists on his faith being a true moral concern. Thus, a mere philosophical approach will not resolve conflicts between medicine and religion. The foundation for objection in those circumstances cannot be removed from its religious underpinnings. This argument can extend to institutions, especially in Canada where even Catholic hospitals are funded by the public purse. As a result, they need to offer public services for the public good. Canadian Catholic hospitals thus have different principles allowing them to morally cooperate in ways that are somewhat divergent from Catholic hospitals in the US.²⁶³

Echoes of Veatch are apparent when stretching Rawls' theorem further. According to Veatch, a physician cannot serve two masters. Thus, a physician's professional Code of Ethics cannot be trumped by his religious morality. Otherwise, he is in disservice to the profession and to his patients. His medical training and professionalism cannot be subsumed by conscientious objections, since that is again, bringing his private notions into the public sphere. For Rawls and

other philosophers who analyze his theories, the ideology of a physician as a public servant is sacrosanct. Concepts of basic justice must be maintained without religion.²⁶⁴ In his day, Rawls did address abortion, since it is a classic case of religious morality grappling with societal mores. Rawls supported a woman's autonomy over her body and her reproductive choices. There is also a political component built into his argument. Indeed, for Rawls, a fetus does not have an intrinsic right to life, since it is not yet an adult citizen. This is controversial as this too betrays a moral (perhaps anti-religious) notion that a fetus is not equal to a developed adult and thus, not deserving of consideration.²⁶⁵ Rawls is careful to delineate that abortion is not murder, again based on political conception of public good and reason. His consistent striving to free society from privately held religious notions, does not permit him to wholly participate in adjudicating moral issues in medicine. Indeed, Rawls states that "respect for persons as free democratic citizens requires that metaphysical and epistemological questions of the foundations of justice be avoided in public reasoning about justice."²⁶⁶ Rawls calls for different gradations of citizenship which could assist in making decisions in a purely political and public sensibility. However, when considering when a fetus becomes akin to personhood, Rawls own argument falls short, save for more developed fetuses (i.e. in considering a later-term abortion.) Yet, we are blessed to currently live in an age where even premature, sickly neonates can indeed fully develop into adult citizens; thus, again destroying Rawls gradation of citizenship and development. Thus, if technology can assist in helping fetuses develop in full-fledged citizens, they too deserve political protection and justice.²⁶⁷ They too can participate in the public sphere and benefit from the public good. It would appear that in difficult moral clashes—indeed, cases where undue hardship may be raised, Rawls' public good theory can only be extended so far in the 21st century.

Thus, to truly establish a philosophical analogy where the public good can be considered outside of religious decision making, as evidenced in public schools, it is essential to marry Rawls' to the more modern concept of indigenous pluralism. Just as Taylor reveals, there cannot be a true, purely secular rationality. There is, (perhaps to Rawls' indignation!) a quiet religious morality that quietly runs underneath secularism. Thus, indigenous pluralism forces the religious group to consider the beliefs of *others* as well. Indeed, a very modern exemplar of Rawls; forcing even niche religious groups to consider the greater society. Indigenous pluralism is at its core a two-way mirror. It gives various religions and cultures the right to their beliefs so long as they respect the religion and cultures of others. Respect is merely tolerance. It does not necessarily mean acceptance.²⁶⁸ Whether indigenous pluralism serves as a setback or helpmate for secularism however, remains to be seen. It is clear however that consideration of the greater good is essential for creating an ethical framework for religious accommodation and undue hardship in secular healthcare.

3. Defining Undue Hardship in Accommodation in Healthcare

The preceding chapter demonstrated how Rawlsian philosophy can indeed be applied to the notion of ‘public good’ within medicine. As a further aid to this argument, this chapter will explore the novel, ethical definition of undue hardship. Understanding and defining this term within the confines of medical ethics is essential to applying it to specific case studies later in this chapter and in more complex situations as presented in chapters 4 and 5. This chapter introduces a new ethical definition for undue hardship however, it is still a framework definition, allowing it to be modified and changed as technology and even religion allows.

This chapter compares philosophy to philosophy. That is, appraising the notions of individual and organizational moral agency within the context of ethical undue hardship. Through exploring moral agency and undue hardship, the limits of accommodation can be better accessed at both individual and institutional levels. This analysis is illustrated neatly vis a vis case studies of abortions (institutional morality—namely Catholic hospitals) and individual moral agency (individual morality—namely ultra-Orthodox Jews). This question will be explored by scrutinizing the regulations that exist within specifically US-based Catholic rural hospitals. How religious and personal ethics may clash within this system (through conscientious objection) is demonstrated differently in the USA and Canada in secular and religious hospitals. This chapter also explores the opposite—what are the limits to personal religious agency within a secular system. This too will be documented through both Canadian and USA lenses.

While chapter 4 documents how religious theology can be shaped to accommodate changes in medicine, this chapter focuses on the secular understanding of whether and how to accommodate religious moral agency. Healthcare accommodation is a two way street. While hospitals must understand and accommodate certain religious principles, religious principles

must also accommodate normative secular ethics. This chapter dissects the latter notion of that statement. Can a rural Catholic Hospital adhere to all notions of religious moral agency when faced with a possibly fatal condition? Likewise, can an ultra-Orthodox Jew reap the benefits of organ donation without ‘giving back’ to the system, in keeping with his understanding of individual moral agency?

3.A. Understanding Undue Hardship and Reasonable Accommodation in Canadian and American Legal Contexts

This thesis using the scaffolding of legal and policy precedents to create an ethical framework and definition for undue hardship. Thus, it is essential to fully comprehend the definition of those terms in both Canadian and American legal contexts. However, this is not a legal or policy analysis. Rather, this exploration serves to demonstrate how the legal definitions of the terms are bereft of true, definable categorization. Thus, the emergence of an ethical framework is so necessary in healthcare.

In Canada, human rights (the categorization of law that undue hardship and reasonable accommodation fall under,) is governed by the Federal Charter of Rights of Freedoms. Each province governs their own Human Rights Commission. For ease, this chapter will consult the Ontario Human Rights Commission for definitions.

Legally, organizations have “...a duty to accommodate to the point of undue hardship...”²⁶⁹ Reasonable accommodation is defined as: “something done to accommodate a disabled person that does not jeopardize safety or pose an undue hardship for the party (as an employer or landlord) doing it also; something done to accommodate a religious need that does not create undue hardship for an employer”²⁷⁰

There are only three considerations which can contribute to undue hardship in accommodation: cost, outside sources of funding, health/safety requirements. There are no other valid, legal concerns which can be considered in a place of employment. The burden of proof of undue hardship rests on the organization, not the individual. It must be quantifiable via evidence which may include expert opinion, financial statements, scientific data, etc. According to the Supreme Court of Canada, cost of accommodation is further definable, to prevent organizations from too easily claiming hardship. Costs can only be considered undue hardship if they are: “...quantifiable, related [directly] to the accommodation and; so substantial that it would alter the nature and/or substantially affect the viability of the enterprise.”²⁷¹ Outside sources of funding must be sought out by the employee to assist with the cost of accommodation (when applicable/available.) Further, health and safety concerns are further detailed to truly consider risk assessment in deciding whether waiving a health/safety requirement to provide an accommodation is reasonable. Notably, if waived, would this pose a risk to others? Would this risk be tolerated by larger society? Risk management and assessment are unique to every case and circumstance.

Whereas the Canadian *Charter of Rights and Freedoms* encapsulates religious accommodation under the same legal umbrella aforementioned, America lacks such detailed *Charter*. Instead, Title VII of the *Civil Rights Act of 1964* protects discrimination against religion in employment situations. The wording of Title VII is explicated differently than the Canadian *Charter* and undue hardship is less detailed and carefully delineated. Indeed, an employee is allowed to refuse to accommodate a religious belief if it would impose undue hardship. In America, undue hardship is defined as ‘more than minimal’ and examples of that are”... violating seniority system, causing a lack of staffing, jeopardizing security or health,

costing...more than the minimal amount.” The U.S. Equal Employment Opportunity Commission advises that each accommodation be considered on a case by case bases.²⁷² The US Department of Health and Human Services has further legislation guiding healthcare vis-à-vis a “Protecting Statutory Rights in Health Care Rule” This is a new rule, scheduled for Fall 2019 but has been delayed. If successful, it would assist in protecting those healthcare workers who conscientiously object to participating in certain services/procedures due to their religious beliefs.²⁷³ This procedures include, but are not limited to, abortion, sterilization, and assisted suicide. The legalisation proffers its own characterizations of reasonable accommodation and undue hardship. Accordingly, an accommodation is one that “*eliminates* conflict ...rather than reduce the conflict.” Their undue hardship definition goes beyond the Canadian definition, to include: whether other employees will be overburdened and the number of employees who request the same accommodation. Much like the Canadian *Charter*, the Rule indicates that cases be mitigated on a case by case basis.

Whereas Canada and the United States of America have ample legislation concerning reasonable accommodation and undue hardship, there are significant chasms in the case law and legal literature. The law supports individuals going against an institution. There is no such legislation protecting an institution (i.e., a Catholic or Jewish healthcare institution) pressing their own religion on non-practicing patients. Further still, while undue hardship has been visited time and again in Canadian courts, judges and even hospital policy-makers are hesitant to draft formal guidelines that are unique to healthcare. That is, whereas an accommodation can be acceptable within a workplace environment (as both Laws currently indicate) healthcare is a completely deviant environment. The rules of healthcare cannot be found in other workplaces. Medical technology progresses quickly. Decisions need to be made equally quickly. Resources

require equitable allocation. Unlike employment or educational/disability law, patients are not necessarily procedural. Each circumstance and pathology is unique. As such, perhaps the silent Courts are correct. The Law is not an appropriate avenue by which to proscribe religious accommodation within healthcare. Ethics, with its direct immersion in the realms of law, policy, philosophy, theology and medicine is best equipped to create such parameters. Thus, it is essential to explore what can be properly and *ethically* identified as undue hardship in both individuals and institutions. It is easiest to begin with the individual patient within a secular hospital setting.

3.A.i. Individual Moral Agency and Undue Hardship

Religion's importance in life and medical decision making cannot be underestimated. A religious patient may find it difficult to render a medical decision completely divorced from his religion. A religious patient consults leaders and teachers in his religious tradition to guide his decision-making process. This begins a complex dialogue between an often centuries old tradition as it encounters modernity. Religious hospitals are built around the same parameters to offer best care and best religious comfort to patients. Roman Catholicism has a long history in North America. As a matter of religious practice, healing the sick is an ethical imperative.²⁷⁴ Families were living in cramped quarters, and placing very ill patients in a hospital's care allowed for the continuation of daily living by well family members.²⁷⁵ Many of these hospices were Roman Catholic. Catholic hospitals maintain a moral culture which all staff must follow. Following Catholic thought is the moral imperative; the rock upon which the hospital is built.²⁷⁶

Jewish hospitals have a long history in North America as well. Traditionally, these hospitals were built out of need as Jewish residents were not permitted to have post-graduate

education in Christian hospitals.²⁷⁷ Since most fundraising was accomplished by Jewish mothers for their doctor-sons, Jewish hospitals were specialized maternity centers.²⁷⁸ Dietary laws were observed and rabbis took chaplaincy roles. In contrast to Catholic hospitals, Jewish Law (*halakha*) was not foundational within hospital walls. Thus, to provide apposite analysis, Israeli hospitals are considered in this particular chapter. In Israel, the Health Ministry is governed by *halakha* (literally, meaning ‘the path’; Hebrew term that means Judaic Religious Law).²⁷⁹ Subsequently, Jewish Law is followed in all matters. While both religious traditions enjoy a long history in healthcare, religious-based medical decisions may prove dangerous. Indeed, by promoting a religious moral culture, medical care may be compromised. The Israeli methodology has been creative: they have created committees, machinery and even monetary incentives to mediate the Law and medicine. While Scripture determines Catholic teachings, final authority rests with the Vatican.²⁸⁰

However, the crux of this chapter concerns itself with consideration of ‘undue hardship’ and patient safety. Indeed, while the right to religious freedom is sacrosanct, it may compromise best medical judgement. Law and hospital policy are hesitant to define ‘undue hardship.’ Perhaps then, it is time for ethics to shape a definition. This thesis attempts to do solely that; to create an ethical definition and application of undue hardship. Indeed, rigidity in religious doctrines applying to healthcare may be risking patient care. It is thus essential to explore the concepts that surround typical undue hardship applications.

Moral agency and moral culture in healthcare settings often betray tension. While moral agency can determine individualized actions, the moral culture of a hospital may be juxtaposed. In financially strained healthcare system, ethical tensions can detract from patient care. Conflict between an individual’s moral agency and an institution’s moral culture can undermine an

organization's mission. Further, a moral agency of a healthcare provider is shifted into what is considered a 'greater' moral culture. Rather than enforcing moral minimums, the Hospital attempts to create collective moral ground.²⁸¹ There are conflicts however when moral agency and moral culture juxtapose each other at the beginning of life, the end of life, and organ donation. In a secular healthcare setting, a religious patient's moral agency may compromise what physicians consider best care. Thus, it is interesting to see how hospitals design their medical interventions to conform with religious principles.

The core of this chapter is concerned with the concept of undue hardship, specifically in the context of religious moral culture. Undue hardship is a companion of what is legally called 'reasonable accommodation.' Undue hardship can be presented when reasonable accommodation cannot be provided. In most cases brought before the Courts, 'reasonable accommodation' is generally assumed to be the medical institution accommodating the religious patient. This chapter purports to flip the onus of accommodation. Thus, the question becomes whether and how the non-religious patient is accommodated within a religious hospital. This is a far more nuanced query, particularly in Catholic settings when certain medical interventions are prohibited. By using an ethical framework, this chapter hopes to establish a more precise definition for undue hardship. Such a definition would better serve the medical world when nuance is important. A (working) ethical definition of undue hardship is defined thusly:

Utilizing the previously described notions of hardship within the confines of human rights Law, this thesis's purported definition of undue hardship is understood to be withholding or refusing any procedure which would be considered 'best medical practice' and/or 'standard of care.' This is exhibited in two distinct fashions. First, within a religious healthcare institution, (such as a rural Catholic hospital), such a religious healthcare institution must morally cooperate

with societal values as dictated by secular policies and aforementioned best standards of care, especially in life-limiting circumstances; and/or, if there is not enough time to find a secular healthcare institution. As such, refusal of care, or limited care when full treatment is medically obligated, would be judged as unethical. Failure to provide adequate medical care is a broader moral concern in which complicity is unethical. Secondly, when an individual patient requests care which is over and above the standard of care, it too may be denied due to undue hardship. In this case, again, societal values and secular policies dictate that standard of care. Where a patient and/or their family is entitled to garner a second opinion, resource allocation and equity protocols demand adherence to definable best medical practice.

3.A.ii Religious and Personal Ethics

In a religious hospital, the tension between moral agency and moral culture is a permanent undercurrent. Religion is a binding community with individual moral codes.²⁸² Religious directives and legislations obviates individual moral agency by dictating new universal norms in the realms of both moral agency and culture to staff. This compels both organizational and ethical changes.²⁸³ How institutions confront the challenges presented by moral choices unique to their religious belief becomes philosophically interesting in healthcare. Indeed, all staff (consciously) and all patients (perhaps unconsciously,) shift individual moral agency to combine with the moral culture. In healthcare, moral complicity can be irrevocably damaging.²⁸⁴ In a religious hospital, a physician is a dual agent; representing ‘best medical practice’ alongside the religious moral culture of his institution.²⁸⁵ Under a religious healthcare lens, there are difficulties surmounting the concepts of moral agency, moral complicity and moral cooperation. Notably, there is a lack of literature that focuses on institutional and religious moral agency specific to healthcare. Subsequently, the literature focuses exclusively on the challenges

encountered by moral agency in religious healthcare settings. As such, queries of loyalty, engagement and organizational structure are apparent. So too is the challenge of whether and how moral complicity and cooperation can be terminal in a religious healthcare setting. Concerns of moral complicity and moral cooperation clashing with personal ethics are most apparent with Catholic healthcare, as illustrated in the infamous Phoenix case. Indeed, the circumstances surrounding this case construct further demand for an ethical notion of undue hardship in healthcare.

In 2009, a young woman was admitted to the St. Joseph Hospital and Medical Center in Phoenix, Arizona due to pulmonary hypertension. She was advised by doctors to terminate the pregnancy due to her ever-worsening condition. After some tests, it was understood she was in far worse shape than previously indicated. Indeed, the physicians believed that both lives (mother and fetus) were in jeopardy and would prove fatal if the pregnancy continued. The patient agreed to the termination. However, since she was already so ill, she could not be relocated to another (non Catholic) hospital. Thus, her case and how to proceed was sent to the Ethics Committee who, under the *Ethical and Religious Directives*, noted that an abortion may not be performed, even in this circumstance according to Directive 45. However, Directive 47 allows ‘indirect abortions’ if the intent is not to abort the fetus, but to save the mother. Subsequently, Sister McBride of the Ethics Committee sanctioned the life-saving abortion. Somehow, the Bishop heard about the case and deemed the procedure enough to excommunicate the Sister and the Hospital from Catholicism.²⁸⁶ Naturally, Catholic commentary (and the secular ethics world) debated the morality of each angle of the case: from the actions of the Committee, to the physicians, even the Bishop.

From the Phoenix case, there is indisputably a foundational concern of patient safety within religious hospitals. Physicians who deem abortions medically necessary are denied the right to perform them, due to the Catholic Directives.²⁸⁷ Some physicians who find themselves medically opposing the *Directives* in certain cases ultimately resign from the Catholic healthcare system.²⁸⁸ Arguably, whereas patients may refuse treatment due to religious beliefs, medical professions cannot have medical appropriateness stymied due to religious beliefs. In a large city, a patient may be able to find another provider, even in an emergency. However, Catholic hospitals purposefully serve underinsured and the poor. These two components obviously clash. Catholic healthcare institutions have a right to showcase their religious identity.²⁸⁹ Yet when this identity compromises patient safety, it deserves to be reassessed. The issue of patient safety surpasses even conscientious objection. According to a recent study, physicians at some Catholic hospitals had difficulty managing ectopic pregnancies as per best medical practice.²⁹⁰ Catholic ethicists advise treatment without taking ‘direct’ action towards the embryo. According to the study, these patients lacked full choice of options and were exposed to unnecessary risk.²⁹¹

3 B. Organization Moral Agency and Undue Hardship

This chapter seeks to appreciate the secular understanding of undue hardship as it compares to a religious understanding. Indeed, most hospitals in North America happily boast a multicultural clergy staff, kosher food option and in some facilities, prayer spaces.²⁹² Anecdotally, some hospitals are happy to provide same-gender physicians when possible, alongside more modest hospital gowns.²⁹³ Most healthcare institutions allude to cultural competency being an integral part in medical care. The literature indicates a further importance for enabling spiritual or religious accommodation in hospital. By all accounts, secular medicine appreciates the importance of religion within their patients’ lives. However, cases of undue

hardship and accommodation are mainly brought to bear when patients feel their medical care is compromised and their religious concerns unheeded.²⁹⁴ Often these are end-of-life cases or involving paediatric patients.²⁹⁵ For a secular hospital, the ethical definition of undue hardship rests on providing the best standard of medical care.

3.B. i: Institutional Moral Agency and Faith

The moral agency of a religious hospital is part and parcel of its moral culture. To wit, what the institution deems to be ‘moral’ is a fundamental component of identity.²⁹⁶ Thus, there is an ethical contention at the outset. Moral agency is understood individually.²⁹⁷ However, a religious hospital governs individuals towards one moral, religious culture. As such, the moral obligations of an individual are swallowed by the moral obligations of the institution.²⁹⁸ As this chapter will later develop, religious understandings of morality may also threaten patient safety. In religious healthcare, the religious moral culture is arguably the largest stakeholder in decision making. Traditionally, a stakeholder would have a multiplicity of loyalties and must balance each in turn. The religious hospital has a singular loyalty that individuals must subscribe to. A healthcare professional has further ethical guidelines, outside of religion, developed through a distinct Code of Conduct. While these Codes are often parallel in ethical instruction, it can sometimes create tension among stakeholders.²⁹⁹ Hence, for stakeholders, moral culture trumps moral agency. Ordinarily, stakeholders are concerned with the business of healthcare and economic goals of the hospital.³⁰⁰ Assigning religion as the fundamental stakeholder forces complicity or cooperation with religious moral agency.

Moral complicity is often predicated by dissenting views on intention/intentionality.³⁰¹ It is a harbinger of concern when it affects what is considered best medical practice. Physicians are ethically permitted to withdraw themselves under the premise of conscientious objection.³⁰²

However, in a religious healthcare setting, this may not be possible. It is understood that certain hospitals hold certain moral values. Layers of ethical complexity are thus added. Religious healthcare institutions strive to create moral communities.³⁰³ Developing this moral community perhaps eases fears of moral complicity. Indeed, religious morality is under the guidance of God. Hence, by aligning one's moral agency with the community, complicity is religiously and morally prescribed. God as a "...unifying maypole" is an anthropological concept.³⁰⁴ Yet, it is a suitable concept for this discussion. A physician has two masters: the institution and a professional Code of Conduct.³⁰⁵ Religious moral complicity may even provide a guise of safety. To wit, medicine is ethically complex. Certain medical controversies have agreed-upon outcomes in religious healthcare settings.³⁰⁶ Thus, moral complicity is moreover permissible, since it can be dismissed as hospital policy.

Indeed, the ethical complexity of medicine is sharply definable through abortion. Through a secular ethical assessment, abortions are medical interventions. Within a Catholic ethics assessment, however, abortion proves more complicated as most abortions are viewed as evil acts, under the *Religious and Ethical Directives* within the United States. While the Catholic ethical approach towards abortions is famous, it, interestingly, is not well known to all. In particular, patients who may not be Catholic (but seek care within a Catholic hospital,) may not know that the hospital will nonetheless apply the *Directives* towards them as well. is an interesting schism which may require clarification in the future. As illustrated in a 2020 empirical study women who received reproductive care at Catholic hospitals were not aware of all the restrictions a Catholic hospital would impart, particularly if they themselves were not of the faith. They wished that they had requested more transparency and/or that these policies were clearly outlined either on the Hospital website or else, orally dispensed while checking into the

Hospital itself. The women surveyed responded that had they been aware of all the religious restrictions, they would have sought care elsewhere. They did, however, state respect for the Catholic hospital's religious rights, they just wished, as non-Catholics, for greater transparency. This need for transparency and the Catholic *Directives* towards a fetus's life is an ever pressing concern, especially for Americans who may only be near a Catholic Hospital³⁰⁷ As of 2016, 46 Catholic hospitals were deemed "sole providers" for a community. This is defined as another, non-religious institution being 35 miles away or greater.³⁰⁸ Thus, while the Catholic healthcare institution is entitled to its moral agency and faith, how this impacts the average patient seeking healthcare, especially in a rural area, remains a problem requiring a solution.

As a further indicator of non-compliance with the Catholic *Directives*, is the exploration of conscience objections. These objections do exist in Canada, however conscience objections draw more attention in the States. In Canada, while a physician/nurse may certainly object to abortions or assisted death, they are also provincially mandated to cooperate in locating the services for their patient. A patient cannot be 'abandoned'.³⁰⁹ As discussed elsewhere in this dissertation, Canadian Catholic hospitals are federally/provincially funded which mitigates how the ERDs are carried out. Further, the Supreme Court of Canada stipulated in a 2015 ruling that the Canadian federal government has one year to legislate physician assisted death in the country. The original frameworks for physician assisted death (currently called 'medical assistance in dying' or MAID,) stipulated that *all* hospitals that receive government funding are duty-bound to either provide these services, or otherwise cooperate to ensure a patient receives the service. While the Catholic Health Sponsors of Canada released a statement vehemently disagreeing with the Supreme Court's decision, as of the writing of this dissertation, the issue has yet to be finalized.³¹⁰ As a result, this dissertation will consider American-based conscience

objections and conscience clauses. Additionally, this is due to the uniquely rural American Catholic hospital. In the United States, conscience clauses were enacted in 1973 by Senator Frank Church which protected healthcare workers from directly being involved in performing abortions and sterilizations. According to the most recent data, as of 2008, 46 states (and D.C.) have similar clauses.³¹¹ The ability to withdraw from services that makes a clinician morally (or religiously,) uncomfortable cannot be ignored in this discussion. This is particularly important since Catholic Hospitals, via their Directives, can and do refuse to offer certain procedures.

While the issue of abortion is arguably foundation to Catholic institutions within America, Jewish medical ethics has similar, ethical viewpoints with the end of life, particularly life support machines. The innovation towards this issue of moral agency occurs in Israel, Israeli hospitals answer to two authorities: the Israeli Health Ministry and rabbinical authority. Israel's Ministry works in tandem with Jewish Law. In that sense, even a more 'secular' Israeli hospital offers only religiously ordained care.. These scenarios also demonstrate the relationship between institutional moral agency and faith. Judaism places the dying person in a *sui generis* classification replete with unique ordinances. These all have immediate application once a patient is defined as a *goses*; one who is not expected to recover from their illness and who will die in three day's time.³¹² The concept of *goses* will be discussed in greater detail in chapter 4. Indeed, these legal-religious categories are distinct and impose *halakhic* considerations upon people who encounter either the dying or the dead. However, modern medicine has disrupted the statuses Judaism has depended upon for millennia, often creating tensions between medicine and *Halakha*. According to the Talmud, saving a life trumps everything.³¹³ This is *Halakha* and uncontested. Judaism simply strives to give every patient a chance at life; indeed, most rabbis would caution even against hydration and nutrition tube removal.³¹⁴ Hydration and nutrition are

considered a basic human need, and should not be removed from a futile patient, exceptional cases aside.³¹⁵

In an attempt to mediate the aforementioned tradition with the modern understanding of brain death, Israel has created a prototype of a life support machine.³¹⁶ The development of that prototype stems from the fact that palliative care is not a recognized field within Israeli medicine.³¹⁷ Perhaps this stems from traditional Judaism. Traditionally, one is in the legal-status of being either living or dead. When a Jewish patient nears the end of their life, they are in a Jewish legal state known as *goses* (someone who is ‘actively dying’) ³¹⁸A *goses* is not permitted to have their death hastened in any way; thus, questioning whether and how pain management hastens death becomes important. Further, nothing can act as a ‘hindrance’ while a *goses* is dying as any interference may prevent death’s onset. Whereas Jewish law, unlike its Catholic counterpart, does not explicitly comment on ‘intention’ of an act, it is, nonetheless an inherent consideration throughout the various Rabbinic *responsa* (religious answers to queries posed by laypeople and Rabbis alike).

It is concerning that despite constant wars, terrorism and an aging Holocaust survivor population, there is no recognition of palliative care in Israel. Thus, this new machine is religiously motivated to solve a modern dilemma. The concept is simple. Modeled on hemodialysis, a life support machine would not be continuous but rather, cyclical.³¹⁹ Traditional life support machines run on a continuous cycle and need to be shut off manually. A cyclical machine, or one that cycles off naturally, such as a hemodialysis machine, alleviates this issue. For Judaism, it is forbidden to stop treatment once it has been started. However, with a cyclical machine, treatment would stop independently. Thus, the family is not transgressing Judaism and the laws of *goses* and a medically futile patient is permitted to die via the cyclical machine

simply running to the end of the cycle and not being permitted to be restarted. Eventually, all Israeli respirators will follow this model.³²⁰ Since this machine is still a prototype, the ethical ramifications have yet to be determined. However it is a novel approach towards conciliation of medical realities. Previous rabbinical authorities have instituted that futile ventilation treatment should be discontinued.³²¹ Yet these rulings are less popular in vitalist Israel.

The next section will take two controversial cases that demonstrate two distinct instances of undue hardship at both the individual and the institutional level. The first considers organ donation and the second considers abortion in far greater detail. Through this detailed exploration, the scaffolding offered above, of moral complicity, moral agency and faith will be fully realized in genuine clinical scenarios.

3.b. ii Case Study: Undue Hardship and Organ Donation

Judaism and Catholicism stand on the religious obligations towards charity, justice and saving lives. In America and Canada, there is an ‘opt in’ system to become an organ donor. Most organs are gleaned from patients on life support; heart death patients are assessed for cornea and tissue donation.³²² It is well known that there is a lack of organ donors globally. Thus, it would be the ultimate good deed for a Jewish or Catholic person to donate their organs. For the purposes of this chapter, only post-mortem donation will be discussed, leaving aside issues of *inter-vivos* donations.

Prior to discussing Judaic approaches towards organ donation, it is imperative to understand the general structure of Jewish halakhic decision making. Jewish ethical thought stems from precedents and anecdotes found within both the Written and Oral *Torah*. Judaism is a text-based tradition and is governed by legal- status. There is an absence of ultimate authority within Judaism. Further, there is a difference in inference and interpretation of Law (= Halakha).

Rather, Judaism utilizes rabbi-experts (*poskim*) who have a wealth of knowledge in the survey of the Written and Oral Torah and specialize in medical ethics.³²³ Yet, each scholar can choose how to interpret the Law; oftentimes one Law is analyzed differently by several *poskim*, causing intellectual disagreement. Judaism, due to its de-centralized leadership has several factions. There are philosophical and religious differences between the opinions of Orthodox (traditional,) Conservative and Reform *poskim*.³²⁴ Conservative and Reform Judaism, in contrast to Orthodoxy, often incorporate societal, policy, or legal issues into their ethical decisions. When discussing *halakhic* issues in bioethics, this dissertation will base its arguments on the mainstream Orthodox scholarship. This is purposeful. The Orthodox community uses the same hermeneutical methodology as the Talmud dictates. For Conservative and Reform Jews, *halakha* is generally more permissive and aligned with more ‘secular’ ethics ideals. More often the not, Orthodox Jews request rabbinical counsel and only consider their religious decisions/guidance normative.

Judaism presents a problematic approach towards organ donations. According to the Talmud, deriving benefit from the dead, or mutilating the dead is strictly forbidden. Further complicating the situation is Judaism’s traditional lack of acceptance of brain death. However, recent rabbinical authorities have supported organ donation. These authorities base their decision making on the Torah-based principles of *pikuah nefesh* and loving thy neighbor.³²⁵ In North America, most Orthodox Jews are ‘living donors’ due to *halakhic* considerations.³²⁶ Living donors means donations that can be taken from a recipient while they are still alive. The most common are liver and kidney. Donating these organs fulfils the Torah-based principles mentioned above. Outside of these living donations, Israel ranks as among the lowest in organ donation, possibly due to the ultra-Orthodox community. Generally, Catholic teachings, through

the Pope, capitalize on the altruistic nature of organ donation. Catholicism does permit organ donation, however with understood ethical barriers. Issues of autonomy and consent are at the forefront of Catholic ethical reasoning. However, Catholic thought establishes limits within virtuosity. These include mistaken diagnosis of death; a prohibition surrounding removing vital organs from the living and; a fear of progressing towards removing organs from severely disabled persons.³²⁷ Judaism and Catholicism share trepidation surrounding a brain-death diagnosis, which is imperative for heart donation.³²⁸ The Vatican affirmed brain death to be permitted within Catholicism; Judaism recognizes brain death however certain communities do not.³²⁹ There are concerns regarding issues of market morality: specifically for Jewish hospitals transplanting vital organs. There is a further issue of scarcity. While saving a life is sacred, there is a scarcity of donors. Some Israeli hospitals are mitigating the lack of donors. While Catholic hospitals encourage donation, donations after cardiac death are prohibited by the Church.³³⁰ How each religious tradition chooses to use the organ donation market is telling of their overall moral culture.

In the healthcare market, there is an emphatic need to balance accommodation while considering the reality of scarcity. This is magnified in the time sensitive and emotionally wrought process of organ donation. To wit, organ donation demand is high; supply is low.³³¹ While some hospitals or even countries are considering a pay-for-donation scheme, most healthcare institutions rely on altruism.³³² The complexities of scarcity in the market are only heightened with religious patients. Religious patients complicate matters at both the donor and recipient level in a secular hospital. Regardless, the hospital is obligated to accommodate someone's religious beliefs until the point of undue hardship. There are two complications towards organ donation and religious accommodations within secular hospitals. The first

obstacle towards organ donation lies around brain death. This impediment is common to both secular and religious hospitals. Most religious traditions have some concerns regarding brain death.³³³ At the donor level, patients from several religious traditions struggle with understanding brain death. Some factions of Judaism will not allow for certain organs (lungs, heart) to be harvested.³³⁴ There are, however, nuances within Judaism when it comes to accepting donations from non-humans. Importantly, there is a generalized misunderstanding about Orthodox Jews being unwilling to accept heart valves from pigs or organs from non-Jews. This is undisputedly incorrect. The concept of *pikuach nefesh* supersedes; as does written commentary from modern rabbinical decisors.³³⁵ Judaism has a famous, overarching principle of ‘*pikuach nefesh*’ which literally translates into saving a life. It can also be translated as guarding a life. Traditionally, all other Judaic tenants may be pushed aside in favour of saving a life. Judaism’s omnipresent determination to ‘guard a life’ governs its ethical decisions, even to the detriment of quality of life, which shall be explored later in this dissertation.

Certain states (such as New York with a large Orthodox Jewish demography) disallow removal of life support mechanisms due to religious or ethical concerns.³³⁶ Under the law, a New York hospital must notify a family that a determination of neurological death is imminent. Should a family wish to voice a concern, the hospital is obliged to accommodate them. Nonetheless, if there are limits to accommodation, the state is certainly not clear.³³⁷ As a result, individual hospitals have crafted a ‘24 hour’ policy by which religious or ethical objections must be ‘resolved.’ While the Chief Rabbi of Israel confirmed the reality of brain death and its accordance to Jewish Law in 1988, a minority of observant Jews may yet doubt neurological death, prolonging treatment needlessly. Further, insurance companies will not pay for patients who are declared brain dead, regardless of religious or ethical objections.³³⁸

The second obstacle is perhaps more immediate than the first. There are a lack of donors for essential organs like heart and lungs. For Orthodox Jews, much of the reasoning stems from theological and textual logic. At the risk of over-simplifying, this chapter will avoid a theological textual approach. Rather, this chapter shall focus on the reasons that may be presented to clinicians in a secular setting. The clinician may meet a two-fold problem. For some, removing organs from a brain-dead patient is akin to ‘murder’.³³⁹ Secondly, there is Biblical precedent for a Jew to be buried ‘whole.’ Indeed, even amputated limbs are to be buried alongside the corpse.³⁴⁰ As a result, organs may only be harvested if there is a guarantee they will be donated to a person rather than utilized for medical research purposes.³⁴¹ For Catholics, organ donation is an altruistic act that is encouraged. However, the Vatican too has wrestled with the concept of brain death. Organ donation after cardiac death is not supported by the Vatican.³⁴² Pope Benedict XVI stated that vital organ donation is a genuine demonstration of charity. Unlike Judaism, the Pope’s statement allows for organs to be donated to science, so long as it is harvested respectfully.³⁴³ The Church is cautious towards overstating brain death to harvest more organs. These concerns are equally pertinent in religiously-centered healthcare settings. Israeli hospitals attempt to set up new systems that encourage pre-dedicated donation. Catholic hospitals ensure that while organ donation is encouraged, organs are not harvested from patients still considered alive, such as PVS patients.³⁴⁴

Israeli Hospitals are taking a more policy-based approach when it comes to organ donation. Rather than focusing on specific religious issues, the government has opted to maximize the local organ market. The Israeli organ market is particularly unbalanced. While Orthodox Israelis often do not donate organs, they are willing recipients of organs. Consequentially, Israeli hospitals must acquire organs from around the globe, at great financial

cost.³⁴⁵ Although some Orthodox Jews are willing to donate organs while living, very few would after death.³⁴⁶ Perhaps this is due to a general lack of education and confusion (even within Orthodoxy itself) surrounding the permissibility of post mortem donation. To mitigate this, Israel enacted the *Organ Transplantation Law* in 2008.³⁴⁷ Israeli Parliament too, has a foundation in both secular and Judaic Law, rendering policies that arguably, are acceptable even to the Orthodox community.

The primary concern with donations rests again on the concept of *goses*. Succinctly, a *goses* is a term given to someone who is actively dying. A more thorough elucidation of this term will be done in the next chapter. Shortening a *goses*' life is murder within Judaism. To prevent this, someone caring for a *goses* is not permitted even to touch a *goses*. The Talmud bluntly illustrates this by terming the person who closes a *goses*' eyes as he is dying as a murderer.³⁴⁸ Modern Talmud scholars have attempted to re-interpret *goses* towards 21st century bioethical concerns.³⁴⁹ While a *goses* is traditionally dead within "three days time", this timeframe is refuted in other notable texts.³⁵⁰ Rabbi Feinstein rules that if there is no longer an ability to cure a patient (and only the ability to extend his life for a short while), the physician may not treat the patient.³⁵¹ Potentially, a *goses* can be classified thus as soon as palliative treatment commences. In so doing, perhaps more Jewish organs may be procured. Significantly, there is no academic literature on the importance of *pikuach nefesh* on Jewish bioethical discourse. According to the Talmud, saving a life trumps everything.³⁵² The Israeli government is thus caught betwixt and between. *Halakhic* protections of *goses* are strong; the lack of donations stronger still. Assuming the halakhic life support machine comes to fruition, the framework of *pikuach nefesh* may be enough. Until then however, the Ministry took a different approach.

To encourage post-mortem donation, the Health Ministry will shoulder the patient's burial costs post-donation. There are further provisions for monetary reward for the family (although not yet enacted upon.)³⁵³ Finally, those who sign a donor card are placed on a priority list should they—or an immediate relative—require an organ. This is a non-medical triage component that has obvious ethical ramifications.³⁵⁴ Finally, patients can choose to become 'designated donors' and can choose specific people if they are in need, or even specific ethnic or religious groups. Generally, Israeli citizens are welcoming towards the concept. They are more willing to give if they are more likely to receive.³⁵⁵ Theologically, allowing donors to designate the use of their organs mitigates the previous issue of using the organ(s) immediately. Further, Orthodox Jews need not be concerned about their organs being used for research. Recent studies show an increase in signed donor cards in Israel, which theoretically strengthens the local organ market.³⁵⁶ However, there are obvious ethical concerns. The State of Israel is already dichotomous. There are fears that designated donation will increase this social-cultural enmity.³⁵⁷

More importantly, Israel is attempting to radically shift its organ market. The changes are an attempt to personalize organ donation. Indeed, a citizen can choose to designate to save his own family member; rather than altruistic donation to a stranger. It shifts the market to the consumer, offering incentives and "power" to those who "opt-into" the system.³⁵⁸ Yet, this consumer-driven approach is disconcerting with traditional Jewish values. Putting aside the titular notion of *pikuach nefesh*, another foundational value is *tzedakah*. *Tzedakah* is incorrectly translated as charity; a more accurate translation is justice. It should be given freely and is an obligation for all Jews. Organ donation is considered the penultimate in *tzedakah* and a wonderful *mitzvah* (deeds of loving-kindness.)³⁵⁹ While helping family is commendable, arguably the *tzedakah* of offering an organ is tarnished. Indeed, those who agree to become

donors are given priority as recipients. There are no parameters outlined for system failures: if the person's organs are not suitable for donation, if there is a more ill candidate on the list who is not a donor, how much import does signing a card give a future recipient. While these new policies solve the issue of market scarcity, it creates far greater ethical ones.

In almost stark contrast to the Israeli organ donation market, Catholic values are at the forefront of organ donation decisions. The foundational *Directives* of forgoing treatment and allowing a patient to die of underlying pathology seamlessly allows for organ donation.³⁶⁰ Indeed, the Catholic values of caring, loving your neighbor and altruism are aligned with organ donation.³⁶¹ The 'gift of life' is referred to positively within Catholic hospitals.³⁶² This contrasts with Israel's shift towards a consumer-driven market. Catholicism relies on its own religious values to drive support, and ultimately 'buy in' for organ donation. This is essentially a Catholic value-dimension approach to healthcare.³⁶³ Catholic theology finds value in quality of life, hence the acceptance towards forgoing treatment. Catholic theology further lends values to death, portraying it as a natural progression ordained by God. In this value-dimension approach, Catholic theology allows death to be acceptable, welcome and even a gift vis-à-vis organ donation. Organ donation both accepts that death is a natural, biological function and enables others to benefit.³⁶⁴

These value-decisions also prevent organ harvesting from candidates who are not considered 'morally dead' in Catholicism. Organs cannot be requisitioned from PVS patients.³⁶⁵ According to medical understanding, and mirrored by the Church, PVS patients are not brain dead. Their brain stem functions although higher order brain function has ceased. Even without mechanical ventilation, these patients will breathe.³⁶⁶ Catholicism cannot accept organ procurement until all brain function has ceased.³⁶⁷ Even a shortage of organs cannot undermine

Catholic values. Further, Catholic values of love, respect and compassion administer the act of transplant itself.³⁶⁸

Another interesting religious/medicine clash lies in the concept of abortion.

Understandably, comprehending abortion through a religious lens reveals complexities which are potentially absent within a secular context.

3.B.iii Case Study: Undue Hardship and Abortion

Whereas abortion is allowable within Judaic law, a religious and medical committee nonetheless supervises it in Israel.³⁶⁹ Each hospital offers abortions and a committee devoted to evaluation abortion requests. The ‘abortion committee’ of Israeli hospitals consists of five people. It is staffed by medical professionals in women’s health, neonatology and genetics alongside a senior social worker. The staffing of a committee depends on the type of abortion being considered: an early abortion or a ‘high-level’ committee which can mean either a significant fetal defect or a late abortion request. Abortion was legalized in Israel in 1977.³⁷⁰ The Israeli Abortion Law has four categories that permit abortions. These categorizations are based on careful analysis and interpretation of Talmudic source-texts. Upon close analysis, all four categories place the desires of the mother tantamount to the fetus. These include social-familial and mental health components. The categories of women permitted to request an abortion are: woman under 17 and over 40; pregnancy from a crime, incest or outside marriage; significant physical/mental defect in the fetus and; the pregnancy risks the mother’s life/mental health/or cause physical damage.³⁷¹

The third and fourth categories of the Law may be purposefully vague. A lack of definition allows for the committee to consider the individual circumstances of each woman. Indeed, the abortion committee, and Jewish law places impetus on the mother. The physicians’

value a patient's autonomy over and above the fetus.³⁷² Childbirth is life threatening. Thus, the Law does not oblige her to take risky ventures.³⁷³ Judaism further considers socio-emotional issues that may arise due to a pregnancy. While Judaism does not encourage abortion, it is a viable option, especially for the health of the mother. While the fetus does have value its value is lesser than the mother's.³⁷⁴ The abortion committees have further concerns for the quality of life of the fetus, especially if it is not initially wanted.³⁷⁵ The committee serves perhaps as a marker of religious decision-making. Whereas abortions are permitted, they are not done 'at will.' Judaism still protects the sanctity of life. There is a lack of literature indicating conflict of moral agency regarding abortions in Judaism. This may further the justification for both the Abortion Law and the committee. Whereas all religious hospitals refer patients to the committee, not all abortions are permitted.³⁷⁶ In so doing, Israel has attempted to create a balance between maternal autonomy and protection of life. Statistics indicate that 98-99% of all requests were honoured by the committees. 92-97% of late term abortions were approved as well. In Israel, late term abortions (literally, at any stage of pregnancy,) are legal.³⁷⁷ Most committee members view the ambiguity of the parameters governing abortion as positive, since it allows them to evaluate the family or requester more holistically. However, despite the permissiveness of the committees, the allowances they make do not come lightly. Indeed, there is significant evidence of wrestling with a woman's autonomy and when a fetus has a value. Some committee members are uncomfortable with later term abortions (30 weeks onward) due to the viability of the fetus. However, for a late term abortion to be granted, significant genetic concerns are normally present.³⁷⁸ Perhaps this is indicative to Judaism's overall protection of life. Abortions are thus carefully considered within the limits of the law.

On the other hand, Catholicism's famous stance on abortion may cause strife in moral agency. Anecdotes refer to non-Catholic physicians working in Catholic hospitals who are unsure about whether they can refer a patient to safe place to have an abortion.³⁷⁹ While religious physicians must refer a patient in a timely manner, physicians working in a Catholic hospital are barred from doing so.³⁸⁰ The *Ethical and Religious Directives* prohibit a Catholic healthcare institution to engage in 'cooperation.' In Catholic theology, there are distinct categories of cooperation that can be applied to abortion, which differ based on intention. The first is formal cooperation, in which the 'cooperator' *intends* the activity. The second is considered material cooperation, whereby the 'cooperator' does *not* intend the activity, but can be morally culpable. Thus, with abortions, direct referrals are frowned upon, indirect referrals are commonplace.³⁸¹ Although, for some Hospitals, even material cooperation is prohibited. Nonetheless, material cooperation permits a Catholic hospital to be part of a larger, secular hospital system. For Catholicism, the sanctity of an unborn life has no parallel. The fetus is respected as a whole person, from the point of gestation.³⁸² Thus, the burden of undue hardship is placed upon the fetus, with the exception of particular Double Effect cases. Here, the fetus demands to be born and only extreme circumstances will prevent this from occurring.

Some Catholic theologians wish to extend the allowance of abortions to mothers who show mental or physical objection to carrying the fetus. Some fear the loss of autonomy, specifically if the pregnancy was due to rape or otherwise unwanted.³⁸³ A chasm is exposed perhaps when best medical practice is compromised by Catholicism's abortion provision. To wit, much ink was spilled over the controversial and previously discussed 'Phoenix' case. In this case, a young patient with hypertension tried to avoid pregnancy.³⁸⁴ She nonetheless became pregnant. Over the course of her pregnancy her cardiovascular condition worsened. Her risk of

mortality was high and the pregnancy was terminated to save the mother's life.³⁸⁵ Whether this abortion was direct or indirect is contested throughout literature. According to Magill, there is yet still no consensus on how to mitigate such a dilemma. Catholicism prevents direct abortion, even to save the life of a mother since evil cannot be done so something good can result. Thus, for Magill and other Catholic scholars, the question the Phoenix case presents is ethically and theologically puzzling. Indeed, what maternal medical condition can permit indirect abortion? This thesis, however, considers the greater question being whether and how best medical care can be achieved within Catholic reproductive principles. The religious definition of undue hardship is different from that secular or aforementioned legal manifestation of undue hardship.

From the Phoenix case and other cases like it, there is indisputably a foundational concern of patient safety within religious hospitals. Indeed, religious tenants may in fact jeopardize patient health and safety. However, these are ignored by patient safety literature and require separate isolation and analysis.³⁸⁶ Instead, patient safety books focus on the questions of miscommunication, handoff errors and hierarchy within the healthcare setting.³⁸⁷ Physicians who deem abortions medically necessary are denied the right to perform them, due to the Catholic Directives.³⁸⁸ Some physicians who find themselves medically opposing the *Ethical and Religious Directives* in certain cases ultimately resign from the Catholic healthcare system.³⁸⁹ Arguably, whereas patients may refuse treatment due to religious beliefs, medical professions cannot have medical appropriateness stymied due to religious beliefs. In a large city, a patient may be able to find another provider, even in an emergency. However, Catholic hospitals purposefully serve underinsured and the poor. These two components obviously clash. Catholic healthcare institutions have a right to showcase their religious identity.³⁹⁰ Yet when this identity compromises patient safety, it deserves to be reassessed. The issue of patient safety surpasses

even conscientious objection. According to a recent study, physicians at some Catholic hospitals had difficulty managing ectopic pregnancies as per best medical practice.³⁹¹ Catholic ethicists advise treatment without taking ‘direct’ action towards the embryo. That is, no medical intervention can be undertaken which would require directly impacting the fetus³⁹². According to the study, patients suffering from ectopic pregnancies lacked full choice of options and exposed to unnecessary risk.³⁹³

While the literature skims the issue, the ramifications of religious-based healthcare is apparent. Whether and how religious accommodations can be enveloped into patient safety is the crux of the issue. There are significant ethical concerns when a patient lacks choice and is exposed to needless risk. Patients and providers’ moral agency conflicts may in fact jeopardize best medical practice. Although the onus of ‘undue hardship’ is pressed upon the institution, ethics and law should come together to suggest that there can be limits to religious accommodation.

As previously discussed, Catholic healthcare finds moral cooperation (specifically for this analysis, in abortion,) unethical. For a Catholic religious institution, facilitating medical partnerships are deliberate to avoid misperceptions.³⁹⁴ For example, Catholic hospitals would be careful to avoid partnering with agencies that offer abortions. This is known as “complicity in evil.”³⁹⁵ As in moral agency, there are two duties in conflict: the (medical) obligation to refer a patient and the institutions’ moral culture. A physician working in a religious institution cannot “transcend” the moral obligations of the hospital.³⁹⁶ However, being unable to treat a patient as an individual deems medically appropriate may cause moral distress and burnout. Further, it could sever the trust relationship between the physician and the hospital. Thus, the novel approach of “...cooperation despite disagreement” (CDD) may be undertaken.³⁹⁷ This is an

assumed contract commonly between institutions that allows for medical cooperation without being supportive of each other's moral culture.³⁹⁸ While this is an innovative solution, it does not apply to the contents of this chapter. The "CDD" contract is not commonly utilized in Catholic or Jewish hospitals. Many patients find comfort in religious traditions during a health crisis. While secular hospitals accommodate religious traditions, clergy and doctrines, they are not formally held to them. To wit, limitations on religious accommodations may be justified over concerns of best medical care. Undue hardship is rarely clearly definable. However in a healthcare setting, so long as the religious practice does not impede 'proper' medical care, it is permitted.³⁹⁹ The limits of undue hardship may be set by various parameters including geography, finances, executive or medical opinion and underlying pathology. Nonetheless, the difficulty in demonstrating a hospital has suffered undue hardship creates complex ethical cases.⁴⁰⁰ This is perhaps most apparent at the beginning of life. Adding another layer of complexity is the reality of two concepts of undue hardship: a secular and a religious one. While these can exist together, ultimately, one must triumph. A secular understanding of undue hardship varies from the religious understanding of the term. This is truly the crux of the issue.

The concept of undue hardship carries through Judaism's understanding of abortion. Indeed, while Judaism values the sanctity of life, life is only defined at a certain timeframe within pregnancy.⁴⁰¹ Whereas Catholicism values the fetus' life as equally as the mothers', Judaism takes the counterpoint. The health of the mother—indeed, what *she* would define as undue hardship is tantamount.⁴⁰² While there are variations within this generality, even Jewish hospitals and physicians would place the mother's wishes above all else. Certainly, there are flexibilities. Some observant physicians may seek other avenues such as counseling before performing an abortion.⁴⁰³ Genetics and hereditary diseases have a tremendous influence on

termination of pregnancy; so too does the Biblical precept to be “fruitful and multiply.”⁴⁰⁴ One concept seems paradoxical to the other. Nonetheless, Judaism recognizes birth as risk taking and dangerous to the woman’s health.

Conversely, Catholic’s view on abortion is absolute. The fetus cannot be terminated, save for rare circumstances of The Double Effect.⁴⁰⁵ Whereas Judaism places the warrant of undue hardship on the mother, Catholicism places it on the fetus. It is the fetus’ right to be born.⁴⁰⁶ Catholic hospitals may not provide abortions to patients. Whereas some Catholic theologians wish to consider the mental/physical health of the mother, they are a minority.⁴⁰⁷ This absolute prohibition may contrast with undue hardship and a patient’s rights. A Catholic hospital can arguably cite undue hardship for not offering abortions. Indeed, from a religious definition, the gravity of the sin contains the hardship.

In determining an ethical framework of undue hardship, it is essential to consider, (as Taylor, Veatch and Rawls contend,) the normative values of society. As chapter 2 demonstrated, pure secularism is always underscored by a religious morality. Thus, to truly evaluate undue hardship concerns within a religiously motivated medical decision, another comparison must be considered. As recent developments in Canadian assisted death protocols have revealed, patients and even physicians are uncomfortable with a doctor prescribing and giving the injection to help a patient die. Many physicians cite moral tension with the act and as such, are obligated to refer a patient to another physician who will perform the procedure. As Veatch contends, a physician cannot serve two Codes of Ethics. Thus, when creating an adequate understanding of how to ethically define undue hardship as it can apply to religion, it is essential to find a superior comparison. Physicians occupy a unique role in society: they are public servants and professionals and yet, have their own moral agencies. Secular society demands that a physician

set aside personal ethics (and religious ethics) in favour of professional ethics and codes. If that were the case, all physicians would perform abortions and assisted death procedures. How then do physicians adequately morally comply with religiously concerning procedures? Those are circumstances where medical knowledge and skill are needed for society's good, or for a purpose outside that of the patient in front of them. An excellent example is from an oral interview with the physician who went alongside the Mossad mission to kidnap Adolf Eichmann to bring him to stand trial in Jerusalem. In his interview, the physician emphasized his moral struggle with being asked to come and sedate the man for the plane ride from Argentina to Israel. The sedation would need to be carefully calibrated. He eventually agreed to come and utilize his knowledge since he was worried what would happen without a trained physician. He was so troubled by his moral complicity, his participation was only revealed many years after his retirement.⁴⁰⁸ This is echoed in another example: that of physicians who treat victims of torture by American governments. They set parameters for torture, arguing that without their cooperation, it would be far worse. Physicians who serve in institutions like the military or prisons are dual agents. Much as those who work in Catholic hospitals, these physicians are governed by a code of ethics that may deviate from the direct goal of their professional training.⁴⁰⁹ A possible solution to this complex problem is found within the penal system, offered by legendary ethicist Edmund Pellegrino.

Pellegrino offers another, nuanced moral complicity. There are physicians who serve as agents to the penal system and must dispense lethal medications to death-row prisoners. Some physicians (and even religious members of society,) view that as cooperation with 'killing' and against the Hippocratic Oath. However, some physicians opt to 'cooperate' for purposes of beneficence: these physicians generally develop a rapport with the prisoners over consistent

visitations. The relationship is built upon trust. They are skilled in calibrating injections and administering them, ensuring a smoother, arguably more humane process. Consequently, prisoners present more calmly for their lethal injection.⁴¹⁰ To other physicians, the injection is merely technical and can be performed by anyone. They purport that medicine is for healing, not killing.⁴¹¹ They would refuse the assignment and refuse to comply. It is likely these physicians would never even consider serving in a prison system to avoid these issues of moral tension.

Interestingly, to create an ethical, secular definition for undue hardship, terminology and concepts from religious thought are truly helpful. Again, this merely strengthens the ideology that secularism and public sphere politics cannot be fully divorced from theology. The Catholic concept of moral distance (*vis a vis* moral cooperation) is remarkably obliging. The more ‘distant’ a morally reprehensible act is from the physician, the more or less he is directly involved with the outcome. That is, is the physician directly responsible for implementing a moral evil? The greater the distance from the intention, even if harmful, a physician’s role shifts to a neutral position—one of a facilitator.⁴¹² A physician has an obligation to society and the greater public good, which is also a consideration. To wit, take again the example of a physician who does death row injections. The ethics of society weigh heavily on the decision to cooperate. A death row prisoner was judged by a jury of peers. Arguably, the physician is performing community service when he cooperates with society and injects the prisoner safely and competently.⁴¹³ He is therefore not operating as a doctor but as a member of the public. Society’s role must be considered in deciding cooperation standards within religious healthcare institutions, insofar as it can be recognized (by society) as undue hardship.

Moral agency and moral culture in healthcare settings often betray tension. Indeed, in a profession that values healing the sick, there is nonetheless great concern surrounding the

business of healthcare. While moral agency can determine individualized actions, the moral culture of a hospital may be juxtaposed. Conflict between an individual's moral agency and an institution's moral culture can undermine an organization's mission. Further, a moral agency of a healthcare provider is shifted into what is considered a 'greater' moral culture. When in a secular healthcare setting, a religious patient's moral agency may compromise what physicians consider best care. Thus, in a religious hospital, there are established moral values that govern medical interventions. It is interesting to see how hospital's design their medical interventions to conform with religious principles.

The core of this chapter is concerned with the concept of undue hardship, specifically in the context of religious moral culture. The concept of 'reasonable accommodation' is generally assumed to be the medical institution accommodating the religious patient. By using an ethical framework, this chapter attempted to establish a more precise, ethical definition for undue hardship. Such a definition would better serve the medical world when nuance is important. A (working) ethical definition of undue hardship is defined thusly:

Undue hardship is understood to be withholding or refusing any procedure which would be considered 'best medical practice' due to religious moral culture. A healthcare institution must, ultimately, morally cooperate with societal values. As such, refusal of care, or limited care when full treatment is medically obligated, would be judged as unethical.. Failure to provide adequate medical care is a broader moral concern in which complicity is unethical.

4: Religious Barriers at the End of Life

In medicine, religion serves two purposes. For some, it is comforting particularly in difficult situations. For others, religion serves as a foundation upon which all medical decisions are based. A religious patient may find it difficult to render a medical decision completely divorced from his religion. In the Abrahamic traditions, a religious patient consults leaders and teachers in his religious tradition to guide his decision-making process. This begins a complex dialogue between an often centuries old tradition as it encounters modernity. Part and parcel of modern medicine is accepting more nuanced definitions of death (such as brain death,) and, understanding when medical treatment is futile.

There is a point at which medical treatment is futile. Medical interventions can slow death but never stop it. Patients who are very ill require time to process the extent of their illness; some need to be in control.⁴¹⁴ Futility and being unable to treat underlying pathology is in line with a natural lifecycle. Rather than having nothing left to treat, a patient is permitted to complete a natural course. This requires recognition and acceptance by the physician. Physicians too must grapple with the notion that medical interventions may no longer be useful.⁴¹⁵ There are religious concerns about the sanctity of life, Clinicians must thus shift their thought process from intervention to compassion.

Spiritual care can assist in the transition between life and death and from medical intervention to compassion. Further, it can assist in tragic or sudden instances of death. Some religious patients cannot die without requesting forgiveness (Judaism) or last rites (Catholicism.) Just as in life, religion and cultural norms and practices dictate how death is accepted. The rise of spiritual care, specifically within a palliative or end of life setting was not recognized until the later portion of the 20th century. While religion and spiritual care of patients is considered

important in patient care, it is still not wholly understood. Both racial and ethnic minorities underuse palliative care, perhaps since their religious needs are not met at the hospital or, they may distrust the process. Terminally ill patients are more likely to hold stronger religious or spiritual beliefs as it enables them to manage and cope. As a direct result of this phenomenon, several research tools were created to assist researchers in determining the spiritual care needs of patients. From McGill University, the *McGill Quality of Life Questionnaire* assesses achievement of “life goals and personal meaning” through several questions spanning spiritual care and treatment options.⁴¹⁶ Another tool, the *Functional Assessment of Chronic Illness Therapy- Spiritual Well Being Scale* is designed to measure the level of comfort a patient derives from spiritual beliefs. *The Systems of Belief Inventory* measures religious and spiritual beliefs alongside the amount of social support required for these practices.⁴¹⁷ Currently, organizations such as the Institute of Medicine and The George Washington Institute for Spirituality and Health created a *FICA Spiritual History Tool* which assesses the strength of religious values on a patient through Faith and belief, Importance, Community and Address in care. The institution urges that “spiritual histories” be taken alongside a medical history.⁴¹⁸

These tools are designed to make spirituality akin to measurable, documentable science. Indeed, studies indicate that patients who have full access to spiritual care have better end-of-life experiences.⁴¹⁹ Religious healthcare institutions such as Catholic or Jewish hospitals provide a more holistic approach towards spiritual care. While they offer religious care alongside medicine, patients and families feel more satisfied.. A recent study indicated that patients and their family caregivers were not satisfied with the level of spiritual care at the end of life. Low scores were reported in “spiritual domain” during the period of bereavement.⁴²⁰ Supporting a family spiritually, particularly after a death should be a physician’s duty. Framing spirituality

around the philosophical notion of compassion may be helpful to bridge the gap between physician and patient. Compassion may also be redefined to include, as the recent ACA outlines, discussions surrounding death and dying. Incorporating an aspect of spirituality (or including a spiritual leader) may help facilitate these discussions. Physicians themselves are uncomfortable with this conversation.⁴²¹ However awkward, these conversations can assist in putting the patient back in control. Together with their physician, they can create a plan towards a peaceful death.⁴²² Often, plans will include an aspect of spiritual care.⁴²³ By freeing both physician and patient from a cycle of futile interventions, the fear associated with death, dying and assistance in dying can be suspended. If time allows, infusing the transition towards death with spirituality could lessen the fears. This method would be within the realm of physician's duty and an ethical approach towards the end of life. Indeed, religion especially colours decision making at the end of life.

A religious context may taint how to approach the end of life. Indeed, religious patients may impose barriers that impede 'best practice' in healthcare. These barriers may also contribute to the institution encountering undue hardship; finding a balance between accommodation and medicine is essential. As such, this chapter explicitly highlights the pivotal clash between religion and medicine: finessing death in an age of interventions. Death and religious rights are the common-most contentious issue seen in Canadian court systems. Echoes of similar themes are found in the United States, albeit to a lesser extent, due to insurance protocols. Creating an ethical framework that balances religious rights within the context of death and dying is thus essential. This chapter discusses death and dying in both adult and pediatric contexts. Further, it distills an ethical-theological argument for Judaism that is novel, allowing the concept of brain death within the legal confines of the religion. Accommodation must come from both within the

religion and medicine. This chapter indicates a conceptual blueprint that incorporates the essentiality of religion during medical decision making. Indeed, ethical accommodation does not wrench religion from decision making. The opposite is true. Authentic ethical accommodation understands the importance of religious decision making and seeks to find answers using the language and value system of a religious patient. This method is the scaffolding that allows for an ethical framework of religious accommodation within the secular healthcare system.

To fully illustrate this scaffolding, the idea of pain palliation in both religious traditions shall be explored. Both Orthodox Judaism and Catholicism have parameters around the preservation of life.⁴²⁴ This is complicated by attempts to palliate pain. As such, both traditions caution physicians to walk a fine line between treating pain without hastening the death of a patient. While the intention of a physician may be to erase the pain, the medical reality is that pain treatment may bring about death.⁴²⁵ Catholic theology uses a principle called Double Effect to determine whether a medical intervention can proceed, even with the moral risk.⁴²⁶ Orthodox Judaism has an overarching principle of '*pikuach nefesh*,' which translates into saving or guarding a life. Traditionally, all other Judaic tenets are pushed aside in favour of saving a life.⁴²⁷ The definition, and subsequent limitations, of 'saving a life' are contested and discussed in this chapter.

The Double Effect guides the painful end of life decision making. For example, while the intention of palliating pain is indeed good, 'bad' effects (such as respiratory distress,) still resonate and must be given weight in assessing whether the treatment is viable under Catholic moral teaching.⁴²⁸ Indeed, a palliative patient requires compassion—a tenet of Christianity and Christian healthcare ethics.⁴²⁹ Whereas analgesics belong in compassionate care, it can shorten a life span.⁴³⁰ Intentionality is the most crucial component of the Double Effect principle for pain

management. Although the four components of Double Effect work in tandem, intentionality ultimately determines the permissibility of relieving pain. Many Catholic ethicists permit the dispensing of opioids to patients since the intention behind the action is 'good.'⁴³¹ In the case of palliative pain management, the intention of the act—to relieve a patient's suffering—outweighs the 'bad' effect of potentially hastening death.

Further, the assumption is that the physician is choosing the best alternative with the least harm.⁴³² Consequently, the intention is undoubtedly knowable in Double Effect. While the sanctity of life is integral to Catholicism, there is no requirement to prolong life if the quality of life is compromised.⁴³³

These factors mentioned above complicated further within a pediatric context. Specifically, pediatric hospitals focus on 'family-centred' care and thus, religious and cultural considerations may add conflict. The complexity of balancing the autonomy of the pediatric patient with their parent-decision makers is also a component. Pediatric palliative care is considered a "total approach to care" involving emotional, spiritual, and social aspects of life and offers support to the family. There is a 'fear of death' specific to pediatric palliative care and indeed, in a time of heightened emotions and stress, a religious family may find it difficult to render a medical decision wholly divorced from religion. As such, religious families may align with religious beliefs, irrespective of the best medical practice. Trying to overcome these barriers would serve as a reasonable religious accommodation. While it is important to consider the possible barriers to religious adults at the end of life, religious decision making affects children as well. Children, decision making and religion is a fraught triad since it is difficult to discern whether the child firmly believes in the religion touted by his parents. Chapter six of this dissertation will detail how to approach children and religion within bioethics consultations.

However, it is important to independently consider the barriers that exist within pediatric care at the end of life. These are dual: medical and educational. There are several medical barriers to pediatric palliative care that are common to all families, regardless of religious practice. They include technology, 'fear of child death,' and communication about end of life goals. As technology evolved, modern medicine does not consider a patient dying unless there are no further medical interventions to be performed.⁴³⁴ Technological interventions have shielded modern patients from the realities of death. Indeed, in the medical world, stopping medical intervention can be viewed as 'causing' death.⁴³⁵ Dying children is both philosophically and emotionally disarming. Further, physicians are traditionally more aggressive in their care of pediatric patients, to give them a full chance of survival. However, a physician must lead patients towards a compassionate understanding of death and dying.⁴³⁶ Emotional hardship—and fear--of children facing death is exacerbating. Arguably, enacting such conversations is the ultimate act of compassion. Compassion is a different philosophical notion than sympathy or empathy. Thus, 'compassion' is defined via three variables: recognition of suffering, benevolence, being "personally addressed" by the suffering and; a desire to relieve the suffering.⁴³⁷ Together with their physician, a family can create a plan towards a peaceful death for their child.⁴³⁸ Religious/cultural considerations may compound fears of death and end of life, but as sociological studies indicate, they may, also, bring peace to the dying. Thus, understanding possible religious/cultural barriers are imperative. Doing otherwise may erect a barrier to palliative treatment.⁴³⁹ Accommodation is possible for some religious/cultural traditions. Clergy can participate in mediation between cultural concerns and medical judgment. In secular hospitals, chaplains and spirituality are regulated and controlled. However, within a Catholic hospital, there is less territorial concern. Rather, chaplaincy becomes prominent and even easier.

Importantly, within a Catholic hospital, there is a sense of homogeneity; more patients are likely to be Catholic. The *Religious and Ethical Directives* are at the nexus the hospital, reinforcing the importance of patient care and humanity.⁴⁴⁰ Moral/ethical issues are governed by Catholic ethics and *Directives*; and there are limitations to certain medical procedures (such as abortions.)⁴⁴¹ Clergy may be in leadership positions and spiritual care is assumed rather than optional.⁴⁴² This is perhaps the greatest delineation. The greatness of spiritual care is married with the importance of medical care. Thus, there is a constant presence of clergy and religious leaders in all floors and wards of a Catholic hospital. Catholic hospitals maintain a moral culture which all staff must follow. Following Catholic thought is the moral imperative; the rock upon which the hospital is built.⁴⁴³ Religious healthcare institutions strive to create moral communities. Developing this moral community perhaps eases fears of moral complicity. Indeed, religious morality is under the guidance of God.

However, outside a Catholic hospital, chaplains are met with several barriers, the most pressing of which is the physician-chaplain communication barrier. Most physicians report consulting with appropriate clergy when a patient faces an end of life decision.⁴⁴⁴ Yet, a lack of communication remains.

Jewish hospitals have a long history in North America as well. Traditionally, these hospitals were built out of need as Jewish residents were not permitted to have post-graduate education in Christian hospitals.⁴⁴⁵ Since most fundraising was accomplished by Jewish mothers for their doctor-sons, Jewish hospitals were specialized maternity centers.⁴⁴⁶ In contrast to Catholic hospitals, Jewish Law (*halakha*) was not foundational within hospital walls; however, some still offer observance of Dietary laws (*kashrut*) and rabbis are the spiritual care leaders. Just as Jewish doctors often built maternity centers, they also focused on the end of life and

palliative care.⁴⁴⁷ In old age homes, Jewish chaplaincy, religion, and culture are foremost. Even non-Jewish patients participate in Jewish traditions. These homes provide Sabbath observance, or a built-in synagogue.⁴⁴⁸ This provides a richness and guidance as patients transition towards the end of life. Even non-religious Jews in secular hospitals wish to consult rabbis prior to making a medical decision or while expecting death.⁴⁴⁹ Comfort is drawn from consulting both medical and spiritual professionals during the end of life.⁴⁵⁰

However, some families find that a clergy visitation is a harbinger of death.⁴⁵¹ Some religious traditions will allow a patient/family to forgo treatment. Catholic moral theology takes notice of the emotional toll on the family; Jewish families stand in juxtaposition to Catholic thought. There is a theological discourse based on preserving and guarding a life, despite the futility of treatment.⁴⁵² Judaism's zeal towards aggressive treatment and prolonging life is particularly true with pediatric patients.

The religious zeal in prolonging life is further compounded within the realm of pediatric medicine. Usually, a patient grants autonomous consent for life sustaining treatment (and all treatments.) However, in pediatric cases, consent is an ethical landmine. In pediatric medicine, a child may not yet be cognitively capable of granting consent. Thus, parents are tasked with making medical decisions while keeping the pediatric patient informed. To some extent, decision making rests solely on the parents, regardless of the child's age or ability to comprehend their situation.⁴⁵³ However, it is essential that children do have a role in their healthcare.

Subsequently, there is a notion of assent within pediatric medicine. The notion of 'assent' remains vague, however, there are some advised methods to assist healthcare institutions gain assent. Recommendations suggest acquiring translators, writing research guides in lay-person language to enable access across the barriers of language, socio-economic status and culture

(specially, in the case of clinician trials.)⁴⁵⁴ For all interventions, the child should be spoken to in an age and developmentally appropriate method, so that she/he comprehends all risks and benefits.⁴⁵⁵ They should be encouraged to sign their own form; some younger children are encouraged to draw their assent. If there is a language barrier, translators should be brought in and all factors of risks and benefits should be explored. Regardless of language barrier, the information should be given both through written lay-language and orally to both parent and child.⁴⁵⁶

Assent allows for flexibility. It cannot be used interchangeably with the notion of consent. Assent empowers children participants while, also providing safeguards via parents or guardian consent. Indeed, most children prefer ‘shared decision making’⁴⁵⁷ The American Academy of Pediatrics released a policy statement noting that the facilitation of a consent discussion is directly influenced by a physician’s experience.⁴⁵⁸ This is a further flexibility that assent provides. A physician can modify the discussion of medical interventions based on the patient’s age or maturity. Plainly, while ‘consent’ is legally mandated, assent provides flexibility for family dynamics, the child’s cognitive ability and emotions, and shared decision making which is foundational for family centered care.⁴⁵⁹ A full discussion of the differences between consent and assent is beyond the scope of this chapter.

Nevertheless, not all families are agreeable to this. The cultural conviction is that the prognosis will upset the child so much, he or she will cease to ‘fight’ the illness.⁴⁶⁰ Further, these families may be hostile towards consideration of palliative care as it would stymie 'hope' and, thus, the chance for a miraculous cure.⁴⁶¹ While the idea of hope is fundamental to maintaining internal strength, ethically mitigating hope is essential. While hope and miracles may be associated with religious or cultural beliefs, it is imperative to gain a complete understanding of

the influence this may have on parental decisions. To wit, foundational belief in hope may lead to reduced medical decision making.⁴⁶² This chapter emphasizes that holistic palliative approaches include spiritual care. This is done via a two pronged analysis: through a novel approach of *pikuach nefesh* at the end of life and through an exploration of pediatric palliative care. Pediatric care is brought into this chapter not to further complicate, but to further illustrate. That is, greater care and attention is placed upon spirituality and religion in pediatric palliative care programs. Believing Jewish palliative patients are also, perhaps, a different entity due to the primacy of the *pikuach nefesh* principle. This chapter takes the importance of that notion into account, however, offers a new theological interpretation, perhaps allowing for a more natural death. End of life cases are represented heavily in the Ontario court system, with nearly all cases citing religion as crucial to decision making. Thus, when emotions are high, this chapter demonstrates the centrality of religion to decision making—and uses religion to mediate the goals of medical interventions.

4A. Pain Palliation, *Pikuach Nefesh* and Double Effect.

Historically, death was part and parcel of living. Illness, lack of medication and wars helped to shape the omnipresence of death.⁴⁶³ Additionally, there was religious weight to death that made it acceptable and even desirous.⁴⁶⁴ Family members came to surround the dying in his bedchamber.⁴⁶⁵ Death followed a script: forgiveness from friends and family was acquired.⁴⁶⁶ In this capacity, death was normal; ritual guided the dying as it exhibited both the finality and the reality of death. Tombs and gravesites are a further religious and ritual allowance for death. They offer a public space for funerals and mourning. They stand as a physical reminder of the coexistence of death, even in the middle of life.⁴⁶⁷ While the cemetery still exists, modern

Americans prefer cremation to grave visitation. People do not make ‘pilgrimages’ to the graveside anymore.⁴⁶⁸ Modern Americans lose ritual, religious and ethical permissiveness for death through the disuse of tombs and cemeteries.

The rise of the modern hospital revolutionized the comfort and mundanity of death. Indeed, by removing death from home, a thought-shift developed, and death and dying became alien to a modern citizen. Alongside historical change, rapid progress in medical technology has turned death and dying into a medical ‘problem.’ Rather than dying from a disease, people are living with chronic diseases. This phenomenon merely allows for a slow decline until eventual death.⁴⁶⁹ Historically, this rise in medical knowledge reduced illness and child mortality.⁴⁷⁰ Indeed, the science of slowing illness has trumped the art of dying. By masking the natural progression of death and disease, a cultural reformation has occurred. Patients think everything is curable, treatable or medicated. Death cannot be stopped, even with modern medicine.

Although dying has been geographically moved to a hospital setting, physicians are still uncomfortable with the notion of death and dying. A physician's discomfort with death is apparent through the misuse of machinery. For example, physicians do not want to turn off machinery; hence it is considered they caused a patient to die.⁴⁷¹ Scientific medicine is at war with death and not merely disease. Rather than search for a disease or an illness, clinicians should start feeling comfortable with death due to ‘natural causes.’⁴⁷² The dependence on technology represents a dangerous shift of blame. Whereas previously, death was to blame for a loss of life, the blame has shifted to physicians.⁴⁷³ Physicians fear the pain they cannot accurately diagnose; indeed, physicians fear dying patients. Nonetheless, the advent of palliative care is forcing medicine to confront the idea of death directly. As several articles suggest, just as

a physician has to treat diseased pathology, it is also their duty to lead patients towards a compassionate understanding of death and dying.⁴⁷⁴

Recent government policies (such as the Affordable Care Act) attempted to mitigate this issue. Albeit, it has mixed results. The policies attempt to align the patient and doctor in crafting a ‘death plan.’ Physicians themselves are uncomfortable with this conversation.⁴⁷⁵ These conversations, however awkward, can assist in putting the patient back in control. Together with their physician, they can create a plan towards a peaceful death.⁴⁷⁶ Patients and physicians must undergo a cultural and academic shift. Further, futility in treatment must be considered not as failure—but as natural. Humans cannot live forever. Futility is neither the last resort nor a failure of medical intervention. Instead, this is inappropriate usage of technology; inventions to save lives are instead impeding a natural course of death. The ethical discussion surrounding these topics is essential. Traditionally, there should be no ethical concerns with dying; it is a natural part of life

Catholicism’s Principle of Double Effect offers an ethical guideline for ethically challenging end of life or palliative cases. At its essence, the tenet of intentionality guides ethical decision making within Double Effect. Intentionality is most apparent during end-of-life care and pain palliation. While all four components of the Principle of Double Effect are integral, the ‘good’ intention of preventing suffering is foremost. A physician *intends* to keep a patient comfortable; he does not intend to hasten death.⁴⁷⁷ Accidentally causing death is undoubtedly a moral ‘evil’ within Catholicism. However, the ‘bad’ effect of (possibly) hastening death does not outweigh the ‘good’ effect of easing suffering. Since a patient’s death is an indirect (yet foreseen) side effect, the act of palliating the pain is morally good.⁴⁷⁸ Recent scientific studies indicate that

opioids hastening death may be a myth.⁴⁷⁹ If true, this strengthens the moral ‘good’ of alleviating pain during palliative care.

Accordingly, the Principle of Double Effect is strengthened methodologically by the help-mate concept of 'extraordinary' care. The purpose of pain palliation is ordinary care; to seek extraordinary care at this point is not morally required. Other philosophical ideals of Catholicism encase the concept of Double Effect. The progression of natural laws governing lifecycle, policy and 'the American consensus' all assist in shaping Catholic methodology. The concept of 'extraordinary' care further shapes the morality of palliative pain management. It is not necessary or morally required to perform extraneous treatments on a palliative patient.⁴⁸⁰ Indeed, the effectiveness of the Principle of Double Effect is its nuanced application. The morally pure act of easing suffering allows for a dignified death within a religious framework. This approach is lacking within Jewish *Halakha*. The Jewish hierarchy of values indicates that *pikuach nefesh* supersedes all else, even palliative care treatment, where heroic interventions are not justified. Integrating the Catholic concepts of 'extraordinary' care and the understanding of intentionality into Judaism offers a new care ethic and possible solution. Judaism, too can offer religiously, legally and ethically dignified transitions to death.

Judaism holds a different concept of intentionality. There is an objective to strive towards *pikuach nefesh*, which outranks all other commandments. After all, the Talmudic Laws are a guidepost for living, rather than dying.⁴⁸¹ Although traditional Judaism posits a universal demand that lives are sacrosanct, this is futile during a palliative care situation. It is difficult to speedily change this situation because Judaism lacks a centralized religious-legal decisor. Nonetheless, change is possible, so long as precedent is proven vis-à-vis interpretation of written Law texts. There is precedent towards Catholic-like understandings of the Principle of Double

Effect and the concept of limiting ‘extraordinary’ care. While Judaism is a compassionate religion, its futile attempts at *pikuach nefesh* in palliative situations seem at odds with this.

The Talmud itself indicates there is a natural end to life. Talmud compilations of anecdotes offer many legal precedents for this. One such anecdote is particularly helpful for understanding natural death. As a rabbi lay dying, his followers cried and prayed to God to preserve his Earthly existence. A rabbi was unable to pass entirely into Heaven as his peers prayed. Praying kept his body in a limbo state between Heaven and Earth. He was clearly in pain, suffering on his deathbed. His maid, witnessing his suffering, urged the assembled to cease their prayers and allow their teacher to die peacefully. When they refused, she broke a sword, the sound shocking the men into silence, which allowed the rabbi's soul to depart the Earth.⁴⁸² Many *poskim* thus infer that death is often preferable to suffering. The rabbi's maid has her virtues extolled since she alone ‘saw’ the rabbi was suffering.⁴⁸³

While Judaism's obligation to save lives is morally noble, it is not unequivocally ethical, especially in palliative situations. Indeed, Judaism does not merely require pain management; it further obligates futile interventions in an attempt to save a palliative patient's life. The Judeo-Christian ethical foundations of the past appeared to be shifting towards a less religious, more 'common' notion of morality.⁴⁸⁴ Ethics used to be a known, commonly understood certainty.⁴⁸⁵ Currently, morality appears to be a shared “public system.”⁴⁸⁶ Systematically, it creates public discourse, which encourages public policy to engage, at least partially, in the creation of ethics.⁴⁸⁷ Likewise, current attempts to mediate policies surrounding physician-assisted suicide are guided, in part, by ethics. Far from being a new phenomenon, the idea of an ‘American consensus’ has been pertinent since 1990.⁴⁸⁸ Religion's encounter with, and willingness to engage within the public's generalized consensus has allowed some change. Modern Judaism is

a continuous search to balance the essence of *Halakha* with the rise of contemporary ethical issues. The quest for balance and change is illustrated through the less stringent rulings purposefully left in the Oral Law since its first redaction. As such, this is further demonstrated through continuous multiple interpretations of the Law by various *poskim* through the intervening centuries.

Rabbi Feinstein deliberately notes that even if a future ruling is contrary to normative *Halakha*, it is still considered permissible under the "fear of Heaven." As such, each rabbi or *posek* must determine the most appropriate ruling for his community.⁴⁸⁹ The Talmud consistently shows a precedent for this. Rabbi Hillel and Rabbi Shammai famously oppose each other on various aspects of *Halakha*. Interestingly, rather than merely citing the 'correct' ruling, the Talmud aptly notes both scholars' arguments in full.⁴⁹⁰ Documenting both arguments allows every generation to determine the correct ruling appropriate for their era. Indeed, the Talmud proclaims both opinions to be "...words of Living God."⁴⁹¹ Rabbi Yitzhak Colon mediates on what he considers the "middle way." Literally, not every Talmudic controversy is expounded upon, and as such, there is no preference towards either stringency or leniency.⁴⁹² Thus, whereas reading the Principle of Double Effect into Judaism may allow *pikuach nefesh* to become more nuanced, nuance must be determined by the legal decisors (i.e. reators of Halakhic decisions) themselves. This novel approach is delineated within the next sections. Judaism's methodology allows for various extrapolations and interpretations. Thus, it is reasonably simple to impose a liberal reading on it. Whether a more liberal reading can impart change onto the ethics of religion, however, is still in question.

4.A. i Double Effect in Catholicism

The Principle of Double Effect is one of Catholicism's most famous ethical principles. The four conditions of Double Effect are: 1) the action by itself cannot be 'morally evil'; 2) the evil effect is not how the good effect is produced, (it is merely a by-product); 3) the evil effect is not the intention and; 4) the evil response must be proportionate –the good effect must be of sufficient value.⁴⁹³ It allows an application of an ethical quandary to four tenets of the principle to determine the correct action. The Double Effect principle is used when medical intervention has both good and bad effects; hence the four tenets provide a way of determining whether if the good intentions outweigh the bad. Applying these conditions in palliative pain management is not simple; even experts disagree. For example, while the intention of dispensing the medication is indeed good, 'bad' effects (such as respiratory distress) still resonate and must be given weight in assessing whether the treatment is viable under Catholic moral theology. This assessment is not simple. While pain management may hasten death in statistically few cases, the weight of its potential import must be calibrated individually for each patient.

Beyond the scope of Double Effect two additional principles in Catholic healthcare, ethics assist in strengthening the permissibility of pain management, without the attendant fear of hastening death. These are the Catholic directives against 'extraordinary' care and the methodological belief in a natural life cycle. Together, these three ethical parameters ensure that a patient is permitted to die comfortably with their pain managed.

Whether and how pain management hastens death is at the crux of Double Effect. Indeed, a palliative patient requires compassion—a tenet of Catholic healthcare ethics.⁴⁹⁴ Whereas analgesics belong in compassionate care, it can shorten a life span.⁴⁹⁵ While the careful dosage is certainly imperative, there are risks associated; palliative pain management techniques can cause

respiratory distress and a loss of mental clarity.⁴⁹⁶ Individuals react to medication differently, which additionally challenges dosages. For instance, patients who have utilized opioids in the past may tolerate them better, compared to patients newer to opioid usage. As a patient declines, the amount of pain relief required may be greater, increasing the risk of respiratory distress. However, some clinicians refute these claims. Morphine, a common opioid, is classified as harmless even while continuously injected in palliative patients. Some patients who develop respiratory issues can trace these back to previous medical conditions, which cause distress irrespective of opioids. Further, some clinical studies on palliative cancer patients demonstrated no clinical proof of hastening of death due to pain relief.⁴⁹⁷ While some palliative clinicians dispute the ‘hastening of death’ effect of pain relief, it must be treated as true ethically.⁴⁹⁸ Although clinical studies refute the science of the matter, it remains an ethical concern for Catholic families and their physicians alike. Indeed, even some ethicists note Double Effect may be irrelevant during end-of-life care.⁴⁹⁹ While causing death is a moral evil in Catholicism, this is not the case for a dying, palliative patient. Indeed, we will all eventually die. It is precisely the lack of unanimity that the harbinger of ‘good’ intent remains an issue. The importance of intentionality in the Double Effect may designate that regardless of scientific controversy, Catholic ethical, religious thought may trump medical concerns.

The modern understanding of the Principle of Double Effect originates with Thomas Aquinas.⁵⁰⁰ He noted that one action might have two effects, a concept which later proved essential and helpful to medical ethics. Intentionality is the most critical component of the Double Effect principle for pain management. While all components of Double Effect work in tandem, intentionality ultimately determines the permissibility of pain relief. Many Catholic ethicists permit opioids since the intention behind the action is ‘good’⁵⁰¹. In the case of palliative

pain management, the intention of the act—to relieve a patient’s suffering—outweighs the ‘bad’ effect of potentially hastening death. Eventually, if the weight of scientific evidence indicates that opioid treatment during palliative care does not hasten death, it only strengthens the ‘good’ intention of the effect. The literature refers to this as a morally 'hard' case; to wit, it is clear that doing some good with undoubtedly cause some harm.

Further, the physician is assumed to be choosing the best alternative with the least harm.⁵⁰² Consequently, the intention is undoubtedly knowable in Double Effect. Although some scholars argue conversely, within medicine, it is perhaps easier to note intention, since physicians and nurses have their ethical obligations towards care.⁵⁰³

When a physician prescribes pain relief, the *intention* becomes essential. Indeed, all physicians *intend* for their patient to be pain-free; hence, the rationale for prescribing the opioid. The possibility of harm thus arises through medical intervention. Additionally, these medications are powerful; dosage and correct dispensing of them are tantamount, particularly in fragile patients. The dosage calibrated deliberately to avoid as many side effects as possible. Hence, the intended result is to end suffering from pain—not to end a patient's life.⁵⁰⁴ Additionally, Catholicism has a 'generalized consensus' built upon natural life patterns. While the sanctity of life is integral to Catholicism, there is no requirement to prolong life if the quality of life is compromised,⁵⁰⁵ Additionally, it acknowledges the vital fact that medical technology may prolong life needlessly and that a natural balance must be struck between medically preserving life (through life support mechanisms) and ending it ⁵⁰⁶ At some point, pain palliation would negate the proper place of God in His Kingdom to give and take away life. Hence, the Catholic principle of a natural cycle of life collaborates with the rationale of Double Effect. The intention

of offering pain relief is clear: to ease the transition of a patient as they progress towards death, without desiring to cause death.

Further proof in the importance of intentionality—and the allowance of pain management for palliative patients—lies within the Catholic concept of 'extraordinary' care. Indeed, these two concepts are separately categorized by Catholic ethicists. Catholics are not morally obliged to seek out extraordinary care.⁵⁰⁷ This belief has been echoed within the *Catholic Ethical and Religious Directives*, formalizing its authority in Catholic healthcare in the US.⁵⁰⁸ This distinction allows for a natural cycle of life to progress. Indeed, several principles collaborate to ensure the dignity of a patient's life, all while allowing its natural progression towards death. This statement is not paradoxical. Rather, it is a religious and ethical acquiescence towards the natural cycle of life. The definition of 'extraordinary' care is care, which is "...burdensome or disproportionate...to the outcome."⁵⁰⁹ Extraordinary means promise little benefit; or in economic terms, the costs outweigh the benefits of care. There is no obligation to preserve life at all costs (unlike Judaism's vitalist stance) Catholic tradition does dictate what extraordinary care involves, leaving little to interpretation. The *Declaration on Euthanasia* clarified that if there are no other remedies for an illness (as with palliative patients,) experimental or risky procedures can be forgone.⁵¹⁰

Catholicism is more permissive and perhaps even encouraging of forgoing treatment in futile situations. While Catholics may not 'hasten' death, they are also encouraged to welcome it when appropriate.⁵¹¹ Significantly, being 'permitted to die' of underlying causes pays homage to the natural pattern of life. Thus, one of the main differences between Judaism and Catholic theology. Since palliative patients are going to die, there is an ethical allowance for them to do so in Catholicism. Catholics infuse the word 'with-holding' with another definition: permitting

someone to die. For a Catholic ethicist, 'pulling the plug' can be morally correct and in line with the 'American consensus'⁵¹² Allowing a patient to die of underlying causes is permitted by withholding life support treatment. When medical care ceases to be useful, medical care ceases. The Double Effect supports this in pain management within the context of palliative care. So long as the physician intends towards merely ceasing pain so a patient can progress comfortably towards death, this is ethically adequate.

4.A. ii. *Pikuach Nefesh & goses* in Judaism

Jewish thought has several principles or commandments that create a 'hierarchy' of importance.⁵¹³ In Judaic ethical dilemmas, certain principles may outrank others when making an ethical decision. The principle to guard and preserve life—*pikuach nefesh*—ranks above all other principles.⁵¹⁴ Historically, *pikuach nefesh* has held this position in the 'hierarchy' of Jewish values by most Rabbinic *poskim* for over two millennia. This concept presents ethical dilemmas, specifically during palliative care. Whereas Catholic healthcare ethics permits forgoing extraordinary care measures, Judaism does not draw such distinctions even in futile care situations. A further complication during palliative pain management is Judaism's legal classification of a dying patient—the *goses*.

Judaism places the dying person in a *sui generis* classification replete with unique ordinances. These all have immediate applications once a patient meets the definition of a *goses*. A *goses* is a patient who will not recover from their illness and who will die in three days.⁵¹⁵ Indeed, these legal-religious categories are distinct and impose *halakhic* considerations upon people who encounter the dying. However, modern medicine has disrupted the statuses Judaism has depended upon for millennia. As such, the importance of *pikuach nefesh* coupled with the classification of *goses*, does not permit individuality or leniency within palliative care situations.

It is imperative to understand the historical and methodological importance of *pikuach nefesh* and the Talmudic discourse on *goses* before attempting to apply it to modern medicine. Rather than develop a religious exegesis, this section will summarize arguments for clarity and later analysis.

Significantly, there is no academic literature on the importance of *pikuach nefesh* on Jewish bioethical discourse. This absence is not accidental. According to the Talmud, saving a life trumps everything.⁵¹⁶ The importance of this contest is echoed later in the Talmud, which states that saving one life is akin to saving an entire world.⁵¹⁷ Thus, though centralized religious authority is absent within Judaism, the notion of *pikuach nefesh* is definite within all discourse. Whereas *poskim* argue about interpretation and application of the Law to modern medicine, the importance of *pikuach nefesh* has never wavered. Maimonides argued for the pre-eminence of the principle, overriding even the Sabbath in its importance.⁵¹⁸ Life is sacred in Judaism; hence there is no concept of ‘forgoing treatment’ in Judaism. Instead, there is a theological discourse based on preserving and guarding a life, despite the futility of treatment.⁵¹⁹ Judaism simply strives to give every patient a chance at life; indeed, most rabbis would caution even against hydration and nutrition tube removal.⁵²⁰ Hydration and nutrition are considered a basic human need, and should not be removed from a futile patient, exceptional cases aside.⁵²¹ There is surprisingly little distinction between the various sects within Judaism on the topic of forgoing treatment. A physician is obligated to save a life, even if it is only for a short period. Additionally, there is a mandate to relieve pain.⁵²² Together, this creates a strong case towards not merely pain management but further attempts to stabilize a dying patient (such as through feeding tubes). While some *poskim* such as J. David Bleich, note that withdrawal of everything *but* pain relief may be permitted, he is alone in his convictions.

Most modern rabbinic authorities utilize the Holocaust as additional support for *pikuach nefesh*. Since Nazi experiments classified Jews as people unworthy of life, modern Jewish ethicists have countered this forcefully. As a result, Judaism does not concern itself with 'quality of life' as Catholic ethicists would. Instead, it maintains a discourse towards saving all Jewish souls, irrespective of a patient's capacity for survival.⁵²³ Likewise, the risk involved with pain palliation is not an ethical concern in Judaism. Since pain causes bodily stress, it is permitted to palliate pain to extend life, albeit however briefly.⁵²⁴

There is one central Jewish text for dying located in the Talmud *Eruvin*. The text itself is concerned with the concept of *goses*—a person who is in a state of dying. Hastening death, even when imminent, is forbidden. Indeed, even moving the *goses* is forbidden.⁵²⁵ Removing all 'hindrances' to death within the environment is essential for the *goses*. Whereas all *poskim* draw attention to the importance of *goses*, disagreements surround what is considered a 'hindrance' to death. Whereas Conservative *poskim* may consider life support machines a 'hindrance' to (natural) death, Orthodox scholars refute this and insist that every moment of life is precious.⁵²⁶ Even within a specific stream of Judaism, there are disagreements of how to interpret the *goses* text to fit the modern era. Long-respected Orthodox *poskim* Tendler and Rosner allow a patient to forgo treatment if it is futile. Rabbi Tendler holds a PhD in microbiology and is considered a key leader in 20th and 21st century Jewish bioethics. He often collaborates with Dr Rosner, a physician and Orthodox Jew who is a further expert in modern Jewish medical ethics. Nevertheless, the Israeli Steinberg Commission, (also under Orthodox auspices) would disagree. It predisposes that a patient would wish a chance at life.⁵²⁷ A second concern mirrors the Catholic fear of hastening death; the Talmud notes several instances that it can classify as

hastening death.⁵²⁸ In palliative pain management, both these concerns are topical for Jewish ethics.

In the Talmud text concerning *goses*, a discussion abounds surrounding a woodchopper. As a *goses* lies dying, he hears a woodchopper working in the forest. The *goses*' family asks him to cease his chopping since the sound is troubling to the *goses* and may act as a disruption of his dying process.⁵²⁹ The modern legal analogy of a woodchopper is under considerable disagreement in modern Jewish ethical discourse. In the modern example of palliative pain management, there are several opinions about the most apt analogy for the 'woodchopper.' Some equate it to life support mechanisms, while others consider the concept of a woodchopper to be inconsequential. Rabbi Waldenberg argues that the sound of a woodchopper is not relevant, nor does it interfere with the dying process.⁵³⁰ There is variability in the Talmudic definition of *goses*. That is if a *goses* lives for more than three days *ex post facto* he was never truly a *goses*. This variability is crucial since this is the only method available to change modern Jewish ethical rulings. Hence, preserving the life of a not-yet *goses* is permitted. Within modern medicine, it is difficult to determine if a patient can be an accurate classification of *goses*. As a result, most Jewish scholars caution against withholding pain medication since the preservation of life is vital.⁵³¹

Parallel to Catholicism, Judaism wishes to prevent hastening of death, specifically for a *goses*. While the woodchopper anecdote alludes to this, it is demonstrated explicitly within the Talmud. Shortening a *goses*' life is murder within Judaism. To wit, someone caring for a *goses* is not permitted even to touch *him*. The Talmud bluntly illustrates this by terming the person who closes a *goses*' eyes (even as he is dying,) to be a murderer.⁵³² The Talmud has further prohibitions lest death is hastened: removing a pillow is prohibited, nor can the *goses* be moved

from where he is.⁵³³ The Talmud further relates that it is prohibited to pray to restore health as a patient then cannot leave the Earth in peace, and may suffer pain as a result.⁵³⁴ Contemporary *poskim* do, however, offer some leniency for personal care: one may assist a *goses* in hydration and cleaning. Importantly, hospital procedures such as blood draws are not permitted to a *goses* since they are deemed ‘unnecessary’ to a dying patient.⁵³⁵ This modern distinction is interesting. While the Talmud equates even a simple touch with hastening death, modern *poskim* allow for cleansing and hydration. Indeed, the latter interventions are far more invasive than a simple touch. Perhaps this is due to not fully be able to classify a patient as *goses* within modern medicine, which makes the three-day period less predictable.

Conversely, this may also be permitted in modernity since it provides comfort to a dying patient. Regardless, it does offer some rare leniency within Judaic law surrounding death and dying. Indeed, as modern Judaism strives predominately towards *pikuach nefesh*, hydrating and washing a patient may be classified thus. While Judaism and Catholicism hold shared values and have similarities in moral thought regarding palliating fragile patients facing imminent death, the methodology in both traditions underscores the differing value-hierarchy in each religion. Judaism’s omnipresent determination towards *pikuach nefesh* governs its ethical decisions, even to the detriment of the quality of life. Catholic ethics emphasizes quality of life, even in palliative care situations.⁵³⁶ The methodologies of each religion are apparent and telling. Jewish scholars draw upon source-texts for their arguments. Thus, for Judaism to acquire a new ethical interpretation in regards to pain management, change can only occur through textual re-interpretation by respected *poskim*. Such reinterpretation is a time-consuming process. In the interim, Orthodox Jews lack an approach equivalent to the clear-cut *Directives*, to inform them and their families on the Jewish ethics on dying.

Further, *poskim* do not offer delineations of 'extraordinary' treatments or use of quality of life concerns. Instead, there is a theological discourse based on preserving and guarding a life.⁵³⁷ Judaism simply strives to give every patient a chance at life; indeed, most rabbis would caution even against hydration and nutrition tube removal.⁵³⁸ Hydration and nutrition are considered a basic human need, and should not be removed from a futile patient, exceptional cases aside.⁵³⁹

Arguably, the emphasis and placement of intention is the main difference between Catholicism and Judaism. In Double Effect, intention to palliate pain is imperative, whereas Jewish ethics emphasize the intention of *pikuach nefesh*. Doubtless, Judaism's intention impedes the natural progression of death. Traditionally interpreted, *pikuach nefesh* is a no-win situation. As long as a patient is not *goses*, the physician is obliged to do everything to save their lives.⁵⁴⁰ Subsequently, when a patient is considered *goses*, there is confusion over what constitutes a hindrance to death. As medical technology progresses, it is imperative to consider a more nuanced approach towards *pikuach nefesh*. By reframing the conversation vis- a- vis the Catholic approach towards 'extraordinary' and ordinary care, this nuance can be accomplished in palliative care. Crucially, this re-framing stems from within Judaism's own source- text. Re-framing or re- interpreting the source text is not without precedent. The Talmud encourages and even enables future re-interpretations. In the *Talmud Yerushalmi* (the Jerusalem Talmud), there is a rather amusing exchange between Rabbi Akiva and his students. A woman asks him whether she is permitted to resume sexual relations with her husband after being ritually unclean.⁵⁴¹ Rabbi Akiva assured her she could resume sexual intercourse, and she leaves. His students are askance; usually, the laws in this regard are more stringent.⁵⁴² Rabbi Akiva notes that there is the majority (stringent) and non-majority (lenient) rulings in the text so that a scholar may choose which is the appropriate solution.⁵⁴³ Within this spirit, re- interpreting traditional texts is

permitted.⁵⁴⁴ Further, there is a precedent within Jewish methodology that allows for other cultures to influence the practice and *Halakha* of Judaism. For example, to accurately dedicate a new Jewish month, rabbis turned to astronomy to calculate the new lunar month⁵⁴⁵.

The equivalent of 'extraordinary' care in Judaism is undertaking risk-taking treatment. It is almost forbidden to undertake risky treatment to manage pain.⁵⁴⁶ The words 'almost forbidden' are purposeful. Rabbinical authorities would never entirely prohibit a procedure since pain is a fearful and vital concept. Systematically, a patient in extreme pain would base their autonomous decisions on a biased scale whereby they can be pain-free.⁵⁴⁷ Judaism recognizes that the intention of a patient in pain is pure: they wish to be pain-free. Pre-eminent *Halakhic* scholar Rabbi Moshe Isserles brings the following rule through an anecdote. A son is permitted to amputate his own father's arm (in the absence of professional assistance) since his father is in pain.⁵⁴⁸ In this ruling, Isserles emphasizes the fear of pain as the crux of his ruling, not the possibility of death from amputation.⁵⁴⁹ To wit, many patients eventually reach a point when they simply want the pain to cease, regardless of intervention risk.⁵⁵⁰ Executional autonomy—the ability to physically perform and move independently—is compromised by pain.⁵⁵¹ Pain may influence a patient's decisional autonomy. If a patient feels 'trapped' by the physical barrier of pain, lest they are coerced into risky medical interventions. However, there are conflicting values in *Halakha* and risk-taking.

A Deuteronomic commandment extols being "watchful" over human lives. This commandment is primarily understood to be a general prohibition against risk-taking.⁵⁵² However, again, this value is put aside in favour of the greater hierarchical value of *pikuach nefesh*. Indeed, Judaism holds pain itself shortens a life.⁵⁵³ A physician must strive towards pain palliation above all else since the fear of pain is itself a barrier to health. If palliation is

successful and a patient does die after administration of opioids, a physician is not morally culpable. The *halakhic* push towards risk-taking protects from unwanted death.⁵⁵⁴ This halakhic consideration shares a loose similarity with the Catholic Double Effect. As such, the physician intended to abide by *Halakha*. As such, this protects him should the patient dies. The physician intended to ease a patient's pain, not cause his death.

While traditional *Halakha* encourages 'extraordinary' care, there is an alternative reading that also parallels the more nuanced Catholic approach. In the case of a palliative patient, saving a life is no longer the primary concern. The very definition of 'palliative' care determines this; it stresses comforting the patient, not maintaining life. Thus, once a patient enters a palliative approach to end of life care, *pikuach nefesh* is no longer a concern. Jewish approached to criminal law can justify this concept, as it is akin to Catholicism's view of limiting 'extraordinary' care.

The Talmud *Sanhedrin* shares a case in which a gang of ten men beats victims to death. The legal concern is whether the man giving the final blow is guilty of homicide or whether the victim died as a collective result of all the beatings.⁵⁵⁵ A further anecdote from a *Midrash* (exegesis on the Torah) concerning criminal law is also apt. In the time of Noah, thieves were plentiful. These were smart thieves since they knew that punishment for theft would only occur if individuals stole a specific value quantity.⁵⁵⁶ Knowing this loophole, they stole small amounts of money as a group. God, Himself, came down to sentence them. God's anger at the thieves was due to their taking advantage of loopholes to accomplish their goals. Although technically their theft was at a monetary minimum, the multiplicity of small thefts became significant.⁵⁵⁷

Similarly, it is not the final blow that claimed the victim of beatings; it was the accumulation of blows.⁵⁵⁸ These blows are akin to 'extraordinary' care. Extending a palliative

patient's life through unwarranted interventions—however briefly—is analogous to a 'collection of blows.' The disease is the final blow that kills a patient since death will result in any case.

Forcing a patient to suffer (through a collection of blows of final treatment) is thus futile.

Further still, using 'loopholes' within *Halakha* is allowing the value of *pikuach nefesh* to trump the exemplar of a peaceful and dignified death offered by Catholicism. It would not be within the spirit of the Law to support extraordinary care in a palliative care situation. Indeed, *poskim* who steer aggressively towards *pikuach nefesh* are utilizing the loopholes that exist within *Halakha* to justify an unrealistic conclusion. It is not the purpose of palliative pain management to *save* a life. Instead, as the Catholic Double Effect suggests, its purpose is to aid in the peaceful transition to death. The continuous push towards *pikuach nefesh* in any (and all) situations is a multiplicity of misinterpreted text. *Pikuach nefesh* in palliative situations resembles 'extraordinary care.' If Jewish criminal law can apply to palliative care situations, the principle of *pikuach nefesh* need no longer apply.

Jewish authorities recognize the shortcomings mentioned above of traditional textual interpretation. Modern Talmud scholars have attempted to re-interpret *goses* towards 21st century bioethical concerns.⁵⁵⁹ Part of the religious-legal difficulty surrounding the *goses* is the ambiguity surrounding a *goses*' classification within modern medicine.⁵⁶⁰ While a *goses* is traditionally dead within three days, other notable texts refute this timeframe.⁵⁶¹ Potentially, a *goses* can be classified thus as soon as palliative treatment commences. In so doing, the *goses* becomes exempt from extraordinary care since it would become a hindrance to his death.

The original source for the three-day timeline of *goses* status is not clear. It may have stemmed from questions concerning when to begin the mourning period. There is a further legal classification- concept known as being “*goses* for a long time.”⁵⁶² Nonetheless, although he is in

a prolonged state of demise, the prohibitions surrounding hastening of death remain. Most Talmud commentators agree that while ‘most’ *goses* die within three days, others can remain in that status for some time. Others claim that a *goses* can survive and continue a healthy life, although this is rare.⁵⁶³ Contemporary *poskim* note difficulties in applying an ancient status to modern bioethical concerns. *Posek* Rabbi Feinstein determines a ‘modern’ *goses* to experience "death throes," and modern medicine is obligated to intervene if a state of *goses* is reversible. Rubenstein acknowledges the difficulty in accurately predicting a death-day, particularly in the context of modern medicine.⁵⁶⁴ The diversity of modern opinions within the context of one primary textual source proves the complexity of the application. If, however, as Rubenstein argues, a *goses* that survives for three days is not considered a *goses* at all, Catholic ‘extraordinary care’ limitations can be applied.

Due to modern technology, being categorized as ‘*goses* for a long time’ is common. Even a patient receiving pain management can be classified thus. However, the notion of ‘*goses* for a long time’ *halakhically* assumes the possibility that a patient may still recover. As a result, *pikuach nefesh* may be permissible. If, however, the modern definition of *goses* is not based on a (much contested) time frame but rather by the *active status* of dying, the limitations as mentioned above to *pikuach nefesh* could be applied. If someone is actively dying, nothing may impede his progression towards death. Moreover, it would allow a more nuanced interpretation of *pikuach nefesh* acting as a hindrance to a peaceful death,

In keeping to a Catholic framework of differentiating between 'ordinary' and 'extraordinary care,' it is clear that the un-nuanced approach to *pikuach nefesh* is analogous to the ‘woodchopper’ who hinders a smooth death. The traditional interpretation of *pikuach nefesh*

interferes with the dignity of death. In contrast, the Catholic Double Effect attempts to mediate 'good' and 'bad' intentions even in palliative pain management.

There is already some support among traditional decisors for this novel approach. According to the Talmud text, even a woodchopper outside a *goses'* room is considered bothersome and can prevent death.⁵⁶⁵ Rabbi Feinstein rules that if there is no longer an ability to cure a patient (and only the ability to extend his life for a short while), the physician may not treat the patient.⁵⁶⁶ Rabbi Feinstein determines this rather revolutionary *Halakha* from his interpretation of a Talmud source—indeed the same source from which other *poskim* ascertain that medical interventions are obligatory.⁵⁶⁷ Feinstein's ruling is doubly monumental. It proves that the re-interpretation of texts is commonplace. It also provides a foundation for *pikuach nefesh* being considered a hindrance to death.

If *poskim* were to accept the analogy of *pikuach nefesh* as the 'woodchopper,' physicians could do without 'extraordinary' measures for a palliative patient. A patient who would benefit from pain palliation, however, would not be obliged to seek after extraordinary treatment. It would enable patients to transition peacefully. Further, it would close several *halakhic* loopholes that are medically redundant for a dying patient. Although Judaism will never reach a generalized *halakhic* consensus akin to the Vatican, perhaps this allowance, which even the most Orthodox *posek* supports, would be considered as an ethical guideline.

4.B. Pediatric Palliative Care

This chapter utilizes pediatric palliative care to demonstrate the importance of spirituality within healthcare as a whole. Due to palliative care being a more recent specialty, children's palliative care is thus evolving. Whereas there is a need for palliative services, it is not yet

formally systematized. Further, palliative care for children may have non-temporal timelines. Some children require palliation services for a prolonged time; others only a short period.⁵⁶⁸ Pediatric palliative care includes symptom/pain management for the patient alongside family support for death and bereavement.⁵⁶⁹ Whereas adult palliative care is understood and financed, pediatric palliative care is underfinanced and underdeveloped. Startlingly, the lack of resources does not align with a lack of pediatric deaths. Data from 1997 indicates that approximately 80,000 children/youth die annually in North America. Nonetheless, there are dual barriers to pediatric palliative care: physician/medical barriers and family barriers. Family barriers include social, cultural, and religious issues. Medical barriers include a lack of comfort with pediatric death and a lack of specialized programs.⁵⁷⁰ Hence, crafting a palliative care program that mutually eliminates medical and family-based barriers is crucial. The literature agrees that offering palliative care within a collaborative healthcare environment is essential. Serving the family alongside the patient is also imperative.⁵⁷¹ Incorporation of palliative teams into normative children's healthcare, however, is still disputed. There are logistical concerns unique to a children's hospital or healthcare setting.

The fears of death are exacerbated at a pediatric level. Moreover, aggressiveness is compounded. Non-palliative physicians are hesitant to bring palliative care into discussions with families. A study conducted with pediatric oncologists displayed this claim. Through collected survey quotes, there is significant mistrust and fear towards the palliative care team.⁵⁷² Several physicians noted 'failure' if they needed to include the palliative team. Further, some remarked on the additional burden this would place on the family. Self-identified nurses and nurse practitioner appear to disagree; they understand the importance of palliation in some patients. However, palliative care is colored by its appointment as 'end of life care'.⁵⁷³ Thus, there is a

lack of understanding of the appropriateness and method of palliative care. Palliative care may in fact encourage healing via symptom management and embracing palliative services at the onset of treatment is encouraged by the American Academy of Pediatrics. They support palliative treatment whether the child survives or dies.⁵⁷⁴ Medical outcomes may be strengthened by palliative care as it allowed the child (and family,) some reprieve of symptoms. Nonetheless, there is stigma attached to palliative care; indeed, children with terminal illness do not acquire palliation at the same level as adult patients.⁵⁷⁵ In a statistical study, reasons for this phenomenon were discovered. Some physicians may resist opioid treatment for children, even though there is no indication that opioids hasten death. Neonates, as a group, receive poor pain management. This is perhaps due to the difficulty in assessing their pain coupled with a misperception of how neonates experience pain.⁵⁷⁶ Whereas analgesics belong in compassionate care, it can shorten a life span.⁵⁷⁷ While careful dosage is certainly imperative, there are risks associated with pain management. Palliative pain management techniques can cause respiratory distress and a loss of mental clarity. Further, as a patient declines, the amount of pain relief required may be greater; increasing the risk of respiratory distress.⁵⁷⁸ Other pediatric findings indicate difficulty for parents to accept the death of their child. This cannot be understated. Child deaths are ‘unnatural’ and tragic and the bereavement period is long and unrelenting. If, however, a physician encouraged palliative services at the onset of treatment, perhaps those end of life discussions are somewhat easier.⁵⁷⁹ Palliative care services also offer support systems for grief and family bereavement.

For some pediatric patients, pain is difficult to assess. Pain can be interpreted as emotional, generalized or specific; all of which crafts a different clinical diagnosis.⁵⁸⁰ Treating pain is both an art and science; particularly if generalized and imprecisely located. Ignoring pain

can mean delaying treatment for potentially fatal diseases.⁵⁸¹ Indeed, these layers create complexity for patient care. The physical and psychological aspects of suffering are varied and individual. This is heightened and made more complex in a pediatric environment. For a pediatric patient, family or friends also carry the implications of suffering.⁵⁸² Understanding suffering changes during the end of life; knowing which treatments would cause further harm is imperative.

A further medical barrier is enacting end of life treatment plans for children. Undoubtedly, children dying is unsettling. Arguably, to enact such a treatment is the ultimate act of compassion. Compassion is a different philosophical notion than sympathy or empathy. Thus, 'compassion' is defined via three variables: recognition of suffering; benevolence; being "personally addressed" by the suffering and; a desire to relieve the suffering.⁵⁸³ To truly be compassionate for each and every patient would be difficult, as a doctor would need boundless capacity. This may not be within the realm of possibility and further would cause mental distress among pediatric physicians. Perhaps, for a pediatric physician, end of life conversations are thus not fully integrated with clinical diagnosis. Perhaps by allowing some 'removal' of the possibility of death, a physician can better serve himself and the patient. However, fully integrating end of life care could conceivably be the most compassionate action. Together with their physician, a family can create a plan towards a peaceful death.⁵⁸⁴ By freeing both physician and patient from a cycle of futile interventions, the fear associated with death, dying and assistance in dying can be suspended. This can be orchestrated in either a pediatric hospice setting or at home.

Indeed, this chapter argues that palliative care is an ethical obligation of children's healthcare. Moreover, it should be 'best practice.' However, creating a framework for such a

service is the challenge. This chapter proposes that if organized via an ethical lens, children's palliative care programs can mitigate religious barriers and infuse a standard of care into pediatric medicine. At its essence, two concepts are ethically and medically crucial to the proper use of palliative care: education and care integration. Instructing physicians and families may relieve fears surrounding palliative care. More education leads to earlier integration of palliative care programs. The literature notes the beneficial impact of earlier palliative interventions.⁵⁸⁵ Earlier integration could undeniably mitigate the reputation of palliative care. Many—physicians included—assume their treatment to be a 'failure' if there is a consultation with palliative care.⁵⁸⁶ Parents may be emotionally staggered when palliative arrives; again, a result of education and poor reputation. Indeed, there is considerable confusion towards children's palliative care.⁵⁸⁷ Whereas education can produce earlier integration of care, normative pediatric ethical questions persist. Undeniably, the ethics of child autonomy, decision making and truth-telling are all impacted by the integration of palliative services. Introducing palliative care at any stage of illness causes a ripple effect. Hence, the ethical difficulties surface. A more encompassing ethical concern is whether and how early integration of palliative care services creates a better quality of life. The notion of palliative care being a harbinger of death is an outdated approach. From analyzing pediatric palliative care, it is demonstrable that the skill set of palliative physicians extends to far more than the last months or weeks of life. Objectively, creating systematized palliative care service is not merely best practice; moreover, it is an ethical imperative. It must promote both education amongst staff and families and encourage early integration from diagnosis. Further still, palliative care has an impressive scope that can integrate into all aspects of healthcare. For this dissertation in particular, how palliative care integrates spirituality and religion at the onset is imperative and requires further analysis.

The design of children's hospitals and hospices keeps little patients in mind. There is room to run, bright spaces to play. Beds are limited to provide best-individualized care to the patients.⁵⁸⁸ There are two current models for palliative care: either there is a designated space within the hospital itself for palliative care or sending the patient to an external affiliate. Mirroring adult palliative care, children may also opt for home-based palliative care.⁵⁸⁹ There are inequalities in access to palliative care, based on geography. Hence, an alarming ethical issue is apparent, perhaps due to a lack of federalized legislation. Increasing systemized palliative care options and increasing access to care would be an advantage to health care professionals, the patient and families.

There are several models of pediatric palliative and hospice services. 2006 brought formalized core competencies to adult palliative care which can be exported into pediatric care.⁵⁹⁰ A major logistical concern of pediatric palliative care is the length of time treatment may be offered. Unlike adult care provided during the last six weeks of life, pediatric palliation treatments may be ongoing over several months.⁵⁹¹ Pediatric palliative care is divided into 4 groups who suffer from “life limiting illness.” These include children with life-threatening illnesses such as certain cancers or organ failure; children who are facing premature death and periods of treatment (e.g. cystic fibrosis); children with illness without a cure, with long-term palliative treatment and; children who have a “severe neurological disability” but non-progressive, but, are susceptible to health issues.⁵⁹² Care can be accessed via the hospital’s own in/out patient services, a children’s hospice or home-based services.⁵⁹³ Pediatric palliative services is more broadly defined than adult palliative services. As such, it brings unique challenges. Certainly the generally negative reputation of ‘palliative care’ is substantial. Patients assume palliative care means the end of life. Pediatric care, by definition, is able to support its’

patients long-term. Understanding the nuance of palliative care services for pediatric patients is imperative to embracing it.

There are benefits and challenges to each palliative care option. Children dying at home may appear upsetting; but surprisingly, parents and families had a reduction in psycho-social ramifications when they cared for their little one at home during the end of life.⁵⁹⁴ Children's hospices have few beds (which may be a problem in more densely populated cities) but also have reprieve programs. Some patients spend time there short-term to allow caregiver and family members a respite. Some even offer programs for non-ill siblings. Children's hospices were created in 1982 in the United Kingdom, spreading to Europe and North America. Currently, the United States of America has one 'stand-alone' children's hospice.⁵⁹⁵ Children's hospitals have few specialized palliative care teams. In the United States there are merely 31 children's hospitals with designated palliative services. This number however is growing. These programs blend attempts at curative treatment with comfort measures.⁵⁹⁶ Families can seek treatment in hospital, at home, or some combination of the two. Symptom and pain management are mitigated and bereavement support and resources are part and parcel of the program. Nurses may visit schools to help classmates understand and the program offers follow-up contact for the family.⁵⁹⁷

The American Academy of Pediatrics supports the blending of curative treatments with pain management. Moreover, they press the importance of developing research in palliative care and increasing education for medical professionals and families.⁵⁹⁸ There is a significant lack of hospice/home and hospital-based palliative care services. Often, families must travel a great distance, which causes financial and emotional distress. This is an ethical issue that may be lessened by further education and even research into the best practice of pediatric palliative care.

According to the policy, failure to integrate palliative care in all its aspects could be considered an ethical and medical miscarriage. The Academy outlines minimum standards for palliative care. These include access to a pediatric palliative specialist 24 hours a day, 365 days a year. It further delineates an interdisciplinary team that includes social workers, child life specialists and nurses.⁵⁹⁹ Whereas the Academy recognizes the importance of palliative care integration, access and scope of service, it fails to address key issues. With these legislated minimums in place, there is no indication of whether and how more specialists will be trained or if funding or more hospice or mobile palliative services will be provided. The policy noted that insurance and Medicaid may not support pediatric palliative care treatments. Yet, the policy offers no proposed solutions for patients who cannot afford treatment. The policy is unquestionably well intentioned and is correct in the minimums it recommends. Nevertheless, it does not provide an ethical discussion on how to mitigate issues and ensure palliative access for all who require it.

4.B.i Religious and Educational Barriers to Pediatric Palliative Care

Earlier integration of palliative care services demonstrably creates better outcomes. Earlier integration of services can only happen with the education of medical teams. Circumstantially, earlier integration furthers effective communication.⁶⁰⁰ Palliative care education is an ethical imperative to allow young patients a good death. Nurses and physicians do not receive impactful training in how to communicate with children at the end of life. Communication difficulties compound if a family opts for home-based care in a rural area.⁶⁰¹ Communication is not the only thing lacking. As previously mentioned, there is a significant lack of skilled specialists in pediatric palliative care. If a sizeable city-based hospital has the specialists, they are reluctant or unable to provide home-based hospice care.⁶⁰² When a commission or hospital legislates educational efforts, the results are astounding and welcomed.

This lack of education ultimately affects families. Parents and caregivers are uncertain of what palliative care entails and, as such, are hostile, scared or confused about its' services.⁶⁰³

Ironically, the concerns of parents align closely with concerns of quality of life, the rationale behind proper palliative care.⁶⁰⁴

There are further impediments to communication that are cultural/ religious or even psycho-social. These obstacles are closely related to the ethical implications of truth-telling and the age of consent in a healthcare setting. Several studies have proved that proper education of healthcare providers increases the utilization of palliative care. There are measurable differences between nurses and doctors about when to engage in palliative care. Whereas physicians may delay a consult out of fear of 'failing' the patient, nurses are more concerned with prolongation of patient suffering.⁶⁰⁵ Notably, nurses and physicians have differences of opinions on the scope, purpose and specializations of palliative care. Proper usage of palliative treatments ensures a path towards a better quality of life and a more ethical option of care.

Sticky end of life conversations requires a level of confidence. Very few physicians train or are comfortable with the notion of the pediatric end of life care. Thus, it is unsurprising that they are not confident in integrating the palliative specialty into normative practice. Pediatric residents lack formal training in palliative care initiatives. Physicians who lack palliative education are physicians who are not competent in palliative care.⁶⁰⁶ This lack of full comfort with palliative care limits the overall outcome of patients and families; the ethical ramifications are resounding. There is an acute awareness in the literature about the lack of pediatric palliative education and comfort amongst pediatric physicians. Positively, the mere presence of a palliative care program alone improves the awareness and educational level of physicians.⁶⁰⁷ Most physicians understand palliative care to involve pain palliation and end of life

communication. However, most pediatric physicians are reticent to establish the need for palliative care at the onset of treatment.⁶⁰⁸ Many physicians also wish to learn how to discuss death directly with their patients and help to mediate conversations with parents and family.⁶⁰⁹ This propensity toward better education demonstrates an ideal. It would empower more non-palliative trained physicians to supervise home-based hospice care for patients. Comprehensive palliative education would alleviate the lack of pediatric palliative specialists and even make home-hospice a more viable option.⁶¹⁰ The physical drive toward education is readily apparent. However, the lack of understanding and resources is apparent as well. Learning the art of proper pain is done through practice, and there is a lack of trained mentors.⁶¹¹ A literature review conducted for researching this chapter betrayed a lack of knowledge of other palliative care services. Indeed, searches for 'education' and 'physician' and 'palliative care' found abstracts that are ignorant of other aspects of palliative services. Abstracts mentioned symptom management, pain palliation and end of life conversations. Few articles mentioned the quality of life concerns, except when discussing parental concerns. Other articles focus on a lack of training on pediatric palliative care in medical school and later, pediatric residency. A lack of comfort with palliative care, alongside a generalized lack of understanding, affects the parents/caregivers of a pediatric patient. It is abundantly clear that more research or educational intervention is urgently and ethically required.

The AAP policies support ongoing research in the field of palliative care. Indeed, research on early palliative engagement would strengthen the specialty. Moreover, there is an ethical imperative to research palliative care, especially since it is not yet widely offered nor understood. Research allows for modification, improvement and engagement with the 'elephant in the room.' Indeed, promoting research in palliative care would force engagement and alleviate

the misconceptions surrounding it. Research could potentially most impact quality of life measurements. Quality of life is notoriously complex and tangible; making empirical studies of it nearly impossible.⁶¹² However, considering the long-term aspect of some palliative care treatments for children, it would be essential to study. The empirical data reflecting the anecdotally understood significance of palliative care would be a qualification towards extending palliative services. Indeed, perceptions of quality of life have been addressed in adults receiving palliative care. For example, when researchers studied the positive affect of nursing homes, they found successes. The creation of a home-like environment with natural stimulations (plants, animals) leads to far less medication usage. While a nursing home is not a perfect simulation of one's own community, these stimulants can have resounding effect.⁶¹³

Assuming the studies are conducted with research ethics board approval, the influence can be formidable. Addressing the patients—the children and youth—directly would create an impactful research method.⁶¹⁴ Moreover, considering the fears that surround death, talking about quality of life could potentially assuage the fear. Research may also help to establish 'core competencies' for pediatric palliative care teams. A recent study formalized the importance of this objective and establishes the motivation for further study. Clearly delineated competencies may enable a growth in pediatric palliative specialization.⁶¹⁵ The six generalized core competencies noted by the study represent a small survey of complexities. These identified competencies are generalized (like patient and family care, and systems-based practice,) however is it notable that an unfulfilled niche has been established.⁶¹⁶

Pediatric palliative care involves all aspects of emotional, social, mental and physical care. Rarely do parents fully comprehend this. Perhaps some of the blame can be placed on the physician's lack of understanding. From a parent's perspective, communication and

understanding of palliative services are reduced.⁶¹⁷ Parents appreciate a transparent, didactic approach to poor prognoses. If a child is dying, they wish to be told compassionately and relayed by a professional with whom they developed a relationship. Overall, parents do not quite understand what palliative care means, even at the end of life. Some felt abandoned by their normative care team once palliative treatment took over the care of their dying child.⁶¹⁸ Further, some parents revealed that they did not realize the goals of care were changing. To wit, while they focused on curative treatment, the physicians and nurses shifted to palliative treatment. Parents associate palliative treatment with end-of-life and pain palliation and felt it inappropriate treatment for their child.⁶¹⁹ Besides a general lack of understanding of the scope of palliative services offered, parents prevaricate over the goals of palliative care. Specifically, parents struggle with understanding whether embracing palliative care is them letting their child go or, in contrast, "preserves" the quality of life of the child. This nuance is important. It harkens back to the policy goals of the AAP: that palliative care can be complimentary to curative treatment.⁶²⁰ This policy encapsulates a key and lesser-known goal of palliative care—to achieve a quality of life as determined by patients and families.

There is a time when futility is natural and even welcomed. Although pedantic death is always untimely and tragic, 'letting go' via palliative care is sometimes misunderstood by parents and physicians. By allowing a patient to die, a doctor is allowing the underlying pathology to take its natural progression. Indeed, doing so may even ease the suffering caused by medical intervention. Perhaps parental fears can be mollified by referring to palliative care as compassionate care. It is compassionate to relieve pain, and not fear it. Futility can even be measured medically and understood compassionately. Regardless, physicians 'refuse' to let

patients die.⁶²¹ Comprehending the notion of suffering will enable the possibility of ending life compassionately, still within the ethics of physician care and duty.

Just as religious beliefs can sway patients' interpretation of disclosure, understanding—that is, the ability to process information based on physician's disclosure—can be heavily influenced by religious beliefs. There are two barriers to full understanding. The first barrier lies in communication and how effectively physicians communicate complex medical terminology.⁶²² The second barrier, more critical to this discussion, is unique to religion and concerns itself with how the patient understands their religion in the context of their illness. These two barriers significantly impact the autonomous decision process. When a physician discloses a medical diagnosis, they are responsible for explaining complex medical terminology to a layperson.⁶²³ The lack of foresight is most ethically apparent in the element of understanding. That is, patients lack knowledge of how they will feel after the surgery, and what complications can ensue.⁶²⁴

Beauchamp and Childress address concerns of information processing (for example, focusing on survival rather than death,) and 'false belief' (if a patient is not adequately informed or ignorant.)⁶²⁵ Each of these can be re-interpreted from within a religious framework. Some religious believers think that God brings illness or suffering upon them. Thus, for a religious person, *real* understanding is not derived solely through a medical diagnosis. Instead, it derives from their belief, their *acceptance* that they may have this illness for a reason. 'False belief' gains another dimension, as it is religious belief—however interpreted-- that may inform a decision. Rather than ignorance preventing a free choice, it can be a religious belief that informs a decision. Whereas religious choices can indeed challenge physicians (for example, urgent blood transfusion with a Jehovah's Witness,) it can be perplexing to overcome. To gain true

autonomous consent, a physician would have to discuss understanding and recommendations through the lens of what the patient permits under their personal understanding of religion. This analysis would prove a very necessary though ultimately daunting task; despite the doctor's best efforts, the patient may still find it challenging to separate autonomy and consent from religious mandates.

It is essential to recognize the importance of influence on 'autonomous' medical decision-making.⁶²⁶ Religion is a tremendous influence on many—, particularly in medical situations. Religion could be classified incorrectly by health professionals as coercion or manipulation.⁶²⁷ Instead, religion must be viewed as a vulnerability that will influence people to varying extents.⁶²⁸ For some patients, their autonomy is significantly impacted within the confines of a particular religious tradition, while others may see the relevant tenets as more variable. However, even when giving consent, it is difficult for a physician to know whether it is an autonomous, consensual decision and what decision is influenced by religion. Thus, measuring other mitigating factors outside of religion (such as competence and capacity) alongside religious conviction is essential for valid autonomous consent.

Sometimes, parents and children are unable to come to terms with palliative care due to cultural, religious or psycho-social concerns. For some, religion serves as a foundation upon which will base all medical decisions. As parents can be emotional during their child's illness, they may place greater importance on religious-decision making. Indeed, in a time of heightened emotions and stress, a religious family may find it difficult to render a medical decision wholly divorced from his religion. A religious patient consults leaders and teachers in his religious tradition to guide his decision-making process. Not being culturally sensitive to religious or cultural traditions can erect a barrier to palliative treatment.⁶²⁹ Latino parents may refuse

palliative treatment, believing that every intervention must be taken. Christian African-American families believe in miracles and, thus, are also aggressive with treatment and dismissive of palliative care.⁶³⁰ Clergy may be called in to mediate between cultural concerns and medical judgment. However, some families find that a clergy visitation is a harbinger of death.⁶³¹ A further, often overlooked cultural barrier is language. Some languages do not have adequate words to describe what is occurring.⁶³² Some cultures infuse power into language. Hence, translating that the child may die will force it into being.⁶³³ The meaning and function of non-verbal cues and physical touch shifts from culture to culture. Native American families find touching a dying child's face disrespectful; Vietnamese families harbour concerns about touching a patient's head.⁶³⁴ The perception of pain also metamorphoses across cultures and traditions. Ladino families fathom pain to be spiritual punishment. South-Asian communities share similar views; their suffering is the pain of incarnation in progress.⁶³⁵ Due to this pain being spiritually significant, these populaces general underreport pain and shy away from pain management.⁶³⁶ Some Asian populations also are reticent to ask for additional pain relief as it is considered disrespectful of the physician's original orders. A physician can remedy this hesitation by explaining that it is permissible to ask for additional medication. Some cultures may seek traditional treatment outside of, or in addition to palliative care.⁶³⁷ The location of end-of-life care is also crucially impacted by religion or culture. Some cultures designate individual rooms for specific uses, possibly making home-based hospice care more difficult.⁶³⁸ Regardless of culture or tradition, it is apparent that palliative care and end of life decision making is a family-dominated decision.

The zeal towards aggressive treatment and prolonging life is particularly true with pediatric patients. A common pediatric ethical trope is the concept of truth-telling. Cultural or

religious upbringing also colour this trope. For Chinese, Korean and Russian families, non-disclosure is the norm. A child is never told of his condition.⁶³⁹ For these families, words have value and can determine that their child does indeed die. Alternatively, the prognosis will upset the child so much, and they will cease to 'fight' their illness.⁶⁴⁰ Decision making rests solely on the parents, regardless of the child's age or ability to comprehend their situation.⁶⁴¹ Comparably, a patient's psychosocial background may erect a barrier in understanding death, dying and palliative care. Parents should be candid with physicians, so that true, autonomous and informed consent is given for all treatments, including palliative care. While Judaism and Catholicism hold shared values and have similarities in moral thought regarding palliating fragile patients, the methodology in both traditions underscores the differing value-hierarchy in each religion. Judaism's omnipresent determination towards *pikuach nefesh* governs its ethical decisions, even to the detriment of quality of life. Catholic ethics places emphasis on quality of life, even in terminal situations.⁶⁴²

The Church proscribes responsibilities that every Catholic parent owes their child. Parents are obligated to keep their child well both physically and spiritually. Difficult decisions are made based on paternal authority. This paternal parental authority is mirrored directly on the authority of Jesus Christ. This Divine authority comes into direct conflict with secular authority that values consensus and individual autonomy. According to the Vatican and other scholars, wife and child must submit to the husband/father in difficult decision making. However, it is difficult to watch a child suffer. Indeed, the human value of a child, and his suffering, is tantamount in Christianity.⁶⁴³ Whereas palliative pain is a difficult subject in Catholicism (due to fears of hastening death,) pediatric pain in Christianity is treated differently. Pain, especially for younger children, is unbearable. A child cannot fully express the amount of pain they are in.

Further, they cannot understand if it is temporal or chronic. It is also uniquely communal: parents suffer alongside the child.⁶⁴⁴ However, if pain is required for proper treatment of the child, then pain is allowable—even welcomed. Pain, so long as it is not excessive, can be character building. However, there is also a desire to treat and help those who are suffering. Nonetheless, aggressive treatment should only be pursued as a last resort. In Catholic teaching a child is not autonomous; regardless of age. All children must therefore use parents as a proxy for decision making.⁶⁴⁵

Judaic views towards children and their autonomy is abundantly clear. Like Catholicism, there is patriarchal domination in decision making. In Jewish law, a minor cannot appoint a proxy decision maker because they have no legal status. In Biblical times, a father could give his daughter's hand in marriage without her consent. Later Rabbinic sources altered this arrangement. If a child is physically injured, damages must be paid to the father.⁶⁴⁶ Legally, (according to the Talmud,) daughters can become emancipated from fathers when they reach the age of majority which is 12. At this age, she traditionally is demonstrating some signs of puberty.⁶⁴⁷ She is also emancipated if and when her father dies. Although less is explicitly written about the minor male, he comes into the age of majority at 13. Similarly, once mature, the male can accept his own financial damages and enter into vows.⁶⁴⁸ It is not a logical stretch to assume that Jewish families would allow the father or mother to assume decision making capabilities. Once a child reaches the legal age of majority, some parents may take that into consideration. Importantly, the age of majority exists for *legal* matters: financial damages, making vows, marriage, divorce, buying and selling. Most Jewish families would consider healthcare decision making to be done either as a family or under parental authority. It would vary from family to family how much autonomy they would allow their child. While 12/13 is the

age of majority, it is doubtful if a secular hospital would assume this age to be an age of maturity without individual assessment.

The question of ‘who decides’ will be explored in Chapter 6 of this dissertation. However, it is important to understand the particular psychological makeup of a child who is ill. Arguably, these children are capable beyond their years. There is research that indicates children with prolonged illnesses (such as cancer or organ diseases) exhibit a higher level of medical understanding and maturity than their peers.⁶⁴⁹ These children may be considered more ‘capable’ due to the time they have spent directly living with their illnesses. However, pain and illness can shift understanding and the consent process. It can tangle with the concepts of capacity and competency. A patient in extreme pain would also base their autonomous decisions on a biased scale whereby they can be pain-free.⁶⁵⁰ Indeed, the most important framework for autonomous decision-making and consent is context. As patient context shifts, the patient’s autonomous ideals do as well. A patient who is riddled with chronic pain also has their autonomous consent compromised.⁶⁵¹ When a patient is presented with the ability to be pain-free, their overall competency may be unreliable.⁶⁵² For chronic pain, standards of obtaining autonomous consent should be modified. Analyzing a patient’s capacity for competence and some elements of informed consent require evaluation. Context—in this case pain—may cause a normally competent individual to be swayed into non-fully consensual choices.⁶⁵³ The theory of autonomy also shifts to accommodate the impact of chronic pain on decision-making. The intention of a chronic pain patient is simple: they wish to be pain free. This reality shifts their perspective of autonomous choice and consent since every decision may be influenced by the promise of being pain free. There is a fine line between making certain choices to being pain-free versus being considered an incapable patient. While uncontrollable pain can cause incapacity for decision-

making, patients with pain are generally competent.⁶⁵⁴ Children with intense pain may make intentional decisions towards ceasing their pain. True autonomous choices then, are difficult to dissect from a child in pain. Just as a religious person cannot separate their religion from their decision-making processes, a pain-riddled patient cannot imagine a life without pain. The power of pain, and the promise of being pain free, is enough to motivate a patient to decide devoid of true understanding. Physicians must carefully modify their discussions surrounding informed consent to ensure that there is a balance between true autonomy and the influence of pain if they wish a child to participate fully in their decision to pursue palliative care.

Conventional pediatric ethic topics involve concepts of the mature minor, truth-telling, and decision making. These have been explored through the lens of religion. However, religion aside, the lack of uniformity and understanding in pediatric palliative care is an ethical concern on its own. Limiting palliative care to end of life patients is dangerous. Not only does it stymie excellent care to a few, but it overlooks the powerful scope of palliative practice. Palliative care is ideally suited to mitigating pain in typical situations. Children with illness that affects the quality of life are essentially robbed of palliative services. Indeed, the overall goal of palliative care is improving quality of life. Moreover, it should be considered ‘best practice’. Children’s palliative care programs can mitigate barriers and infuse a holistic standard of care into paediatric medicine. By educating physicians and families, fears surrounding palliative care may be relieved. Greater education leads to earlier integration of palliative care programs. The beneficial impact of earlier palliative interventions is supported by the literature.⁶⁵⁵ Earlier integration could undeniably mitigate the reputation of palliative care. Introducing palliative care at any stage of illness causes a ripple effect. Indeed, pediatric hospitals are familiar with death but few offer specialized palliative care teams. It must promote both education amongst staff and

families and encourage early integration from diagnosis. Creating a systematized, robust and fully integrated palliative care service is not merely best practice. It is an ethical imperative.

While an analysis of pediatric palliative care reveals its tremendous awareness of the importance of spirituality and religion. The literature reveals a focus towards incorporating religion/religious practices during end of life in pediatric situations in particular. At the same time, there is a lack of causativeness. Granted, religion and spirituality is impactful for families, especially at the end of life. However, the literature does not fully comprehend nor empirically qualify the *value* of incorporating religion into everyday decision making. This dissertation, using the obvious impact of religiously motivated pediatric palliative care is an attempt to truly showcase the importance of religion throughout all decision making processes.

5. Religious Barriers in Clinical Care: Specific Cases and Circumstances and the Confines of Cultural Competency

It is essential to understand the limits of undue hardship and the concept of reasonable accommodation as they apply to specific cases and circumstances. The previous chapter discussed individual undue hardship and institutional undue hardship. This chapter will carry this concept further, presenting finite situations that are difficult to encounter in a clinical ethics situation. This chapter will parse four separate clinical case circumstances where religious accommodation is requested. These cases span mental health (using the Hasidic community,) public health, (the HPV vaccine,) individualized health (genetic engineering,) and pediatric health (oncofertility.) Thorough discussion and analysis of these four cases betray similar themes essential to the crux of this dissertation. In short, each of these cases presents an ethics duology whereby religious and ‘secular’ medical ethics grapple for triumph. Whether and how undue hardship can apply, however, differs in each case. In the instance of broader, societal issues such as mental health and public health, religious undue hardship cannot be applied. In the cases of more individual decision making, indicated vis a vis genetic engineering and pediatric oncofertility, a different type of hardship is presented which this dissertation dubs flipped hardship. Flipped hardship occurs when religious accommodation or religious permission is perhaps antithetical to secular medical ethics. In such cases, limitations on religious accommodation would be ethically permitted. To be clear, this dissertation crafts two definitions for ethical undue hardship in healthcare. The first is undue hardship whereby a ‘secular’ organization is treating a religious patient who asks for a treatment or procedure that goes against secular healthcare ethics. The second, more novel concept is dubbed ‘flipped hardship’ where a religious organization treating a patient who does not identify with the religious ideology of the

organization wants a treatment that the organization is unwilling to offer. However, this treatment is acceptable from the perspective of secular healthcare ethics. As shall be illustrated later in this chapter, flipped hardship is not applicable if the request goes against social contract theory and/or, if there is a certain interpretation from within the religious organization itself which would permit treatment.

In the case of Hasidic Judaism, basic knowledge of Judaism is not enough to offer full appreciation for expressing undue hardship. Hasidic Jews clinically present differently from other Jewish sects, and subsequently, the religious accommodations they require are unique to their communities; thus, in this chapter, the limits of religious accommodations are presented vis-a-vis a specific patient community. Furthermore, the time spent on the Hasidic community serves another, more generalized purpose: to demonstrate that mere cultural competency may not suffice in every clinical encounter.

Recent events in the news media have raised the alarm over religious objections to public health matters. The measles outbreak in New York demonstrates a nuance in law that is harmful to the public at large. Hasidic Jews, in particular, have been targeted by the public for refusing to vaccinate their children due to religious objections. The religious objection clause that allowed the Hasidic community to forgo vaccination has been overturned by the state legislature due to the public health crisis. As such, a very recent demonstration of how religious rights may be vetoed for public health concerns.

Thus, this chapter would be remiss to ignore a current maelstrom between religion and the public good. Rather than merely focus on proven vaccines such as measles and MMR, this chapter chooses to explore the more controversial HPV vaccine. While the science of the HPV vaccine is sound, religious communities balk at the very notion *of* the vaccine. Both Jewish and

Catholic communities believed the vaccine promoted sexual promiscuity. The Catholic School Board in Canada, in particular, challenged the public health initiative when the vaccine was offered in schools. This demonstrates another very relevant case study that signifies the importance of creating justifiable limits on religious accommodation for the demonstrable public good.

Finally, this chapter introduces a new concept called 'flipped hardship.' This is defined as when the hardship is placed upon the religion, rather than the secular medical institution. The demonstration of an example of 'flipped hardship' is best-illustrated vis -a- vis CRISPR technologies. Presently, Judaic scholars have yet to analyze the promise of CRISPR within Judaic law. Catholic scholars have adopted a negative approach to the genetic engineering tool. This chapter attempts to build the *halakhic* scaffolding, which would enable the usage of CRISPR due to past *halakhic* precedent. Philosophically, Judaism's potential for a more lenient approach to CRISPR may grapple with future secular ethical protocols. Catholicism's blanket of rejection may also clash with secular CRISPR ethics. As such, the hardship principle is flipped—Jewish patients may request treatments or services that are beyond the secular norm. Would this be considered undue hardship? How could this define undue hardship in the future for more understood concepts such as brain death?

5A. Religiously Triggered: Background to the *Hasidic* Community and Their Nuanced Mental Illness

Whereas *Hasidim* are included in the umbrella term of *Haredim* (ultra-Orthodox,) Hasidim are distinctive since each community follows a specific *Rebbe*, a spiritual teacher-leader and rabbi. A note on terminology: the term *Haredi* refers to ultra-Orthodox Jews as a collective

whereas *Hasid* (s.-*Hasidim*-p.) refers solely to the followers of the Ba'al Shem Tov.⁶⁵⁶ There are various sects within the *Hasid* community, each lead by its own inspirational rabbinic leader.

This important difference is often absent in the scientific literature. As such, treatment options must be exclusively bespoke to this community since *Hasidim* hold contempt for both the secular world and psychiatry.⁶⁵⁷ Many, if not most *Hasidic* families speak little English,(even in North America,) are patriarchal and do not make medical decisions without rabbinical consultation. Further, the notion of mental illness is still taboo in this insular society. Rather, it is the result of the *yatzar ha-rah* or 'bad spirit' that can be exorcised via prayer, study and repentance.⁶⁵⁸ Indeed, religious ritual governs every minute of life. Additionally, some *Hasidic* communities encourage midnight graveyard visits and religious visions; actions which a secular physician may find aligns with mental illness.⁶⁵⁹ Some rabbinical leaders attempt to mediate an ill community member via prayer and supplication.⁶⁶⁰ A Hasidic patient is thus isolated dually: by his illness and by his community's resistance to secular, Western medical intervention.

In the middle of the 18th century, the Ba'al Shem Tov (literally, Master of the Good Name—Rabbi Yisrael ben Eliezar) was widely recognized across Europe for being a miracle worker. According to legend, he was masterful at healing through *Kabbalah* and encouraged his followers to worship G-d through dance, song and joyous fervor.⁶⁶¹ His magnetic personality and unusual practices attracted many followers and proliferated across central and eastern Europe. *Hasidim* observe the *Torah* code stringently and gender roles are traditionally delineated. All men are encouraged to study full time and women are expected to work (in approved roles,) and take care of domestic life.⁶⁶² There are several *Hasidic* courts each lead by a *Tzaddik* (s. righteous individual,) referred to as *Rebbe*. The *Rebbe* advises, counsels and creates the doctrines for his followers. While some *Hasidic* courts have not appointed new leaders, all *yeshivot* (p.

house of study) have a rabbi who gives counsel. Rabbinical decisions are sought for both profane and the mundane. The level of comfort with secular society varies from court to court; for example, *Beltzer* and *Toldos Aharon*, two streams within Hasidic Judaism, are considered rigorous and unbending.⁶⁶³ *Hasidic* Jews have a close relationship to mysticism and ecclesiastical demonstration of worship. Regardless of court, all *Hasidism* believe in the philosophy of creating religious ecstasy and the significance of mystical texts.

The Ba'al Shem Tov created twelve principles that all male community members must abide by to be considered a Hasid. Some of these principles encourage a sense of devout spirituality and mystique in the everyday. These principles are important to the discussion of mental health within the Hasidic community. Indeed, many secular or Jewish psychiatrists unfamiliar with *Hasidut* question whether visions and other esoteric experience are psychotic or religious in nature.⁶⁶⁴ Rabbi Zalman, an early *Hasidic* leader, noted that "...all reality is nothing...this is worship itself." Further, Rabbi HaLevi, Zalman's pupil cited that losing a sense of self is required to fully worship God.⁶⁶⁵ Another notable theme is that of divine oracular. Rabbi Karo (c 1533) frequently spoke in the voice of the *Shekinah* (the feminine 'side' of God—literally translating as 'divine presence.')⁶⁶⁶ Thus, fervent Hasidim long to be engulfed by the *Shekinah* to hear the wishes of God. Finally, there is constant theme of dueling moralities: of the 'light' vs the 'dark' or the Godly vs. the Satanic.⁶⁶⁷ Rebbe Nahman (the leader of his own Bratslav Hasidim in Uman, Ukraine, 1772-1810) encouraged visions of demons and angels and his followers are famous for nocturnal graveside visits of scholars. Hasidim may also demonstrate self-neglect (for greater spiritual piety) and paranoia with Messianic undertones.⁶⁶⁸ Thus, for mental health interventions to be impactful on this community, a clinician would have to be well versed and comfortable with these tenants of Hasidic Judaism. Most hospitals understand and

accommodate the need for same-sex therapists or kosher food. The esoteric philosophy of *Hasidim* however adds further complexity to both diagnosis and treatment. It is essential to understand the complex makeup of *Hasidic* society and how those aspects may influence a patient's presentation or care. Further, the *Hasidic* perspective and reaction to the symptoms of mental illness enhances insight into the community. All academic literature and observations comes from the outside, secular world.

Mental illness is not restricted to one gender. Unsurprisingly, there is a lack of literature surrounding Hasidic women. This demonstrates a notion beyond gender bias. Hasidic women dominate the public sphere and are the backbone of familial piety. They are expected to stay within the shrouded community. Hence, their health issues are cloaked even more than *Hasidic* males. However, Israeli and New York based researchers have been successful in identifying mental illness within this population. *Hasidic* women are predisposed to eating disorders (ED) and obsessive compulsive disorder (OCD), the trigger of which is unique to the religious world. To adequately treat these patients, secular physicians must be knowledgeable of the 'menstrual purity laws' and the dietary laws.⁶⁶⁹

When a *Rebbe* or family decides to utilize Western mental health services, it is orchestrated in a manner that still ensures spiritual purity and rabbinic permission. In Israel specifically, this community utilizes a rabbinical letter of introduction to refer a patient to a mental health professional or institution.⁶⁷⁰ These letters offer a unique window into this insular world. Several themes from these letters emerge. The first is discomfort. Most rabbis are pained leaving their students under secular care. Subsequently, they require regular reports or send a *mashgiach* (s. supervisor, or in this case a supervisor of the patient's *neshama* or Jewish soul.) Another theme is spirituality/mysticism. The rabbis often allude to the treatments they recommended to

the patient which may include praying, learning *Torah* or being “more social” in the community. The rabbis’ express disbelief at the failure of spirituality and belief to help. A final theme is reluctance/acquiesce. Even some years ago, *Hasidim* would never seek out secular assistance. Each rabbinical letter alludes in some way to hospitals and physicians serving as the last choice. They also require updates on the patient via telephone or letters.⁶⁷¹ The *Hasidic* community has a stereotypical view of psychiatrists and psychiatry. They believe all practitioners to be atheist—even those who are Jewish. Further, they expect that the doctor will ‘prescribe’ leaving *Hasidic* Judaism to be cured of their mental distress.⁶⁷²(The rabbis incorrectly assume that physicians will advise leaving a religious environment to become less psychotic.) Finally, there is general worry about leaving a *Hasidic* Jew inside a secular hospital where women, magazines, televisions and general secular society can harm or entice. Moreover, Hasidic society likes to keep its ‘dirty laundry’ within itself. Going outside the community for assistance may be necessary so long as it is done quietly. Discretion is key for mental health issues in Hasidic society. Stigma and fear still surround mental health; even for treatable and common issues like depression.⁶⁷³ The stigma creates problems for young people who are going through the *shidduch* (Yiddish; ‘match-making’) process. Within Jewish matchmaking, the purity of *yichus* (Yiddish; genealogical line) is essential. Physical illnesses and mental health issues are to be avoided in matchmaking. Marriage within an endogamous society is self-limiting. Mental health problems are misunderstood and considered a ‘blemish’ to getting an advantageous match.⁶⁷⁴ Some rabbinic leaders encourage matchmaking to ‘cure’ mental health symptoms; in their view, the commandments of marriage and children create a spiritual healing for the mind. Being married with mental illness is a hardship on the family. Judaism is a family-based religion. Within Hasidic Judaism, each person plays a unique role within the household. The absence of a

father or mother due to mental illness destabilizes the nuclear family unit and is considered a blow to the community.

Hospitals in both New York and Jerusalem have wrestled with providing cultural and religious accommodation. However, doing so may create a point of undue hardship. The concept of ‘reasonable accommodation’ is generally assumed to be the medical institution accommodating the religious patient. Yet, seeking culturally sensitive avenues may be risking patient care. To truly determine undue hardship within mental health care, it is essential for the Hasidic community to accommodate mental healthcare. By ‘meeting in the middle’ the Hasidic community can receive culturally sensitive care that is respectful of their religion up until the point of undue hardship. Hasidic *Rebbes* must permit leniencies to accommodate treatment; this would fall under the foundational notion of *pikuach nefesh* ([Hebrew] = saving a life).⁶⁷⁵ Once the Hasidic community accommodates *pikuach nefesh* for mental health, undue hardship for religious accommodations may be applied. The application of undue hardship will, in turn, create a template ethical best practices that assures adherence to treatment and hopefully, a path to recovery. If a Hasidic community does not recognize mental health as *pikuach nefesh*, a limit on religious accommodations may be best for practical and effective patient care.

5.A. i. Hasidic Men: ‘Social Deviance’, and complex mood disorders

Gender norms are stereotypical within Hasidic Judaism and interestingly, the literature points towards ‘gendered’ manifestations of illness as well. Hasidic men tend to have serious mood disorders like schizophrenia, bi-polar disorder and manic-depression.⁶⁷⁶ Hasidic men live in the public sphere; going to lectures and study sessions. Likewise, their illnesses appear to be ‘public’ as well. At first, many Hasidic men can hide their illness through religious zealotry. Most men

are brought to hospitals by a concerned *Rebbe* or friend.⁶⁷⁷ Hasidic women tend to have illnesses that mirror their domesticity: postpartum depression, eating disorders and OCD stemming from the family purity laws.⁶⁷⁸ They suffer more privately than their male counterparts. Most self-identify for treatment once they notice their illness harming their family life.⁶⁷⁹

Several case studies illustrate common elements to Hasidic men displaying “social deviance;” often the first sign of acute mental illness. This deviance includes no longer waking up on time to study, withdrawing from study partners or social events and being antagonistic towards others.⁶⁸⁰ Importantly, social deviance can be an umbrella term to describe all actions that do not adhere strictly to religious life. Hasidic life is demanding for men. They are required to study full-time in *yeshivot* (houses of study.) They are required to be fluent in Jewish law and prayer. Men who have learning disabilities or ADD find themselves isolated and appear ‘deviant.’ Further still, men who are not capable of understanding the logic games of Talmudic literature may find themselves ‘passed along’ rather than assessed for more suitable occupations.⁶⁸¹ Even men who wish to question rabbinic authority or have a moment of ‘teenage rebellion’ are viewed as deviant within the cloistered Hasidic society. This all becomes compounded within the *shidduch* system. Most families want their daughters to marry a ‘good learner’ who has proven mastery of Jewish text. Thus, men are forced to conform with community. Those who are ‘passed along’ are presented with a match in hopes that marriage to a virtuous Jewish woman will be curative.⁶⁸²

Common themes within mental health treatment centers include: fervent adherence to religion, hostility to those outside the *Hasidic* community, and an interwoven relationship between psychiatric symptoms and religious observance. With Hasidic men, the greatest challenge becomes separating expressions of religious belief with expression of possible

psychosis.⁶⁸³ Also, many patients are hostile towards their physicians, Jewish or not. Further accusations of atheism, being a ‘non -Hasid’ or being accused of homosexuality are common. Hostile attitudes further delay proper diagnosis and treatment. The literature notes that lingering hostility prevents successful treatment. Additionally, Hasidic patients are difficult to follow-up after initial hospitalization.⁶⁸⁴ This may be due to a reluctance to be continuously ‘labelled’ as mentally ill inside the community.

Very often, the hallucinations reported in case studies are Biblical or Messianic in nature. Other times, the hallucinations are richly metaphorical; puzzling if the clinician does understand Hasidic theology and philosophy. For example, many men only have vivid hallucinations at night. While this can be dismissed as minutiae, nighttime holds spiritual weight in Hasidic thought.⁶⁸⁵ Many of the written texts allude to the dangers of night: both physical and spiritual. The Queen of Demons—Lilith—takes victims who wander alone at night. All Hasidic Jew ritually wash their hands immediately after sleeping to ‘wash the sins’ of the night before commencing holy actions during the day. This ritualized action can manifest considerations of spirit and demons.. The hallucinations can also be sexual. Sometimes, a patient speaks of pursuing a woman nightly via hallucinations or he hears a woman’s voice (or a man’s voice) calling him to sin. Hasidism shelters and separates genders until the matchmaking process. Sexual desires, especially dreams and sexual emissions through masturbation, are unambiguously forbidden. Homosexuality is an absolute sin within the Hasidic world.⁶⁸⁶ Clinicians find it difficult to convince Hasidic men that they are not being punished spiritually. Moreover, they find more opposition when prescribing medication. Hasidic patients have difficulty understanding that pills will take away hallucinations and ‘evil’ thoughts. Additionally, adherence to medication schedule is difficult. Most lose touch with clinicians and health

professionals after the initial few sessions or hospitalization.⁶⁸⁷ Instead of being aware about their illness and using pharmacological interventions, Hasidic patients view themselves as being spiritually tested like the great Rabbis of the past. Just like those great leaders, they too will overcome their illness through greater prayer and devotion.

There are some Hasidic men who are called ‘socially deviant’ due to falling away from their Hasidic upbringing. These cases may be religious rebellion but often is a signal for serious illness. In these cases, their wives are the first to intervene, often noting despondence or even rage during commonplace family rituals.⁶⁸⁸ Family and home life are central to Hasidic Judaism. Thus, it becomes quickly apparent when religious behavior suddenly deviates from the norm. Refusal to participate in Sabbath dinners, becoming lax over dietary laws or forgetting common blessings are all cited as concerning for their partners. Children are the driving force that cause Hasidic women to seek secular health services. Often, they report their children being fearful or commenting on their father’s behavior. While mediating this change in their husband’s behavior women keep silent within the Hasidic community. They report socializing less, and avoiding neighbors who ‘may know something.’ As caregivers, Hasidic women do not get community support. Rather, they carry on in their domestic tasks and hope that God will bring healing to their family.⁶⁸⁹

5.A.ii. Postpartum depression, Fertility OCD, and eating disorders among Hasidic women

The role of a Hasidic wife cannot be understated. Her adherence to the laws of *kashrut* ([Hebrew] = kosher) and menstrual purity create a spiritually pure Jewish foundation for her family. Failure is not an option. Perhaps not unsurprisingly, women’s mental illnesses do not deviate from her domestic sphere.⁶⁹⁰ Obsessive Compulsive Disorder (OCD) is exceptionally linked to the complicated laws of menstrual purity.

Procreation is holy and the main objective for marriage.⁶⁹¹ Moreover, Hasidic women are socially obligated to conceive due to status and traditional domestic sphere roles. Although the matriarchs and women in the Bible are often barren, they are holier because of it. Indeed, whereas they are not obligated to conceive, their pain, suffering and humility come forth organically through prayer. They are pious, religious women for whom child-bearing is the ultimate gift of dedication and belief in God. Yet, as depicted by the barren Rachel, wife of Jacob, a woman feels unworthy of life without children.⁶⁹² A Hasidic woman should be content with having children and raising them in the Hasidic way. Just like their male counterparts, Hasidic women think they are being spiritually tested when they encounter postpartum depression. They may view themselves as failures in spiritually and as mothers. They too believe in God's intervention and seek it as a cure. Women only seek out secular care services when advised to by a rabbinic authority and/or their family members notice that something is wrong. However, women prefer to seek help further from their homes, for fear of being observed. Obviously, the stigma of mental health does not erode once married. While psychotherapy is eschewed since it is often 'too modern' for Hasidic communities, but women are more likely to accept and adhere to medication protocol so long as they are short-term. This is a direct result of stigma and a closed society. Living within a sheltered community compounds the issue; friends and family think that a postpartum woman should focus on other things and put her trust in God as a curative.⁶⁹³ Crucially, there is scant literature on postpartum depression within the Hasidic community. This is not surprising. Often, postpartum depression is an illness fought silently and independently. If a woman does not act dangerously towards herself or her child, it can be dismissed as fatigue. A Hasidic woman is often alone in the home for hours until her husband

comes home. Thus, depression is further isolated within the domestic realm. Eating disorders, however, cross into the public realm which is perhaps why it enjoys more academic analysis.

Eating disorders (ED) such as anorexia or bulimia are present across all ages in the Hasidic world. Girls as young as 15 demonstrate early experimentation with, to full-blown eating disorders. Interestingly, one study claims that more observant girls have lower tendencies towards eating disorders. Several other studies note the opposite.⁶⁹⁴ It is clear however that fears related to matchmaking is often what triggers the disorder initially. Religious men want thin women. Additionally, Judaism revolves around feast festivals and Shabbat meals; designed to be rich and multi-coursed in observance of the holy days.⁶⁹⁵ Talmudic law prescribes how much is to be eaten during some feast-days. Some researchers couple anxiety over ritually mandated food consumption with anxiety over finding a good match, triggering eating disorders.⁶⁹⁶ Disordered eating is a control mechanism. A Hasidic woman leads a proscribed existence; eating may be a way to demonstrate individual governance. Although eating disorders may be a conspicuous mental health disorder, there is nonetheless demonstrated lack of awareness for the severity of the issue within the Hasidic world. Poor parental support (via forced limiting eating) is common. Young girls also feel ‘stress’ at home since they are often responsible for caring for younger siblings. Many report anxiety and stress over *shidduch* prospects. Mothers often unconsciously promote disordered eating; they may have a disorder themselves.⁶⁹⁷ Interestingly, once the disorder becomes severe, more Orthodox families seek out treatment earlier. Orthodox children are statistically much younger upon initial hospitalization. When they are hospitalized however, their disorder is compounded with depression, panic disorders or self-harm. Researchers note that in the Hasidic world, women marry and give birth at a very young age. Thus, they may not be mature enough to self-regulate and utilize self-care. The literature notes that this may be the

only form of rebellion these women know. Like in all mental health circumstances, rabbinic authority is required; more so since there are several fast days within the Judaic calendar. A rabbinic degree (called a *heter*, [Hebrew] = permission/leniency) may allow a woman to eat on a fast day, for the sake of her continued treatment.⁶⁹⁸

Just as precisely as Judaism delineates religious laws, it dictates times and motivations for sexual intimacy between a married couple (dubbed *onah*). Judaism places great importance on fulfilling the woman's sexual pleasure and desires—so long as there is no “...destruction of seed...”⁶⁹⁹ Sexual intimacy is holy when performed within the bond of marriage and thus, must be governed under religious boundaries of *niddah* ([Hebrew]=ritually impure.) *Niddah* refers to the time when a woman is having her menstrual cycle and some measured time thereafter, to ensure that menses has truly ceased. During this time, she is ritually impure, and unable to have sex or even touch her husband. Once her *niddah* period is over, she becomes ritually pure and is allowed physically to her husband.

A normal *niddah* period lasts for seven days, after which she washes her clothing, and “regains” purity after dipping in a *mikveh* ([Hebrew]= ritual bath.) However, modern Rabbinical law doubled the ‘unclean’ time of *niddah* to 14 days rather than seven. During this time, the woman must be careful as to not sexually excite her husband and must take precautions around domestic tasks, touching, handling the same vessels, and even casual displays of intimacy. All Hasidic couples have separate beds for this time period. Further, a menstruating woman must make her circumstances known to her husband obliquely, so as he too is aware to not transgress during the time of menses and subsequent checking for cleanliness.⁷⁰⁰ Additional restrictions exist for women who give birth to a male or female child; their impurities last longer than the Biblical seven days; for a male baby, she must wait 33 days and for a female, 66 before

immersing in the *mikveh*.⁷⁰¹ Many women have felt isolated, “dirty” and unloved, triggering OCD over finding even a spot of blood and ensuring she is completely ritually clean. Talmudic lore suggests that horrific things that can happen when a baby is produced if a woman is unclean. Further, intercourse and intimacy during a menstrual cycle lead to serious repercussions in Talmud times and is still considered a grave sin in modern times.⁷⁰² It is important to realize this is not superstition for this community; it is a way of life that demonstrates piety even within primal actions. The laws of menstrual purity are precisely governed to optimize contraception. Twelve to fourteen days after a woman concludes her cycle, she enters a period of ovulation when she is ovulating and is most primed for pregnancy.⁷⁰³ Hence, Orthodox couples who follow the laws of menstrual purity almost guarantee themselves conception whenever they copulate, hence, fulfilling the *mitzvah* of both coitus and procreation. Adhering to this mandated cycle of sexual relations is considered holy and the reward for adherence is a child.

However, if a woman’s natural procreative cycle commences ovulation prior to the twelve or fourteen days of *niddah* is concluded, she is religiously unable to have sex and hence, would find it difficult to get pregnant since her ovulation occurs outside of the rabbinic timeline. In the Hasidic community, the misalignment of a natural menstrual cycle to the Torah cycle is called *halakhic* infertility. Thus, hormonal intervention for the purposes of *niddah* regulation is not new to the community at large. While birth control is generally shunned, using it for this purpose is allowable under rabbinical decree. If a woman commences oral contraceptives, she can force her natural menstrual cycle to conform to rabbinical purity standards. Medical studies that report on religious infertility clearly define the woman under study as infertile due to “pre-coital ovulation.”⁷⁰⁴ Indeed, women may be fertile independently, yet the laws of *niddah* render them unable to conceive because their time of fertility ends before they are permitted to have sexual

intercourse. Thus, the tightly mandated laws of *niddah* have led to far more than *halakhic* infertility. Many women find the onus of tracking their cycle becomes a trigger for obsessive compulsive disorder. Some may also suffer from body dysmorphia or depression due to their bodies not adhering to what *Torah* law prescribes.⁷⁰⁵ One study attempted to evaluate the demographic size of ultra-Orthodox (both *Haredi* and *Hasidic*) women seeking treatment for religious infertility. The researchers extrapolate that 21% of the ultra-Orthodox population suffers from religious infertility. Another scientific study involving ultra-Orthodox women and oral contraceptive usage to shorten or lengthen their cycle met with positive results.⁷⁰⁶ Women can only utilize contraceptives by rabbinical allowance.

Women feel anxiety, panic and obsess over their menstrual cycle. They fear they are bleeding even a small amount and check themselves constantly throughout the day. Checking involves inserting a white, clean cloth into the vaginal canal to ensure no trace of blood remains. Some women have developed serious lacerations due to frequent checking.⁷⁰⁷ Their worry decreases only during their menstrual cycle. They often consult multiple rabbis to ensure they are ritually clean. Fears of transgressing a foundational commandment creates significant emotional disturbance. One case study reports a woman so fearful of being impure, she begged her gynecologist to remove her uterus. Some women do have sexual relations with their husbands at all since they are unsure if they are ritually pure. Women who display OCD tendencies earlier in life later find these tendencies develop into obsession over menstrual purity. Some obsessions arise naturally from the techniques involved with adhering to *niddah*.. Women are asked to check purity by inserting a cloth; if they find a trace of blood they are to consult a rabbi before washing in the *mikveh*.. Many women show a *Rebbe* their underwear so he can decide if they are ritually impure.⁷⁰⁸ Moreover, the religious culture and language surround menstruation is negative,

possibly influencing OCD behaviors. Women are also at risk to develop depression or more severe symptoms of pre-menstrual mood disorders.⁷⁰⁹ Adhering to religious ritual can create true psychiatric disorders.

The complex dynamic of religion and medicine results in a hegemonic relationship apparent in rabbinic/medicine dialogue.⁷¹⁰ *Hasidic* women seek rabbinical council over medical advice. Furthermore, the significance of adhering to the laws of menstrual purity cannot be understated. There is a triad in medical decision making for a *Hasidic* couple who are infertile. This doctor-patient-rabbi- relationship is fraught with frustrations as two codes of ethics attempt to communicate.⁷¹¹ However, utilizing hormonal birth control is not devoid of risk. Some rabbinical authorities are more comfortable with utilizing reproductive technologies rather than allow for contraceptive use. Using reproductive technologies is not simple under Judaic and Hasidic belief.

Infertility treatments like artificial insemination and invitro-fertilization initially caused concern for *Hasidic* Judaism since conceiving a child outside of sexual coitus was misunderstood by the community. Replacing sexual intercourse with science troubled modern scholars due in part to fears of spermatozoa switching; a large concern for Jewish lineage and adultery claims. The aforementioned prohibition against masturbation was a barrier to accessing fertility treatment as well. As the techniques evolved and became safer, those aforementioned treatments have become commonplace with Jewish couples. Albeit, not without caveat. Despite the importance of fertility, Jewish law is careful to legislate the manner of intercourse. Rabbi Waldenberg, one of the foremost authorities in the field of Jewish medical ethics admonishes those who use artificial insemination, “ruin[s] the tents of Israel...”⁷¹² Opposing viewpoints claim that artificial insemination does not ruin the holiness of marriage, since a husband’s own

sperm does not render the act adulterous and it enables a struggling couple to conceive. For many Hasidic families, assisted reproduction is a means to an end and enables the fulfillment of the commandment of being fruitful. This leads to some restrictions in the permissibility of certain methodologies utilized to harvest sperm. Hasidic Judaism eschews the usage of condoms since it would restrict sperm ejaculations from entering the vagina; which is religious misconduct. Using a Jewish-medical condom (which has small holes allowing for some sperm to escape) is prohibited by Hasidic authorities. Even testing sperm for possible issues is prohibited. Thus, the onus and reproductive treatments fall solely on the woman, often utilizing invitro-fertilization (IVF.). This creates a feeling of pressure, anxiety and failure if the treatments fail. IVF is also risky and often fails; compounding the sense of anxiety a Hasidic woman feels. Additionally, if a women bleeds at any point during her IVF treatment, she is considered *niddah* to her husband and he cannot physically touch her.⁷¹³

IVF is incredibly invasive and expensive. First, the woman is injected daily with fertility drugs to boost production of eggs. Often a husband injects his wife. However, laws of modesty dictate that a woman self-inject.⁷¹⁴ Over the course of treatment, frequent monitoring of the ovaries via trans-vaginal ultrasound and blood tests are paramount and frequent. Once the ovaries' eggs are ready to be harvested, minor surgery is performed to remove the eggs from the woman's ovaries. In a laboratory's Petri dish, the doctor fertilizes the egg. After five days of monitored growth, the embryo shows proof of viability. At this stage, the embryo (or multiple embryos depending on the doctor,) is placed in the woman's womb. In order to achieve pregnancy, the embryo needs to implant itself in the lining of the womb. If the implantation process fails to result in pregnancy, the couple must undergo the entire cycle again. The current IVF success rate is 26%.⁷¹⁵ The emotional and psychological toll IVF takes on secular women is

probably compounded in the Hasidic world. The social and religious obligations to create a family are great. By strictly prohibiting semen emission or even testing, the onus of procreation rests solely on the Hasidic woman. Thus, creating more anxiety, panic and depression due to the social norms of her community.

Religious infertility can easily be solved using low-dosage hormonal birth control pill or via hormone treatments. However, physicians struggle with the ethics of prescribing hormonal birth control for non-medical reasons. While the Pill is often prescribed for ‘off label’ usage like acne control, there are risks associated with birth control including stroke, blood clots and migraines.⁷¹⁶ Most physicians are familiar with Beauchamp and Childress’ *Four Principles* and use this as a guide towards determining ethical concerns. Indeed, the literature indicates a concern over autonomy and beneficence/non-maleficence.⁷¹⁷ For a religious patient, it is difficult to separate autonomous choices from religiously informed pronouncements. Ultimately, this will impact the consent element of ‘decision’ in favor of a medical intervention.⁷¹⁸ Beneficence and its corollary, non-maleficence is also applicable. Both these principles encourage the physician to do what is ‘in the best interest’ of the patient. Thus, by prescribing a Pill that is medically void, the risks associated with the prescription do not outweigh the benefits. The religiously infertile woman would be risking bodily damage without medical benefit for a problem that can be solved outside the medical domain. The principle of non-maleficence would be broken. The beneficent physician would be advised to not prescribe the Pill nor hormonal interventions, as religious infertility is a religious problem and not a medical one.⁷¹⁹ By allowing it to be solved with science, rabbis are categorizing healthy women as infertile; a label which bears emotional weight and stigma and can cause other psychological ailments. The literature is silent on the taxing weight placed upon Hasidic women. Most fertility doctors advise first testing sperm before doing

further interventions.⁷²⁰ There should be an ethical concern here for justifying invasive and expensive fertility treatments without first adhering to medical ‘best practice.’ Certainly, the issue of religious accommodation within healthcare is apparent throughout the discussion on Hasidic Judaism and mental health. Cultural competency approaches, as the next section will analyze, can only begin to broach the issues found within this niche community.

5.A. iii Hardship and religious accommodations in mental healthcare: whither cultural competency?

While the Hasidic community’s adoption of *pikuach nefesh* would ease integration of cultural competency principles, it is not the current reality. Thus, the solution requires a greater deployment of cultural competency as demonstrated in National Health Services’ *Hasidic*-centered psychiatric service and the new hospital in B’nai Brak, a city in Israel near Jerusalem. These services bridge the divide using the best practices of cultural competency. The NHS leadership openly seek community approval through rabbinical endorsement, they attempt to hire mostly observant or observantly-aware Jewish staff, they try to create Sabbath-friendly therapy modules. In return, participants agree to continue their treatment and follow-ups as required or else, lose the valued services. Britain’s NHS is publicly funded; crucial since most *Hasidic* Jews are below the poverty line. This dual-approach ensures that the community sanctions mental health and its care approaches. This partnership further attempts to remove the stigma of mental health by making care more nuanced and accessible for this particular community.

Just as the NHS initiative, the B’nai Brak hospital is careful to create a more curated space for their Hasidic clientele. Indeed, the B’nai Brak hospital employs rabbis who ensure males continue their religious studies. However, this program is considered a privilege and can

be revoked or modified if treatment is not being adhered to.⁷²¹ Yet, these are tremendous undertakings. They require financial backing and training in *Hasidic* thought and religious practices.⁷²² They are also the result of dense populations of *Hasidic* communities within the UK and Jerusalem. This may not be feasible, even in the UK, for an extended period of time. The program was given funding for a finite period of time, whereby it would undergo re-evaluation. Currently, (as of 2018) the program is still in existence. However, whether this is sustainable is questionable, particularly with the advent of the novel Coronavirus in 2019-2020. Further still, while public education and outreach is certainly required, it is essential that change—indeed, accommodation—come from within the religious community itself. Thus, it is perhaps even more essential that *Rebbanim* redefine and reduce the stigma of mental illness. Change is not foreign; even to *Hasidic* Judaism. Within this spirit, a re-interpretation of traditional texts can be assumed.⁷²³ Further, there is a precedent within Jewish methodology that allows for other cultures to influence the practice and *Halakha* (Jewish law) of Judaism. For example, to accurately dedicate a new Jewish month, rabbis turned to astronomy to calculate the new lunar month⁷²⁴. In those times, the practice of astronomy was concerned to be pagan, done by other religions and sects. However, by embracing these ‘other’ notions, the rabbis enabled the Jewish calendar to be calculated accurately for centuries. Following this precedent would revolutionize the approach the *Hasidic* community (and the broader Orthodox community,) takes towards mental health. Moreover, it would permit secular medical intervention to be rationalized and deeply encouraged as it is for physical illness. Incorporating mental illness into the umbrella of *pikuach nefesh* creates a new vocabulary that creates acceptance of mental illness and reduces stigma. This is an innovative approach to accommodation; a dual approach. Indeed, just as an institution can accommodate nuanced communities, as the NHS demonstrates, the religious

community must also accommodate broader changes in medicine. Decidedly, this goes over and above the expectations of cultural competency.

The aforementioned dual- accommodation approach, is, in the opinion of this dissertation, very different from cultural competency. Cultural competency is a foundational concern for clinical ethicists. Indeed, proper cultural competency curriculum can eliminate racial/gender bias, and acknowledges the importance of culture or religion in patients' lives. Yet, this "competency" is often both simplified and Western-biased.⁷²⁵ Often, this promotes stereotypes rather than true understanding, humility and conversation with the community itself. To wit, utilizing cultural competency approaches as they currently stand would not be sufficient for the Hasidic community . 'Tolerance' can only stretch so far.⁷²⁶ Ethical relativism lacks gravitas, particularly in a medical environment where decisions must be made. Herein lies the limits of cultural competency; while it is important to educate and inform medical professionals of cultural/religious differences, it is suitably important to justify decision making firmly within the confines of standard medical practice and values. This dissertation is not suggesting that cultural competency is no longer valid or important to ethics and healthcare. Rather, this dissertation presents two suggestions. The first is that there appears to be a schism between how literature presents as cultural competency versus what is practiced in a clinical setting. This schism does ill service to the field itself and to ethics. Secondly, this dissertation suggests that if cultural competency is not enough to mediate or understand a situation, the dual accommodation approach can perhaps, serve better. Indeed, as dual accommodation has demonstrated, not all religious values can be equally valued and assessed as important. Thus, as moderate naturalism suggests, facts based on biological factors are important. However, contextualizing the values or decisions that need to be made is also, equally important.⁷²⁷ Admittedly, ethical relativism and

cultural competency are two different things. However, they are often conflated; a sad consequence perhaps of busy medical institutions. Just as the NHS and the hospital in B'nai Brak have demonstrated, integration of cultural nuances creates more competent care. Further, this type of nuanced understanding appears to encourage more patient cooperation. Perhaps the limits of cultural competency allow for the rise of cultural humility. Instead of trying to claim expertise in religion, physicians can acknowledge themselves as learners, and collaborate accordingly with their patients.⁷²⁸ Indeed, accommodation must be reciprocal within a medical decision making. Religion can and must demonstrate their own notion of tolerance for secular medical ethics. Perhaps then, this is a broader notion of cultural competency—one that also expects and helps to realize sanctioned change within a community itself.

Indeed, this 'tolerance', can be demonstrated viably via Jewish ethics, which allows for balancing and shifting the weight of ethical principles within the context of a particular situation. The principle to guard and preserve life—*pikuach nefesh*—ranks above all other principles.⁷²⁹ Historically, *pikuach nefesh* has held this position in the 'hierarchy' of Jewish values by most Rabbinic authorities over two millennia. Traditionally, all other Judaic tenets are pushed aside in favor of saving a life.⁷³⁰ *Pikuach nefesh* requires all life- saving medical interventions to occur if a life can be sustained for even a short amount of time. The importance of this contest is echoed later in the Talmud, which states that saving one life is akin to saving an entire world.⁷³¹ The importance of *pikuach nefesh* has never wavered. Maimonides argued for the preeminence of the principle, overriding even the Sabbath in its importance. It is also imperative to alleviate physical pain, since pain causes bodily stress.⁷³²

Rebbeim who encounter mental illness are aware of the suffering and even of the physical and spiritual pain it manifests. They even write to that effect expressively in their letters to

hospitals. Thus, it would not be fanciful to equate ‘spiritual’ pain and suffering with physical pain and suffering, requiring treatment. Medical treatments are permitted over the Sabbath and the follow up is essential. Indeed, the very word *nefesh* suggests its utilization for mental illness. In Hebrew, *nefesh* means soul. In many letters to physicians, the *Rebbe* refers to his student’s *nefesh* being hurt or troubled.⁷³³ If *Hasidism* view mental illness as spiritual illness, then permitting secular intervention to ‘save souls’ is undoubtedly required. As the B’nai Brak new hospital proves, the *Hasidic* community is slowly evolving to understand that *nefesh* incorporates a triad of mind, body and soul. Perfect cultural competency does not exist as it is limiting and, in the case of bioethics, fails to establish authority due to ethical relativism. The concept of humility assists in the reciprocal relationship of religious accommodation.

5 B. Public Health or Personal Interest: Vaccines, and Genetic Editing/CRISPR

Creating a system that can meet the needs of an entire religious community has proven successful in England and Israel. Whereas a more nuanced cultural understanding can bridge the gap for caring for the mentally ill Hasidic community, how far can similar religious accommodations extend? Particularly, how far can religious accommodation extend in the context of public health and progressive technologies? There are recent instances which demonstrate the need for limited religious accommodation in public health issues: most notably, in the realm of vaccinations. Further, a new frontier for the clash of religious and secular ethics may be in the field of genetic engineering/CRISPR. This dissertation anticipates this discourse and presents possible outcomes.

This chapter cannot ignore another recent medical advancement which deftly indicates the clash between religious communities and public health. Indeed, the human papilloma virus

(HPV) vaccine is a recent addition to youth and young adult immunizations. The HPV vaccine was first made available to females between the ages of 9-26 to guard against sexually transmitted HPV virus which can lead to cervical, uterine and other cancers affecting the reproductive system.⁷³⁴ Now, it is recommended that young men get vaccinated as well. It is suggested the vaccine be taken first prior to sexual activity, with an optional ‘top-up’ dose acquired in the mid-twenties.⁷³⁵ The most current research indicates that the vaccine assists even after sexual activity, as it may help the body shed the virus faster.

Unlike other childhood vaccinations, participant usage of the HPV vaccine is sub-optional; surprising since cervical and other reproductive cancers are often recognized too late for curative treatment.⁷³⁶ Researches have concluded that religious sexual ethics is to blame for this phenomenon. Indeed, according to parents and school boards, acceptance of the vaccine *ipso facto* is acceptance of non-marital sexual activity. For both Catholic and Jewish ethics, sexual activity is exclusive within marriage. However, whereas education can shift the Jewish community towards immunization, Catholic ethicists view the vaccine as condoning sexual promiscuity.⁷³⁷ As such, the HPV vaccine was vocally and publicly opposed by the Canadian Catholic School Board. The exploration of their religious ethical values versus the values of secular public health is an excellent exploration of more recent barriers in public health initiatives. Whereas some members pushed for immunization, it took years for public health to be formally welcomed into the Catholic school’s hallways. Moreover, does this acquiescence demonstrate a case of flipped hardship? Does the burden of undue hardship shift to the Catholic School Board? That is, are their religious ethics being unduly swept aside for secular (public health) ethics? The concepts of flipped hardship and its definition can be equally studied vis-à-vis a relatively new concept in genetic engineering known widely as CRISPR.

The advent and dominance of CRISPR-Cas9 (hereafter just CRISPR) is recent; shattering previous genetic therapies first in 2013. It contains a strand of ribonucleic acid (RNA,) which can match any genome.⁷³⁸ There are two potential options for CRISPR: it can render a gene inactive or, modify it with a preferred (non-mutated) gene. This technology is quick, effective and most importantly, cheaper than previous options.⁷³⁹ The implications are tremendous: muscular dystrophy, cystic fibrosis and even Alzheimer's can be identified and replaced with CRISPR. In 2016, testing was approved to apply CRISPR to human embryos. The ultimate objective would be to 'correct' genetic mutations or diseases in utero. CRISPR would need only be injected into one cell before it finds every mutated cell and remedies it. Further still, once grown, CRISPR-edited humans cannot pass on mutant genes—eliminating illnesses that are genetically carried. Germline editing is a novel and exciting concept. However, it still holds many ethical concerns. The shadow of eugenics looms large in ethical discussions regarding genetic manipulation. Within CRISPR, the fear of eugenics is exacerbated since diseases in the germline can be eliminated permanently for future generations.⁷⁴⁰ Further exploration of what diseases or conditions to eliminate is controversial. While diseases like Tay-Sachs and cystic fibrosis are devastating, there are questions over whether and how to classify and eliminate diseases that are not fatal, but nonetheless impact quality of life, classic examples being Autism/Asperger's and Deafness. Further, eliminating one disease may take effect on another; thereby causing an unpredictable ripple effect.⁷⁴¹ Hence, whether and how to erect ethical policies around this evolving technology is still developing. Thus, this dissertation focuses on CRISPR's effects on elimination of diseases with poor prognoses or negative consequences on quality of life. CRISPR can arguably be supported within the confines of Jewish ethics. Conversely, Catholic ethics are demonstrably against the very premise of CRISPR. For many

Catholic ethicists, the ability to ‘play God’ is outside the purview of humanity. Thus, the notion of ‘flipped hardship’ is introduced. If Jewish ethics permits the usage of CRISPR technologies (potentially, over and above the confines of future secular ethical guidelines) does refusal of certain procedures demonstrate undue hardship to towards particular religious convictions? Likewise, would a Catholic patient’s objection to CRISPR technologies (if and when they would become medically normative under ethical protocols,) be considered pressing hardship?

Flipped [undue] hardship is when a religious individual could perceive their religious beliefs to entitle superlative medical interventions that are *beyond the standard of care*. For religious institutions, flipped hardship can be perceived when an organization refuses medical interventions for *all* individuals that are *within* the standard of care. Plainly put, the patient or organization believes that it is their religious right to customize the medical services offered. This can create an unethical binary of patients: those who are believers and who request such services, and those who are not. The religious patient (or religious healthcare organization,) may assume that hardship is being placed upon them since they are not able to enact their religious beliefs in healthcare. This dissertation demonstrates that oftentimes, religious notions can adapt to modern medical discourse, negating hardship concerns from the outset. However, it is not all that simple. The next subsections of the chapter isolate cases where flipped hardship may occur. Nonetheless, what each section didactically proves is that flipped hardship cannot be enacted in most cases explored below. This is because each scenario generally falls under the notion of superlative care for an individual (often in Jewish cases,) , or refusal for *all* individuals within a standard of care based on religious protocols (often in Catholic organizations.)

5 B.i. Religious right? HPV vaccination opposition in Judaism and Catholicism: Flipped hardship?

Public health campaigns can find its philosophical underpinnings in John Rawls social contract theory. Simplistically, subscribing to the theory forces basic assumptions on what is considered a 'right' in society.⁷⁴² To that end, Rawls institutes the notion of 'original position;' whereby there is an agreement that there is "...something essential to the activity of moral reasoning..." but also decided upon socially, as a collective.⁷⁴³ Routine vaccinations can fit comfortably into a modern application of Rawls' contract theory. Indeed, society has found immunizations essential; the collective morality of herd immunity is scientifically established.⁷⁴⁴ Nonetheless, parents refuse common vaccines for their children. Refusal can be grouped into two themes: a lack of communication and safety/side effect concerns. The antithesis to refusal may be found in parent education. The literature is rife with exemplars of how to educate families on vaccine safety, quality and importance.⁷⁴⁵ Thus, this body of literature claims that informed education may sway parents from refusal to acquiesce. Some families feel that physicians do not communicate effectively regarding safety studies; most feel dismissed when they relay their concerns.⁷⁴⁶ Some parents may be concerned about side effects. Vaccination side effects are usually minimal, involving localized pain and perhaps a low grade fever. However, parents are more preoccupied with rare side effects like asthma, anaphylaxis and mortality.⁷⁴⁷

The HPV vaccine is quickly becoming part of routine vaccinations, with the first dose administered to pubescent individuals. Yet, whereas measles, mumps and rubella (MMR) and chickenpox are viral infections, HPV is spread primarily via sexual contact. So, the objections of religious parents of children eligible for the HPV vaccination are also religious in nature: children who abstain from sexual intercourse until marriage are safe from disease. Many parents

felt the HPV vaccine removes the fear of this STI, and thus, promotes promiscuity. It is important to note that the HPV vaccine purely protects against that one virus; it does not and cannot prevent transmission of other sexually transmitted infections or pregnancy. The Catholic School Board of Calgary in Alberta, Canada did not refute the claims of the vaccine at all. Instead, they only refused to allow public health officials into the schools to inject the vaccines. It was not a refutation of science, it was a refutation of religious-ethics.⁷⁴⁸

In 2008, the Alberta Roman Catholic Bishop's office refused in-school HPV vaccination. The School Board noted that even if alumni contracted cervical cancers, they would not waiver. The Calgary HPV vaccination program was introduced in January 2009. 70% of students were vaccinated in the public school system. Calgary Catholic schools had 18.9% vaccination rate. Many former members and administrators of the Catholic school district maintained the ethical imperative of proactive protection over and above sexual-religious principles. A 2012 study noted that HPV vaccination does not increase sexual activity. Many thought this study would calm the Bishop and force his hand. Instead, he wrote a circulatory letter which, regardless of a clear proposition, allowed the Board to vote to consider in-school HPV vaccinations. In November 2012, the Board voted to allow vaccinations to occur in Catholic schools, despite the bishop being disappointed at the outcome.⁷⁴⁹ While the Calgarian bishop was opposed to the vaccine, the Catholic Medical Association (CMA) echoes the importance of the vaccine as prevention for fatal cancers. To wit, they efficiently state that "...preventing disease...is a moral good. Prevention of HPV infection is distinct from, and should not be construed as encouraging, the behavior by which HPV is spread."⁷⁵⁰ Profoundly interesting, is that the CMA does not believe the vaccine should be mandated for school enrollment. They cite alternative ways to avoid HPV and that parents should be the ones who teach and promote chastity and sexual

ethics. The CMA states that parental (ethical) objections should override the public health vaccination initiative. Whereas the HPV vaccine can guard against reproductive cancers, it does not quash the other perceived consequences of premarital sex including suicidal ideation, depression and divorce. While the vaccine is medically and scientifically proven to be effective, the CMA views the vaccine as a potential vehicle to promote conversations of chastity.⁷⁵¹ This is a purposefully nuanced position paper. The CMA is careful not to dispute the claims of the vaccine and overall believes it to be an act of mercy and moral good. However, they separate their understanding of scientific fact from religious ethical philosophy. Indeed, while the CMA does not negate the vaccination, it does not mandate it. This is in keeping with the chapter in this dissertation that discussed the Catholic notion of moral cooperation. Indeed, while the vaccine is medically excellent, the values associated with the vaccine may be considered secular. As such, the CMA cannot cooperate by fully permitting endorsement of this vaccination.

One opinion paper by a Catholic physician-ethicist proffers a compromise between keeping Catholic sexual ethics and promoting approval of the HPV vaccine. For the author, the exemplary Catholic position would be to show mercy to teens and young adults who may stray from the sexual ethics of their parents. Why should they suffer a potential great harm? The argument is strengthened by two points: that the poor and under-insured lack alternative methods for cancer screening (i.e. regular Pap smears,); and it is the parents' obligation to frame the vaccination and its purpose as cancer-preventing. Moreover, if an individual comes to the marriage bed chaste, what if a partner is infected? The desired outcome of the vaccine is to prevent devastating diagnosis-which should be the yardstick by which the ethical onus is applied.⁷⁵² This is using yet another important Catholic ethical foundation of Double Effect. Whereby the (sexual) act of acquiring HPV is not condoned outside of marriage, preventing

terminal cancer is the crux of inventing the vaccine. For the Catholic physician who wrote the article, the positive effect arguably outweighs the (assumed) negative effect of premarital sex. This belief is reinforced by the assumption that parents should educate their children on sexual ethics whereby medical professionals should guard their health.⁷⁵³

Similar themes are echoed within the more observant Jewish community in Israel and the Jewish diaspora. Compliance for ‘school-based’ vaccines (like varicella, MMR) is 90% in Israel, whereas HPV is around 10%. The reason is perceived to be overall low rates of cervical cancers, along with sexual conservatism and the taboo nature of premarital sex. Ritual circumcision is also supposed to lower HPV infection rates. Ritual circumcision is performed widely in the Jewish and Arab populations in Israel, which may account in turn for the lowered HPV infection rates. HPV vaccination acceptance increases when women feel supported in their choice to vaccinate by their social peers or by their physician.⁷⁵⁴ Societal acceptance and subsequently, education of the vaccine is the key for increased participation in vaccination. This is supported by two studies that statistically measured parents of girls and boys (independently) to determine how many promoted the vaccine to their children after being educated by a nurse about its purpose. Interestingly, mothers were more predisposed to vaccinate their daughters than their sons (65% and 14% respectively.)⁷⁵⁵ Whereas sexual promiscuity/non-martial coitus is not expressively permitted in Jewish law, it is not wholly proscribed as it is within the Catholic doctrines. What appears to drive Jewish mothers towards vaccination is education, rather than fear of premarital sex. However, outside of Israel, Jewish Orthodox communities share the concerns of Catholic believers. A study was conducted in the UK which accessed the barriers to the HPV vaccine. As in the Catholic School Board circumstance, Jewish mothers struggled with the claim that the vaccine is preventative since their daughters are to be chaste until marriage.

Further, some mothers wanted to wait until the vaccine was better studied, and/or their daughters were old enough to consent for themselves.⁷⁵⁶ Mothers who accepted the vaccine based their choice on it being supported by public health initiatives and that while they prefer their daughter keep to Jewish sexual ethics, they cannot predict their actions. Thus the vaccine serves as a protective balm towards future sexual choices..⁷⁵⁷ This study demonstrates similarity of a classic clash between public [secular] ethics and religious ethics in two seemingly different religious communities. While the CMA noted the difference between medically and ethically condoning the vaccine, the Jewish view of vaccination—even for HPV—is overwhelmingly positive. Failure to immunize, even with the smallest risk, would be akin to parental negligence.⁷⁵⁸ Although Judaism does not condone premarital sex, there is a small risk either they, or their marital partner, may have had previous sexual encounters. Thus, according to some more modern Orthodox rabbis, it would be imperative to vaccinate against HPV.⁷⁵⁹ Whereas the vaccine would likely not be welcomed into the Canadian Catholic school systems (outside of Alberta,) the medical importance of the vaccine is notable and even commendable under Catholic ethics.

Thus the question of undue hardship remains. Could the Alberta Catholic school have utilized the concept of flipped undue hardship to keep the vaccine outside of their hallways? The pressure Albertans put upon the Canadian Catholic school system may, at first blush, be viewed as flipped hardship. That is, allowing HPV vaccinations to be promoted and acquired within school corridors places undue hardship on the principles of Catholic ethics. Under Canadian law, undue hardship may fall under the following categorizations, purposefully left broad. There are only three considerations which can contribute to undue hardship in accommodation: cost, outside sources of funding, health/safety requirements, as outlined and discussed in greater details in chapter 3 of this dissertation. Under those protocols, the Catholic school system cannot

claim financial hardship/ source of funding since costs would be covered by public health. Further, health/safety of accessing the vaccine would be a nonissue in a school as the nurses would create a sterile environment to vaccinate consenting students. Thus, the school board would have to petition the case under the *Charter*, noting that their religious freedoms are compromised for this particular public health initiative. It is outside the scope and mandate of this thesis to parse the possibilities of such a suit in the Canadian courts. However, if considering the *ethical* considerations of undue hardship, as this dissertation does indeed suggest, the Catholic school system could not assume flipped hardship. This is due to two important markers: Rawls' social contract theory, and the ability for the Catholic ethical Principle of Double Effect largely aligning with public health goals. Again, according to the framework this dissertation proposes, flipped hardship cannot be claimed in the case of social contract theory and/or if the religious institution itself can find alternative interpretations allowing for the medical intervention. Flipped hardship cannot apply in this circumstance.

Under the auspices of Rawls' social contract theory and the importance of public health goals, it appears that flipped undue hardship could not apply. However, this dissertation offers a nuanced perspective for the HPV vaccine and religious accommodation. Herd immunity is not a consideration with the HPV vaccine. Rather, the vaccination only protects those who are individually inoculated. Arguably, the Catholic Medical Association extended an excellent duality where the HPV vaccine is concerned. Medically, the vaccine is sanctioned for its obvious benefits and significant harm reduction when it comes to acquiring certain cancers due to herpes infection. Under religious ethics however, it should be considered a preventative vaccine in case of sexual exposure. It is not endorsed formally *per se*, but rather acknowledged as a shield against future harms. While an individual may ascribe to typical Catholic sexual ethics, there is

no guarantee their partner was as meticulous. The Catholic Medical Association neatly aligns its argument with the four pillars of Double Effect: a) the action is not intrinsically evil; b) the intent of the actor is to achieve the beneficial effect; c) the beneficial effect is not achieved by means of the harmful effect; d) the beneficial effect is greater than the harmful effect.⁷⁶⁰ It can be argued (as it has by several additional Catholic physicians and scholars,) that the vaccination in and of itself is not evil. The benefit of the vaccine and its protection from infection, is not achieved by sexual promiscuity. Finally, the noted reduction in reproductive cancers is noted and can outweigh the fears of sexual promiscuity—which aforementioned studies have since refuted.⁷⁶¹ As this thesis demonstrated with Hasidic mental health approaches, religious ethics can indeed also accommodate public health initiatives. Since the argument for acceptance of the public health protocols can indeed be made via PDE, the ethical determination of undue hardship cannot be assumed in this circumstance. Flipped [undue] hardship can only be considered if the religious institution itself cannot find an alternate interpretation within its own religious edicts and/or social contract theory cannot apply. A version of this may be more neatly found with the Jewish approaches towards genetic engineering and CRISPR.

5.B.ii. Jewish approaches towards CRISPR: Flipped hardship?

Jewish identity is a layered complexity. It is at once history, religion and identity. This both complicates the relationship of genetic engineering to Judaism and creates a foundation for its vast utilization through innovation and technology.

Indeed, Jews are born into the faith: a Jewish mother determines a Jewish child. Further, a son is classified into one of three Biblical castes; some of which come with religious obligations and prohibitions. Finally, even in the 21st century, marrying within the religion is encouraged.

Literally, the importance of inherited traits is found in the Old Testament and Talmud.⁷⁶²

Uniquely, Judaism utilizes genetic science to further the continuity of Judaic tradition. Through organized genetic testing services, Jewish couples can mitigate the mutations that often arise in endogamous groups.⁷⁶³ Judaism can serve as a true exemplar of fulfilling the importance of religious lineage while safeguarding (and arguably strengthening) the genetic future of its followers. To determine whether and how technological advancements can be considered within the realm of Jewish Law, it is helpful to look towards Israel.

The Rabbinical Council in Israel approves all healthcare policy decisions based on principles of Jewish *halakha*. As medicine charges forward, *halakhic* experts must find ways of interpreting the ancient texts to fit modern challenges.⁷⁶⁴ However, Israeli policies also allow for particular usages of genetic testing—mostly sex selection prior to implantation of an embryo-- all of which are directly related to Jewish law. However, the Israeli Ministry of Health does warrant caution; parents must have ‘particular circumstances’ to require sex selection. Further, there are regulations and various phases towards the Ministry granting a request. Since 2005, two out of thirteen petitions for PGD were granted based on religious circumstance. Indeed, these grantees were *Kohanim* (priestly caste—this lineage is passed only through the man directly to his male progeny,) using donor sperm. If a male child were conceived, he would not be a *Kohan* and thus, be subject to public embarrassment.⁷⁶⁵ Other couples petitioned the Ministry for ‘family balance’ according to the Talmud’s elucidation of procreation. For those couples, fulfillment of the religious imperative was based on conceiving one male and one female. While Israel prohibits ‘social’ reasons for sex selection, this reasoning was permitted, perhaps due to an understanding of the religious philosophy.⁷⁶⁶ Other scholars note that PGD can produce children without genetic diseases—without requiring an abortion or emotional duress abortion may cause.⁷⁶⁷

Indeed, if Israeli law can enable PGD to occur for the fulfillment of Jewish principles, this can function as a helpmate towards crafting a theological ethic towards CRISPR.

Gene editing and manipulation is undoubtedly part of the medical future. Secular ethics and researchers must grapple with pertinent ethical choices. At a base level, there are two schools of thought: those who embrace genetic therapy which can enhance lives and lessen the burden of diseases., and those who are critics who desire to ‘draw an ethical line’ around the technology.⁷⁶⁸ Indeed, *Ashkenazic* Jews (Jews of European descent,) have known high predisposition to several rare genetic conditions including the BRCA1, 2 gene and Tay-Sachs.⁷⁶⁹ Reducing or even elimination of these genetic conditions would be welcomed. However, there is balance. Judaism rejects interventions which enable aesthetic changes or sex selection for vanity.⁷⁷⁰ Jewish religious views on genetics suffers from a lack of textual sources from which to glean. Genetic testing and gene editing takes many forms. While Judaism can allow for embracing of the positive effects of technology, there is an overwhelming note of restraint indicated by the rabbinic literature and commentary on the issue. Indeed, all humankind is manufactured *b'tzelem Elokim* (literally, in the image of God.) which is a fundamental consideration when encountering genetic technologies.⁷⁷¹ According to Mackler, modification of DNA does not fall under the “image of God” however, since so much of our DNA makes an individuals’ personality and traits, an abundance of caution is advised. As such, healing is encouraged, so long as respect for persons (and the Divine hand in its creation,) is respected. Yet, Mackler echoes secular ethics by expressing hesitancy in demarcating between therapeutic DNA modification and enhancement. Indeed, according to the *Mishnah*, diversity reflects God’s own image. Thus, Jewish parents desiring a smarter or taller child cannot do so, according to the majority opinion .⁷⁷² This aforementioned reluctance to markedly manipulate God’s creation is

amplified in CRISPR's *raison d'être*. Permanently altering germline cells can be considered creating, as opposed to PGD which *individually* accesses embryos. This is an important delineation and ripe with dogmatic consequences. Whereas individual changes, even enhancement, can be considered science, permanently altering DNA for a complete pedigree resounds with themes of genesis. Moreover, whereas God has put apparent limitations on human's attainment of perfection, science may not yield to a lack of perfection.

Achieving perfection cannot always be scientific. Indeed, the fears of genetic enhancement or even generational disease eradication CRISPR could provide is dependent on the 'domino effect.' While CRISPR can potentially eliminate 'unwanted' traits like schizophrenia, it is unknown whether and how 'unwanted' traits may be related to 'desirable' ones. For example, many artists and musicians suffered from poor mental health. However, their genius too was apparent and potentially wrapped in their illness.⁷⁷³ Rabbinical scholars appear to focus on the 'unwanted' traits; indeed, Jewish bioethics tend to focus on this delicate interplay. As such, the concept of humility, of "walking humbly with G-d" can potentially soften Orthodox zealous pursuit of genetic enhancement.⁷⁷⁴

Genetic manipulation for preservation of health is not new to Judaism. In fact, Jewish approaches to genetic testing services have been lauded for education, organization and eradication/lowering rates of genetic diseases. Pre-marriage genetic testing vis-à-vis *Dor Yeshorim* and more currently, JScreen, have provided comprehensive genetic testing and are studied by other ethnic groups as a benchmark.⁷⁷⁵ Both groups are currently based in the United States, however JScreen is accessible globally. *Dor Yeshorim* began in 1983 in an effort to reduce the occurrence of Tay-Sachs.⁷⁷⁶ When a person gives blood to the program, it gives them an ID number. When they meet someone they wish to pursue seriously, they call and give both

ID numbers and birth dates and find out if they are 'compatible' or 'not compatible.' If a couple is tested after they have already married, and determined to be incompatible, they are provided with genetic counselling. If a married couple is tested before pregnancy, they are given further testing and counselling if one or both is deemed to be a carrier. This is all done free of charge to all participants.⁷⁷⁷

Dor Yeshorim is strongly associated with the Orthodox community. As a result, JScreen was developed through Emory University for all Jews, regardless of religiosity. In the privacy of home, one produces a saliva sample and gets tested for a myriad of Jewish (Ashkenazi and Sephardic) illnesses. JScreen sends the results directly to the patient or their physician, along with recommendations for genetic counselling. JScreen serves all Jews regardless of marital status or religious observance.⁷⁷⁸ *Dor Yeshorim* has 90% participation rates within the Orthodox community. Regardless, as early as 1996, the Tay-Sachs ward in Brooklyn, New York was closed. Previously, they had a waiting list for services.⁷⁷⁹ This has been undoubtedly linked to the success of genetic screening.

Modern medical problems must be resolved with ancient texts, according to Judaism. When a new medical technology arises, several rabbis and scholars will study the procedure and look at source-texts to see whether or not they apply. However, the answers are not always simple. The application of ancient religious text to modern bioethics dilemmas is controversial within Jewish thought. While Talmudic scholars encountered many medical and socio-cultural dilemmas, linear parallelisms to the modern discourse do not always exist.⁷⁸⁰ Thus, when applying textual anecdotes or precedents onto modern cases, there is a substantial fear that the *posek's* own views are being "read into" the application.⁷⁸¹ Yet, the proper application of Judaic law can be mitigated via certain foundational realities that shape the law itself. Indeed, Jewish

thought is constructed upon principles (what Brand defines as ‘religious ideology.’) This ideology serves as a balancing controller towards the modern application of texts. As such, so long as the ideology of Judaism is preserved through modern applications, the *posek* can satisfactorily apply text to modern bioethical predicaments. Religious ideology has intrinsic biases that may promulgate or negate medical advances. *Posekim* also have biases, personal interpretations and hierarchical understandings of Judaic principles. Secular ideologies and contexts may colour what should be a purely *halakhic* decision.⁷⁸² Whether and how the ‘truth’ of *halakha* is displayed within a decision becomes the heart of the decision.

However, even the Talmud was not blind to socio-cultural or other impactful ideologies. Mirroring the Talmud, these socio-cultural and emotional leniencies are unequivocally being utilized in modernity by rabbis. Religious codes cannot be created independently of other considerations. Perhaps a more accurate interpretation of ‘truth’ in applying ancient sources to modern predicaments lies upon understanding the human condition and its complexities.

The only literature on Judaism’s approach to germline modification is written by Dorff, a Conservative rabbi and scholar. Normally, when considering Jewish Orthodox approaches, the Conservative movement would be considered as philosophically (and in some cases theologically,) different. However, Dorff is staunchly traditionalist and moderate in his rulings. Moreover, Dorff’s argumentation has several weaknesses that can be refuted (and strengthened perhaps,) by this dissertation’s approach to Jewishly framing permission for germline modification. Dorff dubs germline alteration ‘modifying human nature.’⁷⁸³ Dorff’s naming it thus connotes a sense of Godliness. Dorff (and Zoloth before him in *Jews and Genes*,) contemplates genetic modification being akin to the Talmudic understanding of magic. Moreover, Zoloth’s application of the Jewish tradition of [social] justice is anemic. Zoloth insists

that germline editing would be inequitable to those who cannot access or afford it. This is true and important to the discourse of medicine and accessibility, however Orthodox Jewry would not consider this approach. Instead, they would probably favor legally based Talmud precedents that would indicate whether or not the technology can be utilized.⁷⁸⁴ As there is a significant lack of literature and rabbinic opinions on this topic, this chapter proposes one. Thus, this chapter suggests basing a Judaic ethic of germline modification on the following three principles: Judaism's approach towards abortion and its understanding of embryos; the obligation to preserve health/Judaic approaches to risk and; Judaic approaches to cosmetic procedures. While this is a religious-ethical theoretical exegesis, it does, later in the chapter, lay the conceptual understanding for applying flipped hardship. That is, if a religious tradition can justify potentially controversial medical interventions, what limits can be ethically applied? Thus, the religious ethics must be formally and rigorously applied, in order to truly 'test' the limits of hardship.

Thus, the potential Judaic precedent for germline editing stems from three principles. Each will be analyzed in turn. The first principle involves Judaic views of abortion and embryo usage in research. This is important as early experimentation in human usage of CRISPR would be conducted on embryos—which is considered 'fluid' under Jewish auspices.⁷⁸⁵ According to Jewish scholars, embryos were *intended* by God to be human and thus, demand respect and value in their usage even in experimentation.⁷⁸⁶ Conception is considered creation and thus, Godly in nature. Destroying creation may only be permitted if the *value* of destruction is comparable. Indeed, using embryos in an attempt to alter the gene for cancer or MS may be considered a worthy purpose for destruction.⁷⁸⁷ The Judaic approach would consider the overarching value of gene modification (to eliminate suffering,) to be considered a virtuous purpose. Thus,

experimentation done by harvesting cells from embryos is permissible in Judaism. Importantly, embryos cannot be created for the sake of experimentation. Jewish ethics are clear that these embryos must be remainders and donated from previous IVF attempts.

The second principle to be considered would be Judaism's obligation towards health and risk-taking. CRISPR is a risky venture and risk within Judaism is a complex notion. Even if a life is saved for a short period of time, a physician is obligated to attempt to do so. Additionally, there is a mandate to relieve pain. Zealotry towards saving life is also mirrored in the pronouncement to preserve and prolong health; moreover, to shun risk-taking procedures. The concept of risk, particularly in medicine, is understood as inherent. Even the most routine practice holds risk: for example, some people react negatively to vaccinations. Yet, the small risk of adverse reactions is mitigated by the larger risk of being susceptible to often debilitating illnesses. A physician often does the risk-benefit analysis, sometimes dictating whether or not a service is even offered to a patient. The most high risk procedures should be avoided at all cost; except for the purpose of saving one's life.⁷⁸⁸ Indeed, one is permitted to desecrate the Sabbath in order to save someone who is trapped, even if they are not expected to survive for much longer. Although, if great risk is the cost for even a short period of longevity, the patient can choose to accept or refuse treatment.⁷⁸⁹ This is an important paradox. Whereas great risk must be avoided, it can be embraced for even short term gain. However, a patient is permitted to fear high risk and even refuse care.

It is true that Jews are prohibited from taking non-required medical risk, however, Orthodox rabbis permit cosmetic surgery, despite the associated risks.⁷⁹⁰ This dissertation is not the first to draw an ethical/logical parallel between genetic manipulation and cosmetic surgery. However, the literature is often one dimensional and cursory. Moreover, it leaves no mention of

CRISPR or other genetic science. Thus, this dissertation attempts to advance the conversation. This serves two purposes. First, it allows greater understanding of the logic Orthodox scholars apply to potentially allow for genetic enhancements. Traditional Judaic textual sources are silent on genetic engineering. Thus, the third principle of this approach is being considered. Being able to understand the Jewish Orthodox approach of genetic intervention from drawing a parallel to the Jewish approach to plastic surgery is a typical exemplar of creating modern Jewish bioethics. It may also serve to offer boundaries towards genetic enhancements. The genetic future of medicine is no longer speculative. It is thus essential that religious traditions create a viable foundation towards approaching them. However, Judaism's pro-natalist ethos may conflict with anticipated secular ethical guidelines.

CRISPR may save lives. Arguably, that is its purpose: to stop genetic diseases that impinge upon quality or duration of life. Therefore, CRISPR must be classified under *halakhic* terms of risk. As CRISPR develops and continues to be tested it would be classified as high risk since the impact and side effects of germline modification is not yet realized. However, for Jews who suffer from CF or other life limiting illnesses, this risk, however high, is permitted for even a moment of additional life. However, there is a tremendous caveat: a patient is able to refuse treatment if the risk is too high. Germline modification affects all *future patients*; can one individual decide for his future generations? Moreover, the modifications made on the 'defective' gene may have implications on healthy ones. Or, more philosophically, what one person considers to be life limiting, another may be able to adapt to. Consequently, what value does Judaism place upon autonomous choices, when an individual choice affects the collective? To solve this query, two ethical parallels may be applied here: not requiring permission to save a life and, destroying a pursuer.

According to the Talmud, permission is not required to save someone. Indeed, if someone expresses not wanting to be saved, one is obligated to ignore his wishes and save him regardless.⁷⁹¹ Additionally, there is a famous responsibility to stop or even kill a pursuer to save someone else. Even minors are obligated in this commandment.⁷⁹² Anecdotally, an individual's actions has impact on the collective. Illustrative of this, if one person refuses to join a prayer quorum, all men present lose the merit of his prayers.⁷⁹³ Together, these principles create a powerful argument towards accepting CRISPR. A person with a genetic mutation does not need to ask permission of all his (potentially) affected kin; the mutation is a 'pursuer' and must be eradicated. Indeed, if a person did not wish to utilize CRISPR, his progeny would lose the merit of the technology, from his 'selfish' decision. While this creates a rather tidy case enabling Judaism's embrace of CRISPR, the problem of enhancement—or improving God's own work—remains. Hence, analyzing Judaism's approach towards cosmetic surgery which literally 'perfects' God's work is a novel parallel.

A paradox exists within Judaism. Whereas a patient is religiously obliged to seek out treatment, they are also commanded to mitigate risk. Medical interventions which are considered 'high risk' with little benefit are to be avoided. Thus, cosmetic surgery would fall into this categorization. Additionally, enhancement surgery is considered to be against the integrity and beauty of God's own creation.⁷⁹⁴ Further, according to Rabbi Walenberg, a doctor is not *licensed* to perform these procedures, since there is no reduction of harm or pain.⁷⁹⁵ Rabbi Walenberg's position goes against other *posekim* who permit plastic surgery. His approach is creationist and serves to 'protect' the sacrosanct nature of G-d as knowledgeable and formidable creator. Further, he attempts a literal interpretation of the physician's obligation to 'do no harm.'⁷⁹⁶ This

reiterates Mackler's important yet difficult distinction, that it is difficult to demarcate between therapy and enhancement.⁷⁹⁷

However, most rabbinical decisions encompass the aforementioned socio-cultural ideologies. Much like abortions are considered based on the mental/emotional anguish of the mother, the desire for a person to improve or change their appearance is measured in terms of emotional duress.⁷⁹⁸ Indeed, if a person seeks physical changes in order to get a better spouse, this is approved. Further, if one's appearance always caused them emotional harm, they are permitted to use a surgical corrective approach.⁷⁹⁹ However, the literature often utilizes the example of a person desiring rhinoplasty, sanctioning it for aforementioned reasons. Yet, there is almost a purposeful silence about whether this allowance would extend to 'vanity' procedures such as breast augmentation. To properly extend this logic to genetics and CRISPR, defining 'vanity' cosmetic procedures is integral. A rabbi may condone a rhinoplasty, but is less likely to permit breast augmentation. A nose is in the 'public' domain and is easy to observe whereas breasts are sexualized and in the 'private' domain. However, this may be merely an exercise in semantics. Whereas a larger nose may cause emotional harm from bullying, the argument may be made that a woman unhappy with her breasts may suffer from reduced self-esteem.

That definition would enable Judaic scholars to truly encapsulate whether certain diseases fall under the scope of 'vanity' (and thus, should not be mitigated with CRISPR) or medically, emotionally or socio-culturally necessary to mitigate. The academic literature is also silent on such definitions. However, cosmetic surgery is permitted if it will alter one's prospects (admittedly, for finding a spouse). Indeed, in this sense, we are assistant to God's creation; moreover, we are obliged to perfect our lives. While self-mutilation is prohibited, there is a Talmudic duty to fix what is broken.⁸⁰⁰ CRISPR then can be seen as a co-creator; a fixer of what

is broken. While this does not solve the dilemma of classifying what genes are considered 'broken,' Judaism may be able to create classification based on the Talmud. Talmudic Judaism had a rudimentary understanding of disease, particularly hereditary diseases. It cites that a person should not marry into "...a family of lepers..." and that "...an albino man should not marry an albino woman..." so the children are 'sheltered' from the illnesses of their parents.⁸⁰¹ This under-developed logic is the basis for endogamous genetic mutations. In a direct, modern correlation, CRISPR should only be utilized to correct inheritable, life limiting or terminal illness that has an excessive likelihood of being passed on. Talmudic precedents create ample permission for Jewish patients to fully embrace CRISPR technologies.

Religion is a binding community with individual moral codes.⁸⁰² As such, this dissertation outlined the uniqueness that exists within Jewish and Israeli law in order to promote Jewish continuity. Yet, while Jewish ethics may permit CRISPR technologies, secular ethics may limit its usage. What may be beneficial to the Jewish community may be questionable in secular ethics. Moreover, genes that particularly affect the Jewish community may not be considered first in CRISPR's initial usage. CRISPR's technology can be subsumed under Rawl's social good theory. That is, if federal funds and dollars are supporting CRISPR, the technology would first stand to serve those genes which are assumed to be either wide-spread and/or life limiting. While Jewish ethics allows one to decide for many, innovations in science often base decisions upon the collective and who this technology may impact the most. For example, if a gene marker for diabetes can be obsolete, far more citizens would be positively impacted, as would the health system as a whole since complications from diabetes would be virtually eliminated. Whether and how germline modification can be permitted must be determined not by the individual undergoing the procedure, but by society. Likewise, while hereditary diseases plague the Jewish

community, CRISPR's powerful ability to alter the germline is, for many, a slippery slope. Some scholars caution against using the technology in a eugenic sweep.⁸⁰³ The line between 'therapeutic' and 'enhancement' would become more blurred. Further, the impact to society must be considered. While Jews would consider even high risk beneficial for a modicum of life, secular ethics is concerned with the risk of changing society itself.

Jewish scholars would deem their acceptance of CRISPR as promoting health. Secular ethicists, however, are concerned with whether it promulgates a slippery slope towards a hostile eugenics. Scientists caution that the technology is still high risk. Moreover, the risk-benefit equation varies from disease to disease.⁸⁰⁴ Hence, the umbrella permissiveness proffered by Jewish sources is antithetical to the realities of the technology. Using CRISPR in some tissues on adult patients may cause excessive tumors to grow. Other cells may be overtaken from 'target' cells. Ethicist also consider the possibility of the human race getting 'hooked' on enhancement technologies.⁸⁰⁵ This is certainly not far-fetched. Many rabbis allow plastic surgery procedures since it has become apropos in modern society.⁸⁰⁶ The same may hold true for genetic modification. As a result, the yearning towards creating 'better' humans may result in a rise of eugenics, not seen since the Nazi era. Technology has currently outpaced ethics and policy. As such, many European countries have banned CRISPR.⁸⁰⁷ It is thus imperative that ethics help shape the dialogue for the future of genetic medicine, so that society does not lose its diversity nor mimic the horrors of the past. Some secular ethicists have apprehensions towards deciding which genes deserve to be edited.⁸⁰⁸ Whether and how genes would be 'triaged' and categorized remains to be seen. A final fear in secular ethics is that CRISPR would eliminate diversity and tolerance. The cost of CRISPR technologies will also divide the social classes. Society may even be further divided into what should and should not be edited out of the human genome.⁸⁰⁹ Some

of these fears are outsized. The cost of CRISPR may first slow its dissemination into society, thus enabling ethics and policies to be codified. However, there is great importance in diversity. Thus, germline modification must be carefully adjudicated and perhaps even limited to life limiting illnesses, so that diversity and tolerance is never lost to society. There is also ‘societal backlash’. That is, the ‘science fiction’ nature of CRISPR may override the facts and dominate the conversation.⁸¹⁰ This too would hinder society as fear may overwhelm progress. A balance must be struck then to fully explore the actuality of the technology before potential distress overwhelms its promise. Thus, whereas Judaism’s religious ethics may permit CRISPR, its relative permissiveness cannot be supported by future, general, CRISPR procedures. To wit, Judaism would permit parents to seek out genetic engineering protocols which could be considered eugenic by secular ethicists. Whereas Judaism supports the ideology of an individual pursuing any medical means to extend or better one’s life, this will clash with public health notions of safe, communal pursuit of health. As a result, Jewish patients who want to partake of genetic engineering must do so within the public parameters and would be unable to request certain modifications. Flipped hardship cannot be assumed here—for, as indicated throughout this section’s analysis, public health and eugenic fears overrides Judaism’s possible emboldened approach to genetic ethics. As previously discussed, while Judaism could very likely sanction more lenient approaches towards genetic engineering, it cannot be considered flipped hardship. The reasoning is based on the aforementioned concerns on eugenics and public health ethics and funding. Indeed, while research and potential cures for rare genetic conditions should and must continue, at first blush, religion should not be permitted to singularly serve as a reason to pursue CRISPR for these diseases. Since CRISPR has irreversible changes for the entirety of future progeny, the innovation should be first utilized in a way that could potentially help many, rather

than a few. As the technology becomes more affordable over time, and scientists better understand its implications, Jewish families may partake of private clinics to explore utilizing CRISPR for more rare conditions.

5.B. iii. Catholic approaches towards CRISPR: Flipped hardship?

Catholicism's stance on CRISPR is less conjectural. Catholicism is hesitant to play the role of G-d. Similar to its approaches towards reproductive technologies, Catholicism takes a more naturalized approach towards genetics. However, Catholic ethics is not wholly against utilizing scientific progress, so long as it is done in keeping with natural order. For genetic engineering, the Catholic approach is nuanced. A distinction is delineated between engineering that can be considered therapeutic and thereby condoned by the Church, and manipulation that could "...alter the human genetic patrimony..."⁸¹¹ This would automatically negate the usage of germline editing—the very intervention CRISPR is designed for. For the Church, the reasoning, is clear and stands on four primary concerns. First, to alter germline genes may alter one's soul. Secondly, the Church seeks to stem potential abuse from CRISPR technologies. The Church also fears that germline editing is too akin to 'playing God' and usurps Divine authority to give gifts as He sees fit. Finally, the Church does not support experimentation done for its own sake.⁸¹² A further parallel can be found with the Church's approach towards synthetic biology of agriculture and the environment.

The Commission of the Bishops Conference of the European Community released a detailed opinion on synthetic biology. Genetic engineering can be categorized as such. Indeed, according to the opinion, synthetic biology is defined as the ability to create or reengineer human life forms. The *Opinion* refers to a paper published by the Commission of the Bishops' Conference of the European Community. This Commission is largely made up of bishops from

the 28 European Union states. Together, they represent the Catholic Church in the EU, and publish opinions on ethical issues that are relevant to the Church written by expert commissions.

The *Opinion* itself is not limited to medical usage of synthetic biology; it further explores the repercussions of it on agriculture, energy and the environment. This is important; the *Opinion* is welcoming of “human intervention” on nature or agriculture. The scientific advances are viewed as a gift from God, entrusted to the proper scientists to use.⁸¹³ This mirrors the Judaic approach to [medical] technology, and may yet offer a window by which germline editing would be accepted. The *Opinion* urges caution, and only utilizing scientific progress for the best intentions and to not compete with God, or view humans as deities. In summation, the correct “moral ends” are encouraged with any and all synthetic biology usage.⁸¹⁴ Curiously, the *Opinion* ends noting that many religions, including Judaism, do not create prescribed bioethics statements but do have statements of opinions. As such, the *Opinion* does not offer policy or ethical frameworks for which synthetic biology may or may not be used. Rather, it asserts that the Catholic opinion is in keeping with mainstream ethics concerns of caution and reflection before usage. This is echoed throughout the (scant) literature on Catholic approaches to CRISPR technologies. It would be interesting to discover what a Papal pronouncement would and would not permit for genetic engineering. While Judaic approaches could possibly be aggressive, secular approaches would undoubtedly be more reticent to categorize what is a disability that hampers quality of life. The *Opinion* notes that Western ethics is built upon the foundation of Church values. Perhaps then, the Church should lead the leap into genetic engineering and clearly define what can and cannot be done. Under the definition proffered earlier, this may indeed be the one instance where flipped hardship does exist. Assuming a Papal pronouncement would be even more cautious than even the secular ethical standards for CRISPR, Catholic

individuals may feel that their own religion is restricting their partaking of a medical intervention. That is, if a Catholic patient wishes to partake of CRISPR technology, but the Church does not sanction the particular edit they desire, this individual patient could very well feel hardship, but from within their own religious tradition. In a case like this, where secular, ethical standards and approaches deviate from the Church, (as in abortion, euthanasia, etc) a rural Catholic hospital may be compelled to offer the service. This shall be discussed in detail in chapter 6. For a city-based Catholic hospital, a Catholic patient may have to go to another, non-religious institution to partake of the service.

5. C. Foresight: Onco-fertility Religious Accommodation in Clinical Care

Another clash between religious and secular ethics happens during pediatric cancer diagnosis. Similarly to CRISPR, oncofertility and subsequent Catholic or Jewish religious accommodations cannot be perceived as flipped hardship. This will be delineated later in this subsection. Cancer diagnosis at a young age is often no longer a harbinger of finality. An array of new methods have lengthened the life spans and improved the prognoses for patients diagnosed with cancers that would have been deemed fatal only twenty years ago.⁸¹⁵ Consequently, more physicians and health care providers are engaging in discussions of reproductive future. Cancers that involve radiation and chemotherapy treatments may risk damaging the male's delicate sperm or affect a female's ovum making fertility difficult.⁸¹⁶ This conversation is called onco-fertility—and is considered a new phenomenon in cancer care and treatment.⁸¹⁷ There are several ethical concerns. Secular ethics questions the decision and consent process, particularly for youth and young children. Further, the method to harvest sperm or preserve ova may be considered invasive and inappropriate.⁸¹⁸ Religious ethics have additional concerns. Both Judaism and Catholicism place prohibitions on masturbating to

procure sperm.⁸¹⁹ Judaic text also questions a minor as decision maker. Catholic doctrines dictate reproductive technology and thus, onco-fertility.

5.C. i. The process of preserving fertility in pediatric patients

Regardless of age, sperm harvesting is a simpler and far less invasive medical procedure than ova collection.⁸²⁰ The technique used to procure adolescent or prepubescent sperm remains like techniques utilized on adult males. Simply, the male must ejaculate into a medical container and the ejaculate is then put into freezer storage.⁸²¹ However, when the patient is not yet physically mature, this method is ethically questionable and may even be deemed inappropriate. Some studies counter this ‘natural’ approach in favour of electro-ejaculation which forces ejaculation while the patient is under mild anesthesia.⁸²² While quick and devoid of any sexual paraphernalia, this method is too, not without concerns. Various studies have shown that sperm collected via surgery or assisted ejaculation is not ideal—whereas sperm harvested through traditional means of self-procurement is stronger and more vital specimen.⁸²³ Young boys who are of pubescent age may be given hormones to speed the process along, or testicular tissue may be sampled in hopes of ‘growing’ mature and viable sperm in the future.⁸²⁴ The former option has its downfalls: hormones like testosterone may create mood swings and irritability in a male and may also jeopardize his cancer treatments. Further, many ethicists question the use of such hormones to rush adolescence.⁸²⁵

Whereas sperm procurement is less evasive, ova harvesting is far more complex since it involves undergoing surgery, often coupled with hormone therapies to facilitate easier collection.⁸²⁶ These cryopreservation techniques have a low success rate. Further, there are concerns as to whether procuring oocytes prior to fertilization is scientifically responsible, as

freezing has been known to cause permanent damage to the delicate tissues.⁸²⁷ Females who choose to freeze their eggs are scientifically advised to freeze an embryo as it can survive in a prolonged frozen state, compared to mere ova.⁸²⁸ Yet, to create an embryo, one requires a donor. Few parents are comfortable with requisitioning sperm for their young daughter. Finally, there is another, still complicated surgery to protect female reproductive organs. The complex and limited ovarian transposition surgery attempts to ‘shield’ the ovaries from the damage of radiation by placing it lower in the pelvis.⁸²⁹ This procedure, although preformed somewhat infrequently, is not considered normative medical practice.⁸³⁰

5.C.ii. Fertility and Reproductive Technology in Judaism

Although Judaism is focused distinctly upon reproduction and is progressive in terms of embracing reproductive technologies, the usage is restricted by *halakha*. Sexual intercourse in Judaism is designed primarily for reproduction—masturbatory emissions are prohibited. Rabbi Waldenberg, one of the foremost *posekim*) in the field of Jewish medical *halakha* admonishes those who use artificial insemination, even as a husband, as it “ruins the tents of Israel...” the act of sexual intercourse is a pure and sacred, necessary to preserve Jewish homes.⁸³¹ Hence, it must be performed in its original (traditional) intended manner. The onus for procreation rests directly on the male. Females cannot be obligated in the *mitzvah* of procreation due to its life-risking tendencies. Whereas she may be religiously unobligated, she is *socially obligated* due to status and traditional domestic sphere roles. Whereas procreation is not the sole purpose of marriage, it is considered part and parcel of it. This idea can be easily traced throughout the *Torah*. Genesis 1:28 observes that, "G-d blessed [man and woman] and said unto them, 'Be fruitful and multiply and replenish the earth and subdue it.'" After the Flood destroyed the world and its populace, Noah's family was blessed with fertility (Genesis, 9:1). Certainly, the various trials of infertility

experienced by the matriarchs—and their desperation to have children, which leads them to offer up maidservants to their husbands—establishes a strong case for children being a pillar of a Jewish marriage. Fertility is thus foundational for the continuity of Jewish faith.

Although Judaism is focused distinctly upon reproduction and is progressive in terms of embracing reproductive technologies, the usage of such technologies is restricted by *halakha*. This leads to some restrictions in the permissibility of certain methodologies utilized to harvest sperm and ova. Orthodox Judaism eschews the usage of condoms since it would restrict sperm ejaculations from entering the vagina—*halakha* refers to this as ‘wasted seed’ and ‘spilling seed.’ Indeed, it is religious misconduct. Masturbatory emissions are prohibited; even for reproductive technology uses. Rabbis Feinstein and Dorff claim that artificial insemination does not ruin the holiness of marriage, since a husband’s own sperm does not render the act adulterous and it enables a struggling couple to conceive.⁸³² For these rabbis, assisted reproduction is a means to an end—the end being the fulfillment of the commandment to procreate.

Harvesting ova is not as *halakhically* complex. With a youth or child, there is no concern of ritual menstrual purity (*niddah*) which is usually observed in a marital relationship. However, these laws pertain to normative and married couples. What is of concern, however is the possibility of frozen embryos. Normally, eggs are not frozen exclusively as they are built of delicate tissues. It is the preference of medical experts that an egg be frozen with a sperm inhabitant—creating an embryo—which has a better chance of long-term survival. Thus, a female patient must consider sperm donation. Most *posekim* assume donor sperm to be adulterous. Similarly, donated eggs are frowned upon for lineage issues.⁸³³

5.C.iii. Fertility and Reproductive Technology in Catholicism

Catholic ethical thought shares the same Old Testament narrative of fertility. Leaving aside the difficulties of masturbation, Catholicism has concerns with ova preservation and transplantation.⁸³⁴ As with Judaism, Catholicism prefers procreation to be wholly within the confines of a marriage bed. Removing the physical act and transferring it to a lab setting is disconcerting.⁸³⁵ Further, the Church objects to fertility treatments at large since they may enable ‘depersonalization’ of children conceived utilizing these methods.⁸³⁶ Only in extremely rare circumstances would artificial insemination be permitted to assist a couple, since, not all couples are blessed by God to have biological children.⁸³⁷ To provide the best outcome for a pediatric patient, embryos are preferred for long-term freezing since scientists have concluded that egg freezing alone has a shorter life span than frozen embryos.⁸³⁸ Catholicism thus struggles with a unique ethical concern. Ova preservation is not sustainable for a prolonged period and yet, potential embryos have a right to life, regardless of what a former cancer patient would ultimately desire.

Some Catholic ethicists would permit pediatric patients to preserve their ova, if the experimental treatment is offered. Being aware of the limitations of current procedures, the end-result allows for marriage-based natural conception. Further, technology rapidly evolves. It is not unwarranted to believe ova preservation can be advanced.⁸³⁹ Indeed, science could compliment the notion of Catholic marriage and conception as ova preservation simply restores the ability to procreate.⁸⁴⁰ Much like Judaism, the importance of coitus is thus not disrupted by science. Further, the patient would not be *obligated* to make use of her restored fertility. If embryos were frozen, there is an ethical assertion towards life. Embryo creation offers additional obstructions. Catholicism rejects the usage of donor sperm, since it taints the marriage relationship.⁸⁴¹

Whereas Judaism places concerns upon knowing a child's lineage (for legal status purposes outside the purview of this paper,) Catholicism renders it akin to adultery.⁸⁴² Again, this severely limits participation within the current state of onco-fertility. Perhaps leniency can be learnt in Catholicism, based on the notion of *intent*. *Donum Vitae* cites that utilization of donor materials would "offend" the call to parenthood.⁸⁴³ Yet, the *intent* of onco-fertility is just that: to preserve the possibility of parenthood. Moreover, becoming biological parents may strengthen a marriage.

5.C.iii. Secular Ethical Concerns

There are several ethical fissures that come packaged with onco-fertility. These issues can be viewed in two ways. First, relating to the autonomous choices made by the pediatric cancer patient, and second, issues relating to future fertility and implantation. There are further implications regarding truth-telling and financial obligations. Whereas preserving future fertility is the ultimate 'endgame,' oncologists may not reveal the statistically low success rates of fertility treatments and freezing techniques.⁸⁴⁴ Options are limited for children who are simply too young. Pre-pubescent boys have no option to protect their fertility. While scientists are experimenting with preadolescent testicular tissue to mature it and create sperm it as yet cannot be offered to patients.⁸⁴⁵ Likewise, pre-pubescent and even mature females have a risky and failure-ridden surgery in an attempt to preserve their fertility.⁸⁴⁶ Yet, a larger consideration involves the acquisition of the sperm/ova. The best sperm is acquired from masturbation and questions arise over the propriety of allowing a child to masturbate with the help of pornographic literature. For females, the hormone therapy and surgery required to harvest ova may exacerbate cancer for some females. As such, it raises ethical questions as to the suffering and quality of life of a patient; is 'suffering' for a potential fertile future unethical for children?⁸⁴⁷ Another ethical concern is what occurs to the reproductive tissue should the child succumb to his cancer.⁸⁴⁸

5.C.v. Pediatric decision making and fertility preservation

There are several ethical fissures that come packaged with oncofertility. These issues can be viewed in two ways: relating to the pediatric patient who is obliged to make a fertility decision, and issues relating to the potential children conceived by such efforts. The possibility of future fertility is the ultimate ‘endgame’ and thus, physicians concerned with the statistically low success rates of fertility treatments may prevent the oncologist from informing patients about the possibility of oncofertility treatments in the first place. Whether or not they are permitted to withhold this information is questionable within the literature. Scientific studies have proven that oocytes in particular are sensitive to prolonged freezing (5+ years) and start to disintegrate and under-perform. Sperm too suffers (albeit less dramatically) when kept in a prolonged frozen state.⁸⁴⁹ Additionally, testicular or ovarian tissue is harvested with the hopes of developing a method of creating sperm or eggs is experimental at best⁸⁵⁰ Prepubescent boys have no option to protect their fertility. While scientists are experimenting with preadolescent testicular tissue in an attempt to mature it and create sperm, it isn’t FDA approved and thus, cannot be offered to patients. Likewise, juvenile females have a risky and failure-ridden surgery in an attempt to preserve their fertility.⁸⁵¹ Additionally, the economics of oncofertility weigh heavily in the mind of some clinicians; in Canada, most provincial governments will subsidize freezing and storing ova and sperm for qualified cancer patients, but they will not subsidize fertility treatments themselves.⁸⁵² In the United States, coverage differs based on insurance policies and hospitals. Thus, for many physicians, the financial burden is not an ethical best practice, nor a responsible ‘prescription’ for suffering patients.

Pediatric females who choose to freeze their eggs are advised to freeze an embryo as it can survive in a prolonged frozen state, compared to ova.⁸⁵³ Considering the financial cost of preservation, success is key. As such, most physicians are likely to recommend embryo freezing

since it is more likely to succeed after some time.⁸⁵⁴ Yet, to create an embryo, one requires a donor. If later in life, this patient decides children are not part of her lifestyle, those embryos would be abandoned (or donated,) which brings up a plethora of further secular ethical and religious dilemmas. Putting religion aside, secular ethics has concerns for the creation of embryos.

The first concern lies in creating an embryo. Hormone therapies and harvesting typically pauses cancer treatments for 2-6 weeks.⁸⁵⁵ For certain cancers (especially leukemia,) chemotherapy must commence immediately; preserving fertility may be untenable.⁸⁵⁶ The concept of time is unique to pediatric onco-fertility. It may be 10 years or more before a woman wishes to use her preserved embryos. As a pediatric patient turns into a teenager, a young adult and adult, whether and how a fertility center should communicate with the patient is still indecisive.⁸⁵⁷ Thus, many embryos may be abandoned in laboratories without directives. Normative procedure would demand forms be signed (allowing the embryo to be adopted, used for research or destroyed.) Cancer diagnosis creates an imperative for decisive action and thus, these directives are often forgotten.⁸⁵⁸ Some laboratories attempt to re-establish communication for a period of five years. If they are unsuccessful, they discard the embryonic material.⁸⁵⁹

Who makes such an important decision, however is essential to discuss. When it comes to whether children or parents make healthcare decisions, most Canadian and US based hospitals utilize the term ‘mature minor’ to determine who to turn an ear to.⁸⁶⁰ A minor is anyone under the age of 16, according to most hospital policies.⁸⁶¹ A ‘mature’ minor is one that is competent enough to make a medical decision and can make an informed, autonomous decision.⁸⁶² Pediatric competency is defined as being able to “...understand and retain and use the information...and then make a decision...” In order to be declared a mature minor, a 15 year old

cancer patient must demonstrate capacity to comprehend and internalize the medical options offered, and be judged to have the competency to utilize the information in an informed way.⁸⁶³ Evaluating maturity is complex. Age alone is not entirely justifiable as qualification for the status. Indeed at any age, pain, fatigue, medication and general anxiety can impact decision making.⁸⁶⁴ Pediatric hospitals are encouraged to involve the patient in decision-making and lean towards ‘best practice.’⁸⁶⁵

The most illustrative example of mature minor decision making and fertility is found in contraceptive access. In certain States, a girl under the age of 16 can seek out a prescription for contraception from her physician without her parents’ knowledge.⁸⁶⁶ Physicians are obligated to assess these cases using the *Fraser Guidelines* which includes assessing competency and capacity of their patient.⁸⁶⁷ Further, so long as the physician is sure the girl will not consult her parents and she will engage in sexual activity with or without protection, they are free to prescribe without parental knowledge.⁸⁶⁸ Contrast this, then, to the choices presented with onco-fertility. A young girl may prevent pregnancy without parental consent. Onco-fertility preserves fertility for a later time. It may be simple to create arguments for easier access to contraceptives for young women, due to economic, physical and life-style choices. Likewise, fertility preservation prior to cancer treatments allows the patient to preserve the option of a biological child when timing is suitable. As far as pediatric cancer treatment has progressed, there is the chance that a child will not survive his illness. Thus, truth-telling, and later, making an autonomous decision towards preserving fertility, may be compromised.

Some physicians may hesitate to discuss future fertility due to fears of misguided hope. This offers further limitations to autonomous decision making. The concept of ‘hope’ is often encountered within the literature; as such, it is an important notion to discuss perhaps due to its

uniqueness to pediatric medicine. Mothers, fathers and physicians all have the same statistically significant belief in hope.⁸⁶⁹ The largest “hope domains” were related to the body and pain and suffering.⁸⁷⁰ Paradoxically, these are side effects of both cancer, chemotherapy and fertility preservation techniques. Fathers are significantly more hopeful than mothers and physicians; they believe in their child’s life being prolonged or else, cured.⁸⁷¹

While the idea of hope is important and perhaps even fundamental to maintaining internal strength, the ethical importance of mitigating hope must be addressed. While hope and miracles may be associated with religious or cultural beliefs, it is imperative to gain a complete understanding of the influence this may have on parental or pediatric decisions. Moreover, when a physician offers hope vis-à-vis fertility preservation, it may lead to uninformed medical decision making. For example, a family may choose to delay traditional radiation and chemotherapy treatments in order to harvest sperm/ova. As discussed earlier in this section, such treatments may exacerbate the cancer or allow the disease to progress to a more aggressive stage. However, hope should not be wrenched completely from pediatric patients and families. When mitigated through complete communication, hope can help parents live day-to-day with a devastating diagnosis. Thus, the importance of clear, didactic and honest communication is not merely an ethical objective but an important one.

5.C. vi. Religion, Oncofertility and Undue Hardship?

Parsing this clinical case is distinct since it is the only one in this dissertation that considers a pediatric lens. As discussed in chapter four, pediatric decision making is a complex entity. Certainly, all the mitigating factors are present within the conversation of oncofertility. The weight of decision whether to preserve fertility is daunting at any age. Pediatric oncofertility merely compounds the issue. Further still, decisions can change. Frozen specimen may not be wanted in later years.

Conversely, patients who did not preserve their fertility may regret it upon adulthood. The role of religion and pediatric decision making was also analyzed within chapter four and much still resonates here. However, the crux of this particular case rests on that religious ethics. Can a Catholic or Jewish make a decision about a child's fertility solely due to their religious ethos? The parents need to give permission, and the child is required to assent, unless they are categorized as a mature minor or emancipated minor. The child too, may subscribe to the same religious beliefs. If, however, a child does not assent and/or does not subscribe to similar religious beliefs, encouraging fertility preservation or refusing so based on religion would be definable as undue hardship, due to the sensitive nature of the procedure, the uncertainty of the decision in the future and the added evasiveness of such procedures. In this case, whereby a minor child does not assent to fertility preservation or a family supports it due to religious beliefs a child does not subscribe to, social contract theory would limit the actions of parents. Indeed, in the case of attempting to fulfill the notions of religious ethics, the private nature of religion may not enter the realm of the public sphere. Further, the uncertainty of the future usage of the sperm or embryo and the evasiveness of the procedure requires autonomous, consensual choices. If a religious pediatric patient wishes to undergo fertility preservation, they would be aided in doing so, based on their own assent and, in this case, consent. In the circumstance of a very young patient with religious parents who want fertility preservation, the previous definition of flipped hardship applies. Even more so, since fertility preservation in very young patients is still quite experimental. Harvesting viable sperm and ova from immature tissues is still not approved by the FDA. This is classically defined as undue hardship and is further, ethically definable as undue hardship. As a result, with this particular circumstance of a very young child, a family should not base their sole decision upon religion. .

6. Religious Evaluation and Accommodation during Secular Ethics Consultation: Towards a New Evaluative Scale

Whether and how medicine must yield to religious beliefs is not clearly identified within hospital culture. It is at this critical juncture that ethics is called upon to negotiate between these differing values. Evaluating the efficiency of ethical consultations in these aforementioned conditions is a difficult undertaking. The ethicist (or ethics committee, hereafter referred to as EC,) is tasked with being able to deduce the veracity of religious beliefs. It is far from a didactic, measurable task.⁸⁷² This assumes two truths. First, it assumes that ethicists or ECs have an expertise in evaluating the significance of religious beliefs to a particular patient or family. Second, this assumes that ethicists can deduce a ‘genuine’ representation of a religious belief. When a religious belief is staunchly opposed to the recommendations of a medical team, an ethicist is solicited to evaluate the ‘truth’ of that belief.⁸⁷³ Some researchers attempt to construct a formula or scale by which a religious belief can be ‘measured’ and balanced against standards of care.

Moreover, it is unclear if modern clinical ethicists are trained with a sufficient understanding of religion. That is, how can a clinical ethicist ascertain if a religious value is integral to a patient’s religious practice, or is being interpreted accurately by the patient. If clinical ethicists are indeed acting as a liaison between religion and medical ethics, they should ideally be trained to recognize nuances in religion and culture. For some physicians, religion and ethics are dissimilar. Ethics is logical reasoning whereas religion is faith.⁸⁷⁴ Nonetheless, ethics and religion are bedfellows in medicine, certainly within North America. A neat paradox is readily apparent. Whereas the forbearers of bioethics may have been theologians, the new generations of ethicists are endeavoring towards a shared [secular] morality.⁸⁷⁵ The definition and scope of secularism is interesting in itself but is not a focus on this chapter. Rather, this is

indicated merely to help elucidate the driving conflict between the believer and the (alleged) secular ethicist. Whereby some ethicists may even share the religious beliefs of patients, it may be only basic. Further still, they may not know anything about traditions that lie outside of the Judeo-Christian traditions, or, in more rural communities, outside the realm of Christianity.

The literature is notably silent on the implied notion that secular ethical decisions are *ipso facto* apposite over and above religious beliefs. Indeed, some physicians dub religiously motivated medical requests as ‘inappropriate.’⁸⁷⁶ It appears that ethics is consulted as though they are capable of swaying a religious patient towards consenting to a physicians’ treatment plan. This is certainly not a correct usage of clinical ethicists; they should make clear that they are in place to facilitate ethics and not impose decisions on patients and families. Thus, clashes between believers and health providers must be understood as clashes between *two codes of ethics*. Indeed, most religious traditions have codified laws that create these codes of ethics. For example, the Catholic approach towards extraordinary care and the Jewish approach *to pikuach nefesh*. These are examples of hallmarks of the religious traditions. Just as there are standard medical protocols, similar ‘protocols’ exist within religious law for believers.

There have been attempts to empirically measure the value of religion within medical decision making. Yet, this is not enough. Further, it creates a legal dichotomy and change of status between the believers-patients versus the clinicians. For example, in a shared healthcare environment like Canada, several cases have been decided in a court of law rather than the bedside. Indeed, these court cases all are patterned as a believers’ request as divergent from medical counsel. The law is tasked with finding an equilibrium, which thus far, no court has done. Thus, a self-defined religious patient can hold onto valuable (limited) healthcare resources under Canadian law, unlike ‘secular’ patients. Thus, a new, *ethical* model for measuring,

infusing and balancing religious ideals into clinical ethics would be indispensable. It would also keep medical decision making at the bedside, rather than in courtrooms. The new ethical accommodation framework can only be used once religious decision making has been identified. This is a key component of the role of an ethicist. Acquiring knowledge of religious traditions is certainly not enough. Ideally, clinical ethicists would have a broader understanding of interreligious knowledge, and pair this knowledge with an understanding of religious *rationalization*. That is, far from being trained theologians, ethicists should at the very least be aware of how deeply religious thinking can impact decision making, at the very least, within the Abrahamic traditions. Attempting to negotiate medical interventions with religious patients and families may prove to be circulatory and frustrating for all involved; as discussed previously, this is due to two clashing codes of ethics. Rather, a clinical ethicist should reframe the conversation which would allow for the religious underpinnings of decision making to surface.

6 A i: The current scope of measuring religion in clinical ethics consultations

Clinicians cannot deny the impact of religion to patients, and even to believing health care providers. Subsequently, care providers wanted an inherent way to discuss and know the religious beliefs of patients. There have been several attempts at crafting a spiritual assessment tool which is used to quantify the weight of religion. In response to the increasingly powerful voice of religious patients, the British National Health Services created a ‘spiritual assessment’ sheet to be filled out with both medical caregivers and patient to ensure the boundaries of religious beliefs will be kept.⁸⁷⁷ The NHS requires its healthcare providers to be “...competent in providing care to patients of differing cultures, religions and beliefs...”⁸⁷⁸ Versions of a similar ‘spirituality checklist’ exist throughout the UK, Canada and the United States. Organizations such as the Institute of Medicine and The George Washington Institute for Spirituality and

Health have devised their own versions of spiritual assessment tools designed to assist physicians and end of life care providers to correctly value particular religious beliefs. The latter organization's FICA Spiritual History Tool assesses the strength of a patient's religious values determined through several categories. These include: Faith and belief, Importance, Community and Address in care. This tool urges that spiritual histories be taken alongside medical history, which indicates the significance the Institute places on spirituality. Further, FICA also offers ethical guidelines towards incorporating spiritual care into medical history taking. FICA can be developed into small plastic cards, designed to fit in a pocket, for at hand spiritual assessments.⁸⁷⁹ Just as staff wear IDs noting the various hospital codes, FICA is just as important to clinical care and must be at hand, albeit it is only one tool and works best within Western contexts and traditions. More research is required to understand the impact of FICA and whether and how it is implemented, alongside other tools which would better serve religious traditions from Eastern and Western traditions and whether and how it could be integrated into ethics consultations.

Current literature suggests that while religious influences are important to decision making, academics are unclear how to fully assess value or weight to it. For most, while the patient's beliefs are respected, some of their religious requests are not. To wit, if a religious request is contrary to clinical judgement, creates a conflict of conscience for medical professionals, or a 'positive' right, it is suitably dismissed.⁸⁸⁰ This outright dismissal is not always correct, as it tends to bias medical judgement. A 'negative' right is interpreted as a patient's refusal to treatment on religious grounds. A positive right is interpreted as a request for clinical care that is normally beyond the scope of best medical practice. This is understood to be two conflicting autonomies: that of the religious patient and that of the physician.⁸⁸¹ Thus, it would appear in clinical environments that spiritual assessment tools are automatically negated

as useless if religious request is juxtaposed to medical judgement. That is, a religious person's requests, refusals or demands are demonstrably cast aside due to not being 'medical' concerns. While a patient with autonomous decision making capacity may refuse treatment (even for religious reasons) it is clear within the literature that health professionals are morally distressed by this. The autonomy and medical judgement of the physician holds a greater authority in literature involving religious and medical conflicts. There is a sense of haughtiness in this argument, and an outright dismissal of religious requests in medical decision making. This is a pattern echoed throughout the literature.⁸⁸² Upon closer reading of the literature, there are undertones of Rawls' social good theory. Religious accommodation should not be fulfilled if society should 'pay' or 'suffer' either monetarily or resource wise to accommodate an outlier request. Further, authors note that burdensome accommodations are often contrary to a physicians' advice. This is a blinding shortfall in clinical consultations. Someone who bases decision making on faith may not concern himself with the 'cost' of his religious accommodation. His religious language may not offer a sense of what is 'good' for greater society. He is merely concerned with keeping to his religious dogma; this is a tale of two sets of ethics.

6 A ii: Clinical ethics consultations: does religion even matter?

Currently, three models for ethics consultation exists: individual ethicist or ethics committees (ECs) or team consultations. The choice of model for ethics consultation it is either a hospital preference, or a personnel allocation issue. Often, hospitals can vary their consultation approach based on the particular case and circumstance.⁸⁸³ Regardless of model, ethics training and processes provide the foundation by which a proper consult can be conducted. Currently, there is debate over whether ethicists require formal certification via examination.⁸⁸⁴

However, this chapter is more concerned with whether and how meaning is given for religion or cultural concerns. The literature on clinical consults and its efficacy all contain empirical data. The data is derived from surveys sent to ethicists and participants in ethics committees or, sent to physicians/nurses who call for an ethics consult. The literature does not include data from patients' satisfaction of an ethics consult. This would be worthwhile research.

Within the empirical data of clinical ethics consultations, there is distinct reference to religious influences in survey takers, but this is not reflected fully within the conclusion of the studies. For this chapter, careful analysis on *why* ethics consults are requested was looked at. The results, thus, are mixed. For example, there are a small portion of clergy or chaplain/spiritual care personnel who self-identify as being involved in ethics. Some surveys even inquire about the religious leanings of the survey-taker.⁸⁸⁵ But, isolating religion as an outright factor to calling a consult is limited, often to 'typical' examples of Jehovah's Witnesses, and, requests by Muslim patients for same-gender physicians. Surveys generally ask the clinical ethicists to grade how proficient they are in several common ethical consult themes; religion/culture is not easily discernable from the data.⁸⁸⁶ For an outside reader, it appears that religion and cultural clashes may be classified under the general terminology of 'moral distress' such as removing life support mechanisms or even discussing end of life care and practices.⁸⁸⁷ One survey is particularly interesting. It focuses on 100 ethics consultations undertaken at the Summa Health System in Akron, OH. In the retrospective study, the ethicists outline themes within their new palliative care consult service and their general ethics service. While religion is not discussed bluntly in the survey themes such as 'patient refuses withdrawal of treatment' and 'patient non-compliant with medical regimen' may have a religious underpinning.⁸⁸⁸ The concepts of religious decision making is not considered at all by the study's authors. It would be

interesting to see if any of those end of life conversations were, indeed, had with religiously motivated patients and families. However, when consultation studies discuss religion, it is often noted within the same breath as commonplace with ‘difficult’ patients⁸⁸⁹. Perhaps religion is not directly confronted due to the notion of creating a secular ethics or having a common morality in healthcare institutions. Yet, this behoves the shadow that religious decision making can cast and the current reality.

Another study focuses on the role of religious decision making specifically in the context of ethical consultations at end of life care, specifically on life-sustaining treatment. This was another retrospective study conducted by the Optimum Care Committee (the hospital’s end of life ethics committee,) at Massachusetts General Hospital between 2012-2014. Cases were identified where the committee was called in due to disagreements over life sustaining treatment options. This study primarily identifies ‘religiously centered conflict’ as a driving force in clinical ethics consultations. 95 cases were considered thus; most of these cases concerned patients who aligned their beliefs with the Judeo-Christian traditions. A large portion (49.5%,) were Catholic. The study discusses that over a quarter of the ethics consultations had religion as a primary factor for requesting the consult. There is an analysis of themes that clinicians and ethicists realize from consultations with religiously motivated patients. There is a sense that death and dying is a spiritual experience, and often ‘in the hands of God.’ Apposite this are those patients who opt for aggressive interventions as a method of ‘religious coping.’ They do note that those who are more religious (and are non-White, non-English speaking,) tend to use ‘religious language’ (albeit the specific language/phrases are absent from the discussion portion of the article,) to express disdain for withdrawing life sustaining treatment. Interestingly, religious families who are White and English speakers tend to couch their requests in non-religious terms.

The authors note that this is due to a perception that medical professionals are more keen to honour non-religious requests.⁸⁹⁰ This is an essential component, integral to this dissertation. As proffered earlier, many religious patients/requests are considered non-compliant by the health professionals and antithetical to medical best practice.

These two studies demonstrate several factors very well. Indeed, religious influence does play a key role in medical decision making and can be empirically, didactically measured. Additionally, religiously motivated requests may be seen as contradictory to medical care and patients/families are dubbed difficult or non-compliant by medical professionals. The second study delved slightly into the experiences of non-Western, non-White patients but does not fully explore this concept. This is a significant detriment to not merely this study, but to the ethical milieu. This dissertation is also guilty of this phenomenon, focusing on Jewish-Christian, White passing traditions. It is apparent that there is a tremendous chasm in medicine and in ethical consultations. Religion is an important aid to decision making for many families. However, families feel like they need to cloak their language in non-religious terminology. The data does demonstrate that a concept of ‘miracles’ is regularly mentioned by patients and reflected upon, especially in discussions of maintaining life sustaining treatment.

6 A iii Medicine and miracles: autonomous choices?

Anecdotes spread throughout the literature make reference to believing in miracles as important for religious patients, not only in the aforementioned study.⁸⁹¹ Medical professionals may feel frustrated by this. However, this belief in miracles provides an incredibly important foundation to the thought-process of religious believers. Indeed, many ethical determinations are based on the ‘reasonable person’ standard. However, the definition of a reasonable person shifts significantly in a religious context. For example, a ‘reasonable’ patient undergoing cancer

treatment would consent to blood transfusions as required. A ‘reasonable’ Jehovah’s Witness, however, would balk at the notion.⁸⁹² Conversely, if a Jehovah’s Witness patient decided to consent to blood transfusions in certain situations, they are not rescinding their religious beliefs. Rather, consent and disclosure is a constant ebb and flow. Just as religious beliefs can sway patients’ interpretation of disclosure, understanding—that is the ability to process information based on physician’s disclosure—can be heavily influenced by religious beliefs. Some religious believers think that God brings illness or suffering upon them.⁸⁹³ Thus, for a religious person, *true* understanding is not derived solely by a medical diagnosis. Rather, it is the *acceptance* that they may have this illness for a reason. ‘False belief’ too gains another dimension. Rather than ignorance preventing an autonomous choice, it can be religious belief that informs a decision. It is important to recognize the importance of influence on ‘autonomous’ medical decision-making.⁸⁹⁴ Some patients and families directly indicate they are waiting for a miracle. Many ask for medical treatment to be heightened to encourage this miracle to come. Health professionals admit discomfort with the notion of miracles and try to insist upon traditional medical protocols. However, religion can be a vulnerability that will influence people to varying extents.⁸⁹⁵

However, it is difficult for a physician to know what is an autonomous, consensual decision and what decision is influenced by religion. It is essential to recognize the importance of influence on ‘autonomous’ medical decision-making.⁸⁹⁶ Religion could be classified incorrectly by health professionals as coercion or manipulation.⁸⁹⁷ Instead, religion must be viewed as a prism that will influence people to varying extents.⁸⁹⁸ For some patients, their autonomy is significantly impacted within the confines of a particular religious tradition, while others may see the relevant tenets as more variable. A religious patient’s reason for not consenting to a procedure is possibly not considered ‘rational’ or ‘reasonable’ by some physicians. When

religion is alluded to or miracles directly asked for, patients are considered to no longer be rational or reasonable. However, they are far from incompetent. Indeed, a religious patient should contextualize their (religious) rationale towards decision-making to their physician.⁸⁹⁹ This is significant. Instead of insisting or requesting specific treatment options, a patient or their surrogate decision maker should try to express why or what their religion demands of them. Yet, it is important to ensure the patient's religious decision is autonomous through *their own* interpretation of their religious tenants. For example, they should express why they desire for a miracle and how this may influence their confidence or hope in care. This is usually evident during end of life clinical consultations, as apparent in the studies discussed above. When end of life discussions occur, more conversations and contextualization of religious attitudes are expressed.⁹⁰⁰ Thus, academic literature supports the importance of engaging with spirituality and religion vis-à-vis a clergy to offer support. Clergy can help align the notion of miracles to the medical plan. Doing so dubs these clergy as 'religion-interpreter'⁹⁰¹ It is important to use the clergy as an interpret of religion and not a harbinger of miracles. There are anecdotes of rabbis being versed in miraculous cures or possess incredible knowledge that aids physicians in caring for a patient. This is commonplace as studies indicate that even non-affiliated patients reach out for clerical support during times of distress.⁹⁰² Some rabbis offer a clear distinction between caring for a patient's spiritual needs whereas a physician cares for physician ailments.⁹⁰³ These rabbis are careful to not intertwine the notion of miracles with medicine. Rather, focus on spirituality as a helpmate to traditional, medical interventions. This duality is currently witnessed in the relationship between spiritual care and ethics. Clinically, spiritual care and ethicists generally walk hand in hand. Although clergy assistance is a companion to mediating these

ethical discussions, it does not excuse an ethicist from being trained in some concepts of theology.

6 B: Children, religion and clinical consultations: the outliers

Children, as noted previously in this dissertation, offer more complexity to ethical consultations. This is further compounded when religion is applied to difficult conversations. Thus, children will be explored in this subsection, as a further example of the themes that are demonstrated in adult clinical ethics consultations. A professor once said that if you like ethics and are a physician, you should become a pediatrician.⁹⁰⁴ While this may be true, there are remarkably few formal ethical consults required in a pediatric hospital. This is perhaps due to the interdisciplinary nature of pediatric care in pediatric specific hospitals⁹⁰⁵ Thus, ethics is not stymied to end of life discussions or with ‘difficult’ patients. Rather, it is holistic and intrinsic to the hospital’s day to day. However, religion impacts children differently, which may not be fully understood even in ethically-driven hospitals. It is assumed that parents/guardians are always acting with the ‘best interests’ of the child in mind. However, that notion is one dimensional.⁹⁰⁶ Religious views on child consent, maturity and miracles may also color medical choices. Classification of a child as a mature minor may be in opposition to a religious view. If a child views religion differently from parents, this provides another ethical discourse.

The notions of child assent, consent and measurements of mature minors are important. Whereas most scholars note the importance of integrating a child into decision making, the definition of child assent is lacking. Assent does not connote full understanding of the issue and thus, cannot be considered full, informed consent. The definition of assent is vague enough to offer concealment for a child’s refusal. A child’s present requests may be denied for future or long-term goals.⁹⁰⁷ The American Academy of Pediatrics released a policy statement noting that

the facilitation of a consent discussion is directly influenced by a physician's experience.⁹⁰⁸ A physician or medical researcher can modify the discussion of the illness, risks and possible outcomes based on the patient's age or maturity.

A so-called 'mature' minor is one that is competent enough to make a medical decision so long as he fully comprehends all risk factors.⁹⁰⁹ This competency is defined as being able to "...understand and retain and use the information...and then make a decision..."⁹¹⁰ Thus, in order to be declared a mature minor, a young patient must demonstrate *both* capacity and competency. He would have to comprehend and internalize the medical options offered, and be judged to have the competency to utilize the information in the best way. It is up to the medical team (and sometimes the family,) to determine if the patient is able to make such a decision. Age is certainly a factor, however, pain, fatigue, medication and general anxiety are influences considered before allowing a child to render their own decision.⁹¹¹

Historically, ethical consults in pediatric environments are codified within patient policy surrounding palliative and end of life care. This is a strength. Serving fragile populations such as neonates creates definable procedures on issues that can be ethically challenging. Additionally, most pediatric hospitals integrate palliative care, which further reduces ethical dilemmas.⁹¹² If families are always aware of, and have a hand in, creating end of life plans, they may be more agreeable to physician advice. In fact, this may lower the amount of ethical consultations requested since all pediatric procedures are transparent to all families. Thus, ethics consultations are viewed as a 'last resort' attempt to mediate opposing parties and the cases are often complex. This is apparent in the structure of the bioethics program in pediatric environments. The overall culture of safety and transparency allows for an infusing of ethics into every program in the

hospital.⁹¹³ Pediatric ethicists can be available 24 hours a day and often overwhelmingly offer consultations regarding the end of life.⁹¹⁴

Unlike in adult hospitals, pediatricians and pediatric hospitals holistically value religion and spirituality and ask patients and families about it⁹¹⁵. Their reasoning is practical: how will your religious beliefs affect the care of your child?⁹¹⁶ Pediatricians are not trained in the importance of this information, much like clinical ethicists. This is evidenced via a study involving pediatric oncologists and general pediatricians at various USA based hospitals. These hospitals excelled in clinical care and research and were thus selected. Some of the included hospitals were: The Johns Hopkins Children's Center, UCLA Medical Center, Cleveland Clinic and Mayo Clinic. Most pediatric physicians surveyed for this aforementioned study experienced clashes between religion and medicine, whereas others in non-pediatric environments witnessed clashes only after working for several years.⁹¹⁷ Perhaps this is due to the vulnerable populations that these care providers work with. Pediatricians noted that the children themselves displayed strong notions of spirituality and even miracles, as did parents and families with very ill children. Pediatricians are not afraid to directly ask about religion and nuances in perspectives.

Despite ethics being infused into everyday pediatric hospital activities, there is still conflict that would require an ethics consultation. Most of these occur at the end of life. However, although religion and spirituality are recognized and spoken about, the data, certainly in surveys that address ethical consultations, is not unanimous throughout all the data on ethical consultations. While pediatric literature does indicate greater importance and integration of spirituality and religion in families and children, there seems to be a binary of understanding how much impact religion has on medical decision making. To wit, an interesting pattern within

the empirical data that analyzes ethical consultations: either religion is unequivocally a factor in decision making, or it is swept under more broad categories such as ‘family centered care’.

Plainly, there is no consensus on whether religion/spirituality should be considered part and parcel of ‘family centered care’ or whether it is a separate, but important entity in decision making. This is demonstrable through a study conducted by the Department of Bioethics at the Cleveland Clinic. It provides 300-400 adult/pediatric consultations per year. This study focuses on pediatric consultations (defined as patients under 18 years of age,) between January 2005 and July 2013. Most of the ethical consultations involved end of life discussions,⁹¹⁸ This data point alone can indicate the importance of family centered care. Indeed, the authors of the study noted that consults indicated the following themes: informed consent (specifically, parental permission;) pediatric assent/disagreement. The study then noted that a few consultations (four) concerned withdrawing life support against the families’ wishes and a professional’s obligation to treat a patient whose family physically resisted treatment and was considered abusive/threatening to the staff.⁹¹⁹ Now, these cases are isolated in the discussion portion of the article, yet, the *why* behind these four cases is not addressed. To that end, there can be an assumption of culture or religion (particularly in the withdrawal cases,) and perhaps, even in the abuse to staff consultation. Interestingly, the article includes a chart which isolates reasons for ethics consultation with percentages of how often those reasons are indicated.

Religion/spirituality is absent from this list. It may fall under “refusal of non-life threatening treatment” or even “miscommunication/misunderstanding,” or still yet, “non-compliance.”⁹²⁰ Again, as seen in previous studies, these may be ‘code words’ for religiously motivated ethics consultations. However, this sweeps the importance of religiously motivated decision making under larger themes that do not effectively indicate the *reason* of why an ethics consultation is

requested. Yet, there are ethical shades of grey when a parent utilizes religious values for requesting particular medical services. While a religious parent feels he is acting in moral and ‘best’ authority, a hospital may view otherwise. A religious parent may be influenced by his traditions understanding of the adult/child relationship.⁹²¹ As previously discussed, a parent may thus consider themselves religiously mandated to make a decision in the best interest of their child. In these cases, what is in the child’s ‘best interest’ may also be considered, by the parents, as *religiously motivated* best interests. The classic example of this would be a Jehovah’s Witness family who do not want a blood transfusion for their child; they refuse it due to the best interests of their child based on the teachings of their religious tradition. Thus, again, there is a clash of two moral agencies (secular and religious,) which must be mediated. Subsequently, this too may require an ethics consultation as there are many circumstances that can affect the decision being made: from the age of the child, to the desires of the parents, to the impact of such a decision. If religion and spirituality are not specifically recognized as the primary cause of the consultation, everyone involved may feel that the consultation is circulatory and difficult.

When discussing religion, special attention must be paid to the concept of miracles here. Academic literature supports the importance of engaging with spirituality and even speaking openly about miracles in a pediatric setting.⁹²² For some religious traditions, especially Catholicism, miracles are a foundation of belief, especially with children.⁹²³ Some pediatric patients find solace in religion and the constant belief that something miraculous could happen. Leaving the concept of miracles aside, the notion of ‘who makes a decision’ also complicates the ethical consultation within pediatric ethics.

Pediatric clinical ethics consults are additionally complicated by the notion of shared decision making. This may be coloured by the desirous wish for a child to survive and have a

future. Shared decision making is when a clinician and parents (ideally with the assent of a child,) decide medical interventions.⁹²⁴ Yet, these decisions are complex and layered. Some parents may push for a miracle via extensive medical interventions, since these interventions exist, they should be utilized to their fullest extent. They may also over-estimate the extent of the child's potential for a future or of their own ability to act as a caregiver. Moreover, clinicians are more likely to be emotionally impacted by the death of a pediatric patient.⁹²⁵ The pain of loss may also colour their clinical judgement and push for more interventions. Thus, a carefully understood notion of *moral* shared decision making needs to be implemented. Moral shared decision making (Moral SDM) must come to a moral compromise, whereby all parties (parents, clinician and ideally, children,) negotiate on values until a happy medium is found.

Collaboration, by definition, means that some moral ground must give way.⁹²⁶ Each party must relinquish certain values to come to a collaborative decision. This is difficult to do and to rationalize what moral compromises can be made individually and collaboratively. A collaborative decision is not always the best decision.⁹²⁷ There is also a sense of realism that impacts this conversation. Institutions like hospitals may not be able to relinquish certain moral grounds due to policies or legal requirements. Moral SDM may be made even more complicated by requiring parties to acquiesce religious moral ground. Just as in principlism, religious ethics also have value hierarchies. Indeed, while some religious ethics contain declarations that may supersede others (for example, the Jewish concept of *pikuach nefesh*,) it is not feasible to assume that all believers have a scholarly grasp of their religious tradition and know which values may override others. Believers may feel insulted if an outsider suggested that one religious morality may be compromised for the sake of another. Yet, if a clinical ethicist were fluent in the conceptual theology, this could be a worthwhile, productive conversation. Rather than a clinical

ethicist being considered as a complete outsider, speaking in the language of a religious tradition can narrow the bridge of communication. Thus, while Moral SDM is not a perfect tool for shared decision making, it can be used in conjunction with traditional consultation models.

6.B i. Assent and the limitations of ‘mature minor’ assessment tools within religion

Before providing a survey of Judaic and Catholic ethical considerations on children’s assent and consent, it is imperative to consider the secular ethical obligations. Two concepts, assent and evaluating a mature minor are ethical regulations that clinicians contend with. Whereas most scholars note the importance of integrating a child into decision making, the definition of assent is lacking. For some scholars, assent does not connote full understanding of the issue and thus, cannot be considered full, informed consent.⁹²⁸ The definition of assent is vague enough to offer concealment for a child’s refusal.⁹²⁹ Moreover, whereas obtaining parental consent is primary, assent may be viewed as secondary. A child’s present requests may be denied for future or long-term goals.⁹³⁰ Parents’ may curtail their child’s autonomous choices due to ‘best interest. However, dissent is not the moral opposite of assent. If a child dissents to treatment, his concerns cannot be taken lightly. A child’s desire to participate against parental objection is a further issue.⁹³¹ Indeed, balancing the desires of both parties is fraught. Hence, the nebulosity of terminology almost negates the importance of including children in the decision process. Assent allows the consent conversation to be approached based on the personal maturity level of each patient.

There is a further, troubling concept within discussing medical interventions or research with children. The concept of ‘mature minor’ is utilized in most North American hospitals.⁹³² A minor is anyone under the age of 16, according to most hospital policies. A ‘mature’ minor is one that is competent enough to make a medical decision fully comprehending all risk factors. This

competency is defined as being able to “...understand and retain and use the information...and then make a decision...”⁹³³ There is also an issue of capacity; which goes hand in hand with competence. Age is certainly a factor, however, pain, fatigue, medication and general anxiety are factors also considered before allowing a child to render their own decision.⁹³⁴ However, little literature exists explaining the age choice for maturity. While there are several methodologies to empirically evaluate maturity, there is no consensus. However, there are some advised methods to assist clinicians. Recommendations suggest acquiring translators, writing guides in lay-person language to enable access across the barriers of language, socio-economic status and culture.⁹³⁵ The child should be spoken to in an age and developmentally appropriate method, so that he/she comprehends all risks and benefits.⁹³⁶ They should be encouraged to sign their own form, acknowledging they wish to be included in a research study or procedure.⁹³⁷ Some younger children are encouraged to draw their assent. If there is a language barrier, translators should be brought in and all factors of risks and benefits should be explored. Regardless of language barrier, the information should be given both through written lay-language and orally to both parent and child.⁹³⁸

Assent allows for flexibility. It cannot be used interchangeably with the notion of consent. Indeed, the vague nature of the term allows it to be adaptable. Children’s assent for medical intervention allows for both child empowerment, physician/researcher assessment and legal safeguards. There is research that indicates children with prolonged illnesses (such as cancer or organ diseases) exhibit a higher level of medical understanding and maturity than their similarly aged peers.⁹³⁹ These children may be considered more ‘capable’ due to the time they have spent directly living with their illnesses. However, pain and illness can shift understanding and the consent process. It can tangle with the concepts of capacity and competency. Before

assessing the various tools utilized to measure whether a minor is mature, it is imperative to consider the effect long term illness has on a patient's ability to consent.

As discussed in further detail in chapter 4 of this dissertation, there is a lot of research that indicates that children who have terminal or chronic illness are capable beyond their years. There is research that indicates children with prolonged illnesses (such as cancer or organ diseases) exhibit a higher level of medical understanding and maturity than their peers.⁹⁴⁰ These children may be considered more 'capable' due to the time they have spent directly living with their illnesses. However, pain and illness can shift understanding and the consent process. It can tangle with the concepts of capacity and competency. Indeed, the most important framework for autonomous decision-making and consent is context. As patient context shifts, the patient's autonomous ideals do as well. Patients who are riddled with chronic pain also have their autonomous consent compromised.⁹⁴¹ When a patient is presented with the ability to be pain-free, their overall competency may be unreliable⁹⁴². The intention of a chronic pain patient is simple: they wish to be pain free. While uncontrollable pain can cause incapacity for decision-making, patients with pain are generally competent.⁹⁴³ Children with intense pain may make intentional decisions towards ceasing their pain. True autonomous choices then, are difficult to dissect from a child in pain. The power of pain, and the promise of being pain free, is enough to motivate a patient to decide devoid of true understanding. Physicians must carefully modify their discussions surrounding informed consent to ensure that there is a balance between true autonomy and the influence of pain if they wish a child to participate fully in their decision to pursue palliative care.

Adding further complexity is when a physician wishes to keep the religious values of a patient within the realm of 'do no harm.' The best illustration of wishing to protect a child's

religious community is female circumcision (also referred to as female genital mutilation or FGM.) Women who are not ritually circumcised experience social ostracization from their community. They cannot be married to fellow community members and she risks being cast out from her nuclear family.⁹⁴⁴ Thus, a compromise is struck between her religious quality of life and social welfare and her physical safety: .some physicians make a small incision on the vagina as a compromise, because some who are denied the procedure by a physician end up going to a religious leader for it, often suffering further harm due to infections and lack of sterile environment.⁹⁴⁵ While some physicians may balk even at this notion, as a patient undergoes a procedure that is not warranted and has no medical benefits. However, some physicians note that it is imperative to protect the integrity of the religious obligation and the community that it offers, although these are difficult to assess outside of the religious community. Further, these physicians argue, this type of surgery protects the child. When they are grown, they may autonomously chose to have the entire ritual circumcision procedure.⁹⁴⁶ This is the perfect example of an adaptive ‘sliding scale’ analogy that shall be addressed further in the chapter. This nuance in approaching both religious and secular ethics demonstrates the potential clout of a theological background for ethicists. By balancing the essential principles of female circumcision procedures (to fit within their chosen religious community,) with the principle of non-maleficence, a creative bridge is formed. Incidentally, if this patient grows and leaves the religious community, she is not mutilated as she would be traditionally. She would be left with what has been described as a superficial cut, allowing her to lead a fully autonomous future.⁹⁴⁷ The prospective future is always a factor in pediatric care. Perhaps this is a further reason to infuse ethics into decision making.

The Fraser guidelines are exclusively for situations involving minors and contraception access. Currently, the legal age of consent varies from 12 to 19, depending on country.⁹⁴⁸ Even within the United States of America, there is significant deviation from state to state. Few formalized tools exist to empirically determine the maturity of a minor. Various hospitals and research centers have developed their own frameworks. The Alberta Health Services (AHS) in Alberta, Canada has delineated themes that are apparent across all the measuring frameworks. AHS demarcate six factors towards determining maturity: age, intelligence, maturity, serious health care decision, informed consent and freedom from parents/or married/ or has children.⁹⁴⁹ The more serious a medical invention, the older the child must be. Additionally, intelligence is defined as the ability to understand the risks, benefits, alternatives and consequences of treatment or forgoing treatment.⁹⁵⁰ This framework exists for both medical treatments and research. Clinical trials, especially for terminal illnesses are serious interventions and heavy with risk. Since it stands outside of normative medical care, it is up to the researcher to decide if enrollment in a study is beneficial. Naturally, should the child or the mature minor object to the trial, it should not and cannot proceed.

Nonetheless, there is a presumption that if parents volunteer children to participate in research they are doing so due to the ‘best interest’ philosophy. This is complicated. Ethically, there may be a ‘sliding scale’ of perception that can be applied to research and risk. The promise of hope and better treatment may influence decisions as well. Tired and hopeful parents may see the offer of a clinical trial as something to cling to if only to maximize time with their child.

Although all parents want what is in the best interest of their child, participation in research trials may be unduly swayed. Some families feel that participation may garner them preferred or better treatment. Many parents may wish to provide their children with access to services and

medicine they normally could not afford.⁹⁵¹ Parents with terminally ill children admit a sense of defeat; they do not wish to refuse a clinical trial since it may allow more time with their child.⁹⁵² Ill children are more likely to volunteer for research studies and trials. Parents of ill children view risk more optimistically, even if there is no proven therapeutic effect. Conversely, healthy children are likely to enroll in research for altruistic purposes. Ill children perceive ‘helping others’ as a mere by-product of their participation.⁹⁵³

Knowing this, there is a distinct concern for autonomous decision making. Indeed, decisions must be made voluntarily, devoid of undue influence. Ethically, the decision making factors mentioned are troubling. Risk, even viewed from rose-coloured glasses is still risk. Moreover, the suffering and quality of life of a terminally ill child must be assessed within decision making. Optimistically viewed risk may be more troubling. Optimism may cloud judgement. Parents may be unduly swayed by a concept empirically difficult to study: hope. Parents fear making the wrong medical decision on their child’s behalf.⁹⁵⁴ It is assumed researchers provide accurate information regarding the study and its possible outcomes. Perhaps clinical discussions must change based on the individual circumstances of the family. Parents bear the burden of the research as well. They must travel and be absent from work. Some felt that enrolling in a study would garner more ‘face time’ with a medical team. Whether these are true and accurate representations is not the point. This impression—accurate or not—must be rectified. A medical team or research team must carefully remove notions that may sway patients and families to create a decision. Only then can best interest of the child be considered a true autonomous decision made by parents. It should be approached utilizing consent from parents and child assent—or cooperation.

6.B. ii. Catholic and Jewish approaches to child assent, maturity, & miracles

When dealing with children, religion can often deviate from modern ethical standards. For instance, Christianity holds the nuclear family at its center. The Roman Catholic Church encourages children to act with respect and obedience towards their parents.⁹⁵⁵ Whereas secular ethics honours the individual, Catholic ethics honours the family unit.⁹⁵⁶ Moreover, parents have a moral authority to pass onto their children. The desire to assist others may lead some Catholic families to participate in medical research, even if the research is not directly beneficial to the child.⁹⁵⁷ Catholicism then, can serve as a help-mate to medical research. Catholic believers also subscribe to faith-based miracles. This trait may cause them to participate more in medical research and clinical trials.

The Church proscribes responsibilities that every Catholic parent owes their child. Parents are obligated to keep their child well both physically and spiritually. Difficult decisions are made based on paternal authority.⁹⁵⁸ This paternal parental authority is mirrored directly on the authority of Jesus Christ. This authority is Divine. According to the Vatican and other scholars, wife and child must submit to the husband/father in difficult decision making.⁹⁵⁹ Indeed, the human value of a child, and his suffering, is tantamount in Christianity.⁹⁶⁰

Whereas palliative pain is a difficult subject in Catholicism, pediatric pain is treated differently. Pain for some Catholics mirrors the pain suffered by Christ, however, some scholars believe that God does not intend His believers to suffer too. Pain, especially for younger children, is unbearable. Nonetheless, the Catholic view holds that aggressive treatment should only be pursued as a last resort.⁹⁶¹ Some parents may be making medical decisions based on a fervent belief in miracles. Miracles play a large role in Catholic healthcare philosophy. Catholics do heavily believe in healing, compassion and hope.⁹⁶² Some pediatric patients find solace in

religion and the constant belief that something miraculous could happen. It then becomes a question of whether participation in a clinical trial would merit as miraculous or be considered extraordinary care. Logically, then, perhaps an attempt at a clinical trial would be supported by Catholic patients. If it proved to be arduous to the child or contributed to further suffering, participation could cease.

Judaism is nuanced in their approach towards children, minors and decision making. Much like Catholicism, Judaism relies on a nuclear, heteronormative family unit. In Judaism, a father is legally the head of the household. A father has legal obligation to care for children financially until they are married.⁹⁶³ While ancient Jewish law does not have precedents for consent for medical research or intervention, two codes of law can create an ancient template for a modern problem.

In Jewish law, a minor cannot appoint a proxy decision maker because they have no legal status. In Biblical times, a father could give his daughter's hand in marriage without her consent.⁹⁶⁴ Later Rabbinic sources altered this arrangement, requiring consent for the marriage to take place. In the Talmud, there are laws that discuss what happens if a minor is physically injured by another. If so, damages must be paid to the father.⁹⁶⁵ Legally, (according to the Talmud,) daughters can become emancipated from fathers when they reach the age of majority which is 12. At this age, she traditionally is demonstrating some signs of puberty.⁹⁶⁶ She is also emancipated when her father dies. Although less is explicitly written about the minor male, he comes into the age of majority at 13. Similarly, once mature, the male can accept his own financial damages and enter into vows.⁹⁶⁷ It is not a logical stretch to assume that Jewish families would allow the father or mother to assume decision making capabilities. Once a child reaches the legal age of majority, some parents may take that into consideration. Importantly, the age of

majority exists for *legal* matters: financial damages, making vows, marriage, divorce, buying and selling. Most Jewish families would consider healthcare decision making to be done either as a family or under parental authority. It would vary from family to family how much autonomy they would allow their child. While 12/13 is the age of majority, it is doubtful if a secular hospital would assume this age to be an age of maturity without individual assessment. A more pressing concern for decision making rests on the foundational Jewish principle of saving a life and whether and how this principle can be integrated into medical research or clinical trials.

Similar to Catholic views, there is an absence of literature surrounding Jewish approaches to clinical trials, medical research and interventions. However, Judaic views towards children and their autonomy is abundantly clear. Like Catholicism, there is patriarchal domination in decision making. Importantly, the age of majority exists for *legal* matters: financial damages, making vows, marriage, divorce, buying and selling. Most Jewish families would consider healthcare decision making to be done either as a family or under parental authority. It would vary from family to family how much autonomy they would allow their child. There is a further principle in Judaism that prohibits putting one's life at risk. Arguably, much risk is involved with clinical trials. The prohibition against risk-taking is normally reserved for people who are well. Children who are candidates for clinical trials may no longer have to be averse to risk. It is "almost forbidden" by the rabbis to undertake risky treatment to manage pain.⁹⁶⁸ The words 'almost forbidden' are purposeful. Rabbinical authorities would never fully prohibit a procedure or clinical trial since pain and suffering is a fearful and important concept. This is illustrated through an anecdote and ruling cited of the pre-eminent *Halakhic* scholar Rabbi Moshe Isserles. According to him, a son is permitted to amputate his own father's arm (in absence of professional assistance,) since his father is in pain.⁹⁶⁹ In this ruling, Isserles emphasizes the fear

of pain as the crux of his ruling; not the possibility of death from amputation.⁹⁷⁰ To wit, many patients eventually reach a point when they simply want the pain to cease, regardless of intervention risk.⁹⁷¹ However, there are conflicting values in *Halakha* within risk-taking. A Deuteronomic commandment extols being “watchful” over human lives. This is largely understood to be a general prohibition against risk-taking.⁹⁷² Yet again, this value is put aside in favour of a greater hierarchical value of *pikuach nefesh*. Judaism holds that pain itself shortens a life.⁹⁷³ A physician must strive towards pain palliation above all else, since fear of pain is itself a barrier to health. Thus, Jewish families would almost always lean towards choosing clinical trial participation.

6.B. iii. Applying Undue Hardship: children’s voluntary participation in clinical research and religious accommodation

Trials are a great ‘carrot’. Often, the trial is exciting and may offer new treatment options. However, persuasion (by a physician or researcher,) is a powerful driver that can impede autonomous consent. For example, participants in the Tuskegee syphilis study had access to transportation and insurance. Further, they had free medication and hot meals. These persuasive ‘perks’ caused participants to enroll in the clinical trial.⁹⁷⁴ Similarly, the promise of a procedure removing pain or curing an illness, can be incredibly persuasive as well. So too can the controlling aspect of continuous pain on a patient. Executional autonomy—the ability to physical do and move as one wishes—may be compromised by pain.⁹⁷⁵ It is readily apparent that ‘best interests’ may be a tug-of-war of ethical values. Medical researchers and clinicians assume best interest to be most beneficial to the child. This would incorporate a child’s assent or autonomous choices. Religion may favour the interests of belief and may sometimes reject the secular notions of child autonomy. This is the crux of the clash: two codes of ethics each present with various

ideals of what is in a child's best interest. There has been public conversation surrounding this clash. Court cases involving Jehovah's Witness or Christian Science children prove that when medically necessary, the state will flank with physicians to provide care.⁹⁷⁶ Those are extreme examples; and the medical interventions required were a matter of life and death. Medical research however is completely voluntary. An interesting theme develops. The concept of 'best interest' appears to change. Families with ill children perceive risk differently from families with healthy children.⁹⁷⁷

To wit, limitations on religious accommodations may be justified over concerns of best medical care. Legally, the term of 'undue hardship' is utilized in religious accommodation decisions.⁹⁷⁸ The limits of undue hardship may be set by various parameters including geography, finances, executive or medical opinion and underlying pathology. Nonetheless, the difficulty in demonstrating a hospital has suffered undue hardship creates complex ethical cases.⁹⁷⁹ Adding another layer of complexity, as registered often in this dissertation, is the reality of ethical undue hardship. This is interesting to explore within clinical trials since medical research is voluntary.

A secular understanding of undue hardship in medicine and accommodation varies from the religious understanding of the term. While a religious father feels he is acting in moral and 'best' authority, a hospital may view otherwise. Patients and providers' moral agency conflicts may in fact jeopardize best medical practice. Although the onus of 'undue hardship' is pressed upon the institution, ethics and law should come together to suggest that there can be limits to religious accommodation. This is easier to maintain since medical research is voluntary. Since it stands outside of normative medical care, a hospital and staff cannot be disciplined for failure to accommodate religion. It is also important to determine the genuine religious beliefs of the child,

if a researcher suspects religion is playing a large role in decision making. Some children do freely believe in their parents' religion, although it may not yet be settled belief.⁹⁸⁰ If so, it is up to the researcher to decide if enrollment in a study is beneficial to the child's overall wellbeing, or if the child is trying to follow his/her religious beliefs. Crucially, there is more flexibility due to the voluntary nature of studies. The notion of hardship then would be pressed onto the child who is enrolled against his assent at the instance of his parents. While this is not uniquely a religious problem, the additional deciding factor of religious decision making enables its discussion here. .

Whether and how religious accommodations can be enveloped into patient safety is the crux of the issue. There are significant ethical concerns when a patient lacks choice and is exposed to needless risk. It is essential to disentangle whether a parent is enrolling a child in a study based on religious principles. Religious accommodation cannot be provided for voluntary things and as such, religion should not unduly influence the voluntariness of a patient or family. As such, to participate in medical research, religious individuals must remove their 'veil of belief.' Within a healthcare system, they are being provided public goods. The burden of undue hardship cannot be placed on the healthcare institution. Whether and how to place the burden of undue hardship can be best illustrated in clinical consultations.

6 B iii Finding the balance and applying the new theory : balancing religion and medicine within a clinical consultation

As this dissertation has demonstrated, religion is often the driving force of a medical decision. Thus, a new framework is required for understanding religiously motivated requests and placing possible limitations upon them in healthcare institutions. This dissertation suggests a rather novel approach. Clinical ethicists should be educated in theological foundations and

skilled at using the language of religion. Doing so creates a 'shared language' and decreases the power-inequality that may be prevalent. The notion of 'us' versus 'them' is apparent throughout the literature; showing comfort with the language of believers blurs the lines of power dynamics.

The traditional sliding scale theory balances level of risk with the level of ability required for competent decision making⁹⁸¹. As previously discussed, a religious patient also takes into account the tenants of their religion during medical decision making. The standards for welfare and quality of life are also colored via religion; rather than sole emphasis placed on good medical outcomes.⁹⁸² While Beauchamp and Childress' scale imagery connotes a balancing of autonomy and protection, a religious patient's scale demands a third arm. Thus, creating a truer sliding scale; one that also encapsulates religion.

Ethics programs should delve into topics such as genetics, end of life, surrogate decision making and offer foundational understand of important philosophies and theories including religion. . Outside of a university with a religion mission, theology is an afterthought and not expressively taught. Contrast this to the aforementioned history of ethics, whereby most ethicists were first theologians. Secularism, and whether and how there is a true secular discourse is part of this discussion, yet tangential to this issue and shall not be further explored in this dissertation. However, the more novel question considered shall be whether theological training enhances bioethics. Further, how should ethicists *think* about religion? ⁹⁸³

It would be foolhardy to expect ethicists to become expert theologians. Theology is also not a science, which is the failure of religious assessment tools; religious values cannot be neatly entered into an algorithm. Modern religious followers attempt to understand secular culture from their religious lens. Religion is anthropologically and sociologically impactful. Religion can be malleable, as witnessed by various *Directives* or by Jewish bioethics *responsa* literature. Indeed,

chapters 4 and 5 of this dissertation have demonstrated that flexibility within religious Law is possible and applicable. Yet, this does not mean that certain religious standards are removed entirely. Rather, it allows for the acceptance of modernity that aligns with religious ethics. For example, Judaism places great value on reproduction. While the advent of reproductive technologies has allowed many Jewish families to fulfill this obligation, it is not permitted as is. Instead, reproductive technologies have been modified to adhere to Judaic values and objections regarding sex and intimacy. Yet, this too evolves with the social situation or sect of Jewish patients. While cultural competency experts may be loosely trained with stereotypical lists of religious beliefs, the true understanding of a “lived religion” is far more nuanced.⁹⁸⁴ This creates far more of a challenge for bioethicists.

Using the language of Rawls, religion should be understood and routinized in hospitals. However, while teaching religion is difficult; teaching the language of religion is more difficult. The literature is silent on how to teach religion to ethicists, or whether specific training (i.e. Fellowships, where religious patients and approaches may be encountered,) are required. Although there is a push towards secularism, it is clear that religion still holds an outsized impact on medical decision making. Consequently, this chapter and the suggested framework will attempt to utilize the aforementioned resources to create a roadmap towards integrating religious education into an ethicist’s ‘toolkit.’ It is important to note that this framework currently is modeled to only serve Catholic and Jewish religious traditions. It may also apply to Islam as well, since in that belief as well, dogma and right belief is essential.

While basic religion and culture can and should be taught in bioethics programs, ethicists should keep the notion that religion is socially lived and experienced. Using the concept of a religious veil assists with this premise. Religious patients don a veil of belief from which they

make many of their medical decisions, especially those that occur at the beginning and the end of life.. If an ethicist adopted this veil and the language of religion, it may help to fully identify the religious values that are integral to a patient. By speaking in the ethical language of a religious tradition, concerns may be clarified and the contradictions between medicine and religion temporarily bridged. To speak in the language of a religion, an ethicist must be proficient in the *principles* of that tradition.

The bioethical principles of autonomy, beneficence, non-maleficence and justice can shift in importance based on the particulars of a case. They may also move to greater or lesser significance on the hierarchal ladder based on the personal ethics of a physician or patient. Different circumstances may result in individual principles being promoted in the hierarchy.⁹⁸⁵ This hierarchy exists within religious ethics as well. Some religions have principles that permit modification when certain actions or behaviors are normalized in greater society. For example, when reproductive technology became more readily available, Jewish ethicists and scholars formulated new aspects of *halakha* enabling Jewish patients to partake of the innovation. This allows for progress in religious ethics as medicine evolves.⁹⁸⁶ As this dissertation has demonstrated, accommodation and limitations is a dual approach: just as medicine must accommodate and understand religion, religions must also accommodate secular progress. While some religious people will absolutely disagree with this approach, it has been already proven to be successful. As witnessed vis a vis the NHS initiative to Hasidic mental health, and with the Catholic School Board allowing the HPV vaccination, when public health advocates appeal to the leaders of the religious tradition, some bridges can be built. Whether they admit it or not, ethicists and clinicians all juggle moral principles before rendering a decision. This is weighing and balancing of the ethical principles, however, this is demonstrated very differently

in clinicians and religious patients. This mode of decision making is fundamentally different from believers who use religious principles. Clinicians consider complex contextual information to base their ethical decision.⁹⁸⁷ In contrast, believers utilize their religious identities, almost solely, to base their ethical decision. For example, while a clinician may advise to stop life support for a brain-dead patient, a religious decision maker does not perceive the contextual information surrounding the medical decision. Rather, a more religious patient may simply hear that life support is being removed, which lays counter to a religious principle of preserving life, particularly in the case of Jewish patients. This is why it is so important for a clinical ethicist to speak in the language of religion. This means an ethicist must speak with an understanding of the religious principles that are impacted in medical decision making. The hierarchy of religious principles may shift depending on the specific situation. The hierarchy may then be negotiated utilizing Moral SDM techniques.

Now, the ethicist can apply the adapted sliding scale imagery to discuss religious principles with a patient. As previously indicated, the sliding scale imagery connotes a balancing of autonomy and protection.⁹⁸⁸ Yet, this adaptive imagery requires a religious third arm. This does several things. At first blush, this demonstrates understanding and facility with foundational religious values. It also allows a patient to showcase their personal perspective on their religious practice by protecting those moral grounds. It would be incorrect to judge religiously based consent or non-consent as incompetent. The definition of incompetence requires a person being unable to express themselves, understand the situation and unable to give a reason for their decision alongside other criteria. A religious patient's reason for not consenting to a procedure is possibly not considered 'rational' or 'reasonable' by some physicians. However, they are far from incompetent. A believer needs to state which religious principles are

integral to them. This can be done alongside the ethicist using the Moral SDM. This would echo a patient's own interpretation of their religious tenants and subsequently, force them to 'rank' the importance of certain principles. Then, the ethicist and patient can work together towards a shared compromise. Used together, a sliding scale and Moral SDM model could potentially be a far more nuanced way of understanding religious principles within clinical consults.

Additionally, when an ethicist speaks in a way that is sensitive to religion, or uses religious language, it creates a bridge across a communication chasm and dissolves some of the power dynamic that currently exists. Rather than religion and medicine clashing within hospital corridors, they can live alongside each other. Moral shared decision making (Moral SDM) means that a moral compromise is created. All parties (patients/families and clinicians) negotiate on principles until a solution that is mutually agreeable is found. Collaboration, by definition, means that some moral ground must give way.⁹⁸⁹ Assuming that an ethicist is fluent in the principles of religions, they can assist patients in determining which values may have flexibility within a religion. Further, they can help clinicians understand which values are simply non-negotiable to believers.

A theory is worthless if it is not applied to real clinical situations. Thus, the next few paragraphs shall demonstrate applying the layers of the theory to a commonly found situation. This scenario has been gleaned from the literature and chosen for its frequency of occurrence. For this case study, Catholicism has been chosen. Judaism subsequently follows. This further reinforces the notion that this model currently assists in ethical consultations involving Catholic and Jewish families.

An older (aged 75) man is admitted to a hospital with end-stage dementia. His son (Paul) is aware that comfort measures have been discussed. His father has been refused by several

hospitals since he has several illnesses and injuries (including sepsis, respiratory issues and heart concerns.) His son wants full code procedures. Paul also believes that God has spoken to him and is urging treatment his ailing father. He has been fasting and praying for his father's miraculous recovery. The father's own pastor has said that before his illness, he expressed he did not wish this type of treatment—he preferred palliative care. The medical team are reluctant to follow through with a full code and the patient's conditions continue to worsen.⁹⁹⁰ There are several 'values' that must be juggled in this case study. First, the older man's dignity is a value. He is clearly suffering from his medical ailments and is rendered incapable of making a decision due to his dementia. The son's religious values are also important—and integral—this this discussion. The institution's policies on futile care, and the medical teams' moral distress are important values. It is clear that Paul cannot fathom the reluctance of the hospital team since he is armed with the voice of God. Speaking with him about futility would be useless.

Applying the model suggested in this chapter may provide a foundation for an apt discussion for the son and medical providers. A religiously fluent ethicist can tease out that Paul is relying perhaps on two religious principles: miracles and demonstrating faith to God. A fluent ethicist must balance these values with the contrasting realities of his father's situation. Further, the son may not be able to understand why the physicians are lacking the same religious fervor. First, using the language of his religious beliefs, an ethicist may talk to the son about the notion of miracles. He may suggest that God often helps those who help themselves; clearly he has helped his father this much and he must be allowed to go to Heaven and enjoy his heavenly rewards. Or, the ethicist may suggest that while the son is demonstrating faith by fasting and praying, he must believe ultimately in God's plan. If God wanted to save his father via a miracle, it may have already happened. Perhaps it would be best to allow his father to pass comfortably.

This thought-process does a few things simultaneously. Using the modified sliding scale theory, the ethicist is not reproaching the son for his beliefs. Rather, he is noting and even celebrating them. He also used the language of religion to speak directly to the son. A moral SDM is implicit here. Indeed, the ethicist presented two scenarios which align with a religious teaching and with the recommendations of a clinical team. If Paul agrees to let his father go to Heaven, this would also align with the true expression of surrogate decision making. An ethicist cannot override the known requests of a competent patient, which is a principle in secular medical ethics. Indeed, the father directly indicated his wishes when he was still capable of making decisions. However, if the son suggests that he wishes to pursue aggressive treatment, an ethicist could use the principle of honouring one's father against the principle of miracles. To wit, Paul would best serve his father on Earth by honoring his requests to die peacefully. This is a more nuanced, even gentle way of allying religious requests with standards of best medical care. The strongest asset here is the clinician being fluent in the language of religion and religious principles of the believer.

Imagine this case the same, only assume the father and son to be Orthodox Jews. A pastor would be replaced by a rabbi. This would require more nuance in the theory, however it is still applied in the same fashion. An ethicist would commence with stating that medical interventions like antibiotics have been started, but life support/ventilation has not. This is important since according to Jewish law, once an intervention is started it may not be easily stopped. It is also important that a rabbi has 'permitted' the notion of comfort measures only by speaking to his father. Indeed, in complex medical issues, many Jewish believers would seek out a *posek* who can advise on Jewish medical ethics. If the son uses the principle of *pikuach nefesh* or saving a life, an ethicist may gently push back using the principle of both the rabbi's authority and the principle against prolonging suffering. This may require a little time spent on getting towards a

collaborative decision, based on moral SDM. However, the theory still holds, so long as an ethicist is fluent in the language of religious tradition and focuses on the principles/values of religion.

There are various articles, data sets and surveys that all converge on the same information. Indeed, religion and spirituality is integral to clinical care. Yet, there is a general aversion or even frustration towards ‘religious’ patients. It is obvious that further scholarly research is required. Certainly, removing the concept of religion from hospitals projects a false neutrality. Undeniably, while Rawls and governments wish we live in a society that has shared, universal values, the reality is we do not. The future of this research will be helped significantly by acknowledging the obvious impact religious thinking has on medical decision making. Centering the importance of religion must come from within bioethics. Balancing all aspects of ethics and assigning weight to religiosity may be achieved utilizing a modified ‘sliding scale’ framework. This concept, coupled with Moral Shared Decision Making (Moral SDM) will allow for the nuances of religion to fully integrate into clinical ethics consultations. It certainly cannot come soon enough.

This dissertation further promised to make a new, ethical definition for undue hardship as it concerns religion in healthcare institutions. Where and how is undue hardship defined within an ethical framework, and how can it be applied within a clinical consultation? Below is a chart that indicates helpful questions for limiting the scope of religious accommodations within a secular healthcare institution. Discussion and application of that chart follows suit.

Accommodating Religious Ethics in a Secular Healthcare Institution Framework

In order to accommodate a religious request, evaluate it against these four suggested parameters, inspired in part by the UNESCO Code of Human Rights:

<p>1) Does the request go against ‘best medical practice’ or standard of care?</p> <p>a. If it does, is there a way to modify the religious request to fit the standard?</p>	<p>2) Can you utilize the language of religion to explain the medical decisions that must be made?</p> <p>a. See a clergy member or ethicist for guidance —see chapter 4, 5, 6 for nuances and instances</p>
<p>3) Is the request a danger/pose a safety risk to the patient, other patients, staff, etc.?</p> <p>a. If so, can the request be modified? Is it a medical request or another type of request (i.e. Shabbat candles for Jewish patients)</p>	<p>4) Is this request in keeping with the ordinances of religious tradition?</p> <p>a. An religious tradition is defined as a tradition that is organized and recognized and/or has laws, ordinances, doctrines or texts . These can be written or orally dispensed to believers. Again, this definition applies to Catholic and Jewish belief systems.</p>

Defining Undue Hardship and Creating the Limits of Accommodation: Withholding, Demanding or Refusing Care:

RELIGIOUS PATIENTS

- Does the patient’s demand for care be outside best medical practice?
- Does the patient’s refusal of care fall under standard of care?
- Does the patient’s request to withhold treatment fall under standard of care?

RURAL RELIGIOUS HEALTHCARE INSTITUTIONS

- Does the medical intervention fall under best medical practice?
- Can the medical intervention fall under the jurisdiction of moral cooperation?
- Would refusing or limiting the medical intervention go against the standard of care?

- Is there an equipped, non-religious institution to transfer the patient to without jeopardizing their health further? If not, the religious institution may be compelled to perform the intervention.

This chart and subsequent questions was inspired by the simplicity of ‘four questions/considerations’ promoted by several books and ethical literature.⁹⁹¹ When it comes to this dissertation’s ethical definition of undue hardship, it focuses primarily on understanding, accessibility and safety. That is, do the clinicians and the patient/family *understand* each other? As discussed, medicine and religion often clash due to using two different codes of ethics and its related languages. Additionally, is the accommodation *accessible*? This can mean accessibility via the religion itself (as discussed in chapters 4 & 5 whereby religion offers leniencies to accommodate e.g. mental health etc.) or accessibility in the traditional method of not requiring anything over and above what can be permitted within a hospital. Finally, this framework considered safety. Patient safety (discussed in chapter 2,) is paramount when it comes to accommodation. Safety can be understood as whether an intervention will be safe for a patient or not, or ,whether *not* proceeding with an intervention will be safe or not. It will also consider whether the request is safe for the clinical staff and/or other patients. Although this is something not considered completely in this dissertation, it is essential to consider. Each question does not stand alone, rather, they serve to work together. Each accommodation request must be analyzed through each of the four questions before being accepted or rejected.

The first question concerns the definition of best medical practice or standard of care. Many religious requests ask the clinical staff to go over and above the standard of care , as is often the case at the end of life. According to standard offered by this dissertation, a hospital is

under no ethical obligation to consider these requests. However, to mediate this decision, it is important to consider whether the religious request can be modified to meet the standard of care. This further creates counterbalance. That is, if a religious request *can* be modified and accommodated, it is doable. It adds an additional layer of respect for the religious tradition and demonstrates that religion does indeed have an onus to accommodate when it is able to. If not, the Hospital has attempted to mitigate the conflict and is able to reject the request. An important consideration is certainly ‘standard of care’ and how this is defined in medical institutions. As Ruth Macklin writes, the standard of care evolves as medicine progresses. She illustrates this by surveying the new protocols of HIV care in third world countries. Indeed, as she conjectures, the art of medicine rests on that very adaptive ability.⁹⁹² As medicine progresses, standards change as this dissertation has reflected, particularly illustrative through the discussions of mental health and germline editing. A cursory academic database search incurs over 2.5 million results discussing various innovations within standards of care between 2005-2019 alone. It is beyond the scope of this dissertation to delve wholly into this sea, however how to define the notion of standard of care is certainly an endeavor worth pursuing. Thus, ‘standard of care’ for the purposes of the application of this framework, is very dependent on vague legal definitions and then, further outlined by individual healthcare institutions. The current, American legal definition for standard of care is thus: “That which a minimally competent physician in the same field would do under similar circumstances”⁹⁹³ Each state and sub-clinical specialty has further parameters of standards that must be adhered to, on top of the official definition offered by the US Supreme Court.⁹⁹⁴ In Canada, a similar trope is followed. Indeed, “...standard of care to determine negligence is not one of perfection but rather the standard of care that might reasonably have been applied by a colleague in similar circumstances.”⁹⁹⁵ The ethical undue

hardship framework then, depends upon this definition of standard of care. Certainly, as medicine progresses, the standard of care progresses and thus, the framework can and should also remain flexible in that regard.

The second component demonstrates how accommodations should be either rejected or accepted in a way that a religious patient/family can understand. This dissertation has already delved into why it is important to use the language of religion. Clergy/chaplains can be excellent helpmates in this task and should absolutely be consulted, alongside clinical ethicists.

The third parameter is about safety. Refusing abortions in certain medical situations is medically unsafe. Prolonging life sustaining treatment in brain dead patients is also medically unnecessary. Thus, the safety of the request is tantamount for it to be considered. Another aspect of safety is whether it would be safe and reasonable for the Hospital staff to accommodate such a request. For example, if a patient requests a doctor of the same gender, but she/he is already occupied or not proficient in that clinical area, the request can be denied. Safety also extends to other patients—an example of this would be fire in patient rooms which is a common request for certain religious ceremonies involving candles and/or smoke.

The fourth parameter is not without controversy. Religion and culture is a changing thing and there are numerous religions and sub-cultures therein. However, for the purposes of this ethical framework, it serves Catholic and Jewish approaches to faith. This framework does understand that not all traditions have codified law, as the Abrahamic faiths do. This current model serves a distinct purpose: to help mitigate cases brought forth by Catholic or Jewish families, while it may help some Muslim families too as these religious traditions share a sense of ‘right belief’ that is not necessarily present in other religious approaches.

The final part of the ethical undue hardship framework outlines questions that can be asked of patients (individuals,) or hospitals (institutions,) themselves to determine the limits of accommodations. They attempt to reinforce the four parameters in the chart, as well as offering very topical questions for religious hospitals. Turning to this latter consideration, this dissertation is truly limiting the scope of religious authority in *rural* Catholic hospitals. This is an important (and not uncontentious!) decision. As previously mentioned, often, Catholic hospitals are the only available healthcare for certain rural communities. Further, Catholic hospitals are extremely ubiquitous, with over 600 hospitals. However, Catholic hospitals and healthcare systems are increasingly merging with non-religious Hospitals due to economic turbulence. This further complicates the issue of conscience clauses, particularly since ERD 70 and 45 insist that all material cooperation be avoided, even with a non-religious partnered hospital. One researcher has conducted an empirical study which explores whether direct female sterilization has occurred in Catholic hospitals in several different states, which would be in direct conflict with the *Ethical and Religious Objectives*. In total 176 institutions were surveyed. Ultimately, the research indicates a large percentage of patients have indeed been sterilized (72.1% of all patients who received a diagnosis requiring direct sterilization) within Catholic hospitals, in direct contrast of the *Directives*. This is called “diversity of practice” which is mirrored across large, partnered, Catholic healthcare systems in states as diverse as California and Illinois. There is obviously extreme divergence in carrying out the ERD, which may be due to a lack of oversight in ensuring uniformity.⁹⁹⁶ Whereas this is certainly a religious and ethical issue for the Church, this may be the boon which would allow for rural Catholic Hospitals to be compelled to perform procedures outside of the ERD in emergency situations. Indeed, this dissertation posits that rural Catholic hospitals, have, a stronger, ethical commitment to patient

safety. This is due to issues of proximity and access—often a patient in distress cannot make it to another (non -Catholic) hospital or else, cannot afford it. However, this framework understands the Catholic notion of cooperation--- if there is another hospital that is reachable safely, the rural Catholic hospital can shuttle a patient there to undergo medical treatments they do not do. This is not completely unachievable.

7. Conclusion

Indeed, religion and spirituality is integral to clinical care. Yet, there is a general aversion or even frustration towards ‘religious’ patients. It is obvious that further scholarly research is required. Certainly, removing the concept of religion from hospitals projects a false neutrality. The future of this research will be helped significantly by acknowledging the obvious impact religious thinking has on medical decision making. Centering the importance of religion must come from *within* bioethics.

To that end, this dissertation has offered several novel approaches that can certainly assist with this goal. First, this thesis does not object to the importance of cultural competency, rather, it presents a helpmate when encountering patients who are Jewish or Catholic. Secondly, this dissertation notes that accommodation is a shared responsibility; a two-way street. There are changes that can be contrived from within the religious-ethics narrative of the faith itself. Further still, rather than a clash of decision making, the clashes between medicine and religion are *ethically* based. Ignoring this, refusing to speak in the language of religion, exacerbates this schism. Within a shared healthcare system (such as in Canada,) or within rural religious hospitals (such as in the USA,) there are undoubtedly demarcations that must be made, albeit in an ethical manner. To that end, perhaps the greatest contribution this dissertation presents is a definition and a framework that attempts to do just that. The ethical definition of undue hardship clearly articulates a method that defines the scope of reasonable accommodation for religious individuals within a shared healthcare system, or for religious healthcare systems when they are the principal providers of care. While this thesis focuses primarily on Catholic and Jewish bioethics, the proposed definition and framework might also be applied to Islam. Over time, this can hopefully be extended to other religions and faiths.

During a clash between religious and medical ethics, religion can take three different forms. As such, religion can act as a rock, which the patients turn to for comfort; a fortress which creates further obstacles to obtaining consent; and finally, as a deliverer, leading them to believe in miracles. With the guidance offered by this dissertation, there is another form of deliverance which can, in time, lead to greater discourse about placing limits upon religious accommodations and whether and how these restrictions can be ethically implemented.

This dissertation is truly a step forward as it proffers useable and practical solutions that exist outside of a courtroom. While much ink has been spilled on these clashes between medicine and faith, this dissertation attempts to offer an ethically based elucidation to the problem. This dissertation may also offer scaffolding towards the macro problem of public responsibility versus private freedoms. After all, placing firm guidelines dictating the limits of religious accommodation in healthcare is merely the instigation of that aforementioned macro argument. Indeed, what does a citizen owe his fellow citizens in a liberal democracy? What is that democracy obligated to do to protect its citizens, religious or not? Further, the theological innovations offered in this dissertation may yet inform the future response of religion to medical progress. Ethics enables proactiveness rather than reactivity. Ethics has indeed better coloured, and successively can inform this conversation.

ENDNOTES

- ¹ “Judge declines to rule in case on Ontario’s definition of death.” CBC News Online , November 13, 2018; Doctors say he’s dead. Jewish law says he’s alive. Can a hospital turn off life support? CBC News Online, February 15, 2018. . <https://www.cbc.ca/news/canada/toronto/shalom-ouanounou-case-moot-decision-1.4904343>; <https://www.cbc.ca/news/canada/toronto/shalom-ouanounou-arguments-1.4536864> accessed online.
- ² Marcus, Brian et al. *Comparison*; Savulescu, Julian. “Two worlds apart: religion and ethics.” *Journal of Medical Ethics*. (1998) 24 383; Orr, Robert D. and Leigh B. Genesen. “Requests for ‘inappropriate’ treatment based on religious beliefs.” *Journal of Medical Ethics*. (1997.) 23. 142-147
- ³ Flannelly, Kevin et al. “A Systematic Review of Religion and Spirituality in Three Palliative Care Journals, 1990-1999.” *Journal of Palliative Care* (2004) 20(1):50-6
- ⁴ Messikomer, Carla M. Renee C. Fox, Judith P. Swazey. “The Presence and Influence of Religion in American Bioethics.” *Perspectives in Biology and Medicine*. (2001.) 44. 485-490; Orr, Robert D. and Leigh B. Genesen. “Requests for ‘inappropriate’ treatment based on religious beliefs.” *Journal of Medical Ethics*. (1997.) 23. 142-147; Messikomer, Carla M. Renee C. Fox, Judith P. Swazey. “The Presence and Influence of Religion in American Bioethics.” *Perspectives in Biology and Medicine*. (2001.) 44. 485-490; Marcus, Brian et al. *Comparison*; Savulescu, Julian. “Two worlds apart: religion and ethics.” *Journal of Medical Ethics*. (1998); Cadge, Wendy, Elaine Howard Ecklund, Nicholas Short. “Religion and Spirituality: A Barrier and A Bridge in the Everyday Professional Work of Pediatric Physicians.” *Social Problems*. (56.) 702-719; Carter, Brian, et al. “Why Are There” 98-101; Moskop, John C. “Moral Conflicts and Religious Convictions: What Role for Clinical Ethics Consultants?” *HEC Forum*.(2018.) 3-9
- ⁵ Benjamin Berger Berger, B. (2008). Cultural Limits of Legal Tolerance, *The Canadian Journal of Law and Jurisprudence* 21(2), 245-278.; Berger, B. (2015). Belonging to law: Religious difference, secularism, and the conditions of civic inclusion. *Social & Legal Studies*, 24(1), 47-64.
- ⁶ Kislowicz, H. (2013, Fall; 2015/12). “Sacred laws in earthly courts: Legal pluralism in Canadian religious freedom litigation” *Canadian Journal of Law and Society*. (2013) Fall 2015 12. Kislowicz, H. “Law, Religion, and Feeling Included/Excluded: Case Studies in Canadian Religious Freedom Litigation.” *Canadian Journal of Law and Society* (2015) 30(3), 365-380. Cambridge University Press.
- ⁷ Flood, Colleen M. “Just Medicare: The Role of Canadian Courts in Determining Health Care Rights and Access.” *Journal of Law, Medicine and Ethics*. Vol. 33. 2005
- ⁸ Ontario Human Rights Commission. All documents online. <http://www.ohrc.on.ca/en/policy-preventing-discrimination-based-mental-health-disabilities-and-addictions/14-undue-hardship>
- ⁹ Durante, Chris. “Agreeing to Disagree: Indigenous Pluralism from Human Rights to Bioethics” *Journal of Religious Ethics*. (2009) 37(3):513 - 529
- ¹⁰ Moskop, John C. “Moral Conflicts and Religious Convictions: What Role for Clinical Ethics Consultants?” *HEC Forum*.(2018.) 3-9;
- ¹¹ McCarthy, Melissa. “Religious influences in Public Schools: The Winding Path Towards Accommodation” *Saint Louis University Public Law Review*. (2004) 23:2. 565-596
- ¹² Savulescu, Julian. “Two Worlds Apart: religion and ethics.” *Journal of Medical Ethics*. (1998) 24, 382-384
- ¹³ Messikomer, Carla M. Renee C. Fox, Judith P. Swazey. “The Presence and Influence of Religion in American Bioethics.” *Perspectives in Biology and Medicine*. (2001.) 44. 485-490
- ¹⁴ Durante, Chris. “Agreeing to Disagree: Indigenous Pluralism from Human Rights to Bioethics.” *The Journal of Religious Ethics*. (2009.) 37. 513-529
- ¹⁵ Durante, Chris. “Indigenous Pluralism” 520-527
- ¹⁶ Durante, Chris. “Indigenous Pluralism.” 525-528
- ¹⁷ McCarthy, Martha. “Religious Influences in Public Schools: The Winding Path Towards Accommodation” *St Louis University Public Law Review*. (2004) 565-596
- ¹⁸ McCarthy, *Public Schools* 570-580
- ¹⁹ McCarthy, *Public Schools* 570-585
- ²⁰ McCarthy, *Public Schools*
- ²¹ Schroeder, Donald, N.” John Rawls and Contract Theory.” *Soundings: An Interdisciplinary Journal*. 56.3, 1973 1-10
- ²² Schroeder, *Rawls* 6-10
- ²³ Schroeder, *Rawls* 8-10
- ²⁴ Graham, Jesse and Jonathan Haidt. 2010. "Beyond Beliefs: Religions Bind Individuals into Moral Communities." 140
- ²⁵ Orr, Robert D. "The Role of Moral Complicity in Issues of Conscience." *The American Journal of Bioethics* (2007) 7 (12): 23-24
- ²⁶ Kelly, David F., Gerald Magill and Henk ten Have. *Contemporary Catholic Health Care Ethics*. Washington DC: Georgetown University Press, 2013,134-135
- ²⁷ Rimon-Zarfaty, Nitzan. “The Israeli abortion committees' process of decision making: an ethical analysis” *Journal of Medical Ethics*; (2012) 38:26 26-27
- ²⁸ Rimon-Zarfaty, Israeli abortion 26-27

-
- ²⁹Mackler, Aaron L. 2003. *Introduction to Jewish and Catholic bioethics: a comparative analysis*. Washington, D.C.: Georgetown University Press. 142-143
- ³⁰Rimon-Zarfaty Israeli abortion 26
- ³¹Rimon-Zarfaty, Israeli abortion 26
- ³²Rimon-Zarfaty, Israeli abortion 28
- ³³Talmud b Kiddishin. New York, NY Artscroll Press.
- ³⁴Mackler, Aaron L. "Respecting bodies and saving lives: Jewish perspectives on organ donation and transplantation." (2001) *Camb Q Healthc Ethics*. Fall;10(4):420
- ³⁵Rimon-Zarfaty, Israeli abortion 28
- ³⁶Stulberg, Debra B., Rebecca A. Jackson, and Lori R. Freedman. 2016. "Referrals for Services Prohibited in Catholic Health Care Facilities." *Perspectives on Sexual and Reproductive Health* (2016) 48 (3): 111-117
- ³⁷Stulberg, Debra B. et al Perspectives 112-113
- ³⁸Mackler, Aaron L. "Respecting bodies and saving lives: Jewish perspectives on organ donation and transplantation." (2001) *Camb Q Healthc Ethics*. Fall;10(4):420, 142-143
- ³⁹Freedman Lori et al "When There's a Heartbeat: Miscarriage Management in Catholic-Owned Hospitals." *American Journal of Public Health*. (2008) 98; 1776
- ⁴⁰Mackler, *Respecting Bodies* 134-135
- ⁴¹Mackler, *Respecting Bodies* 140-141
- ⁴²Freedman et al *Heartbeat*, 1776-1777
- ⁴³Foster Angel M., et al "Do Religious Restrictions Influence Ectopic Pregnancy Management? A National Qualitative Study." *Policy Matters*. (2011.) 21:2, 104-5
- ⁴⁴Foster et al, *Religious* 107-8
- ⁴⁵Schwarz, Ernst and Salvatore Rosanio. 2011. "Religion and the Catholic Church's View on (Heart) Transplantation: A Recent Statement of Pope Benedict XVI and its Practical Impact." *Journal of Religion and Health* 50 (3): 564-574; Olick, Robert S. Eli A. Braun, and Joel Potash, "Accommodating Religious and Moral Objections to Neurological Death," *The Journal of Clinical Ethics* 20, no. 2 (2009): 183-91.; www.core.org
- ⁴⁶www.hods.org; Mackler, *Respecting Bodies* 451-453
- ⁴⁷www.catholiceducation.org
- ⁴⁸Mackler *Respecting Bodies*; Schwarz, et al, "Religion and the Catholic Church's View on (Heart) Transplantation: A Recent Statement of Pope Benedict XVI and its Practical Impact." *Journal of Religion and Health* 50 (3): 564-574
- ⁴⁹Mackler *Respecting Bodies*; Schwartz et al *Religion* 50 (3): 564-574
- ⁵⁰Schwartz et al, *Religion* 50 (3): 564-574
- ⁵¹Sperling, Daniel and Gabriel Gurman. 2012. "Factors Encouraging and Inhibiting Organ Donation in Israel." *Journal of Bioethical Inquiry* 9 (4): 479-497.
- ⁵²Sperling, *Factors* 479-480
- ⁵³Rubinstein, Jeffery L.. "Can A Goses Survive for More Than Three Days? The History and Definition of Goses". *The Journal of Jewish Ethics*. 2:2 2016 5-6
- ⁵⁴Rubeinstein, Jeffery, L. *Goses* 5-10
- ⁵⁵Rubeinstein, Jeffery, L. *Goses* 5-10
- ⁵⁶Alan Jotkowitz "Nomos and Narrative in Jewish Law" *Modern Judaism* 33:1 2013 56-5861-62
- ⁵⁷Aaron Mackler, *Introduction to Jewish and Catholic Bioethics A Comparative Analysis*, 25-37; David F. Kelly, Gerald Magill, and Henk ten Have, *Contemporary Catholic Health Care Ethics*. 142
- ⁵⁸Bleich, David J. . "Palliation of Pain." *Tradition* 36:1 2002 89-90
- ⁵⁹Kelly, David F. *Contemporary Catholic*, 142
- ⁶⁰Yoelit Tikvah Lipinsky. *Hepsed & Bechi: Halakha, Bioethics and Post-Mortem Artificial Insemination*. 2015 6 Unpublished MA paper. University of Toronto.
- ⁶¹Mackler, Aaron L. "Respecting bodies and saving lives: Jewish perspectives on organ donation and transplantation." *Camb Q Healthc Ethics*. 2001 Fall;10(4):420-9 30
- ⁶²Gill, Robin. *Health Care and Christian Ethics* Cambridge University Press: New York. 2006. 94
- ⁶³Gill *Ethics* 121-122
- ⁶⁴Cavanaugh, Thomas A. "The ethics of death-hastening or death-causing palliative analgesic administration to the terminally ill" *Journal of Pain and Symptom Management* (4) 1996 248-254
- ⁶⁵Cavanaugh, Thomas A. "The ethics" 252-261; Sulmasy Daniel P. "Double Effect—Intention is the Solution, Not the Problem" *The Journal of Law, Medicine and Ethics*. 28 2000 27-28
- ⁶⁶Kelly, Magill, ten Have *Contemporary* 34-35
- ⁶⁷Alan Jotkowitz. "Nomos and Narrative in Jewish Law" *Modern Judaism* 33:1 2013 56-58
- ⁶⁸Babylonian Talmud Sanhedrin 37a.
- ⁶⁹Mackler, *Introduction* 108-111
- ⁷⁰Bleich David, J. "Survey of Recent Halakhic Periodical Literature: Palliation of Pain," *Tradition: A Journal of Orthodox Jewish Thought*. 36 (2002) 90-108
- ⁷¹Bleich David, J. "Survey of," 100-105
- ⁷²Lutz, S (2011). "The history of hospice and palliative care". *Current problems in Cancer*, 35 304-30

- ⁷³ Weiner, Lori et al. "Cultural and Religious Considerations in Pediatric Palliative Care." *Palliative and Supportive Care*. 11. (2013) 47
- ⁷⁴ Callahan, Daniel: *The Troubled Dream of Life: In Search of a Peaceful Death* (Simon & Schuster, 1993; Georgetown University Press, 2004), 81
- ⁷⁵ Dougherty CJ¹, Purtilo R. "Physicians' duty of compassion." *Camb Q Healthc Ethics*. 1995 Fall;4(4):426-33.; Dugdale, Lydia (ed.): *Dying in the twenty-first century. Toward a new ethical framework for the art of dying well*. The MIT Press, Cambridge (MA) and London (England), 2015
- ⁷⁶ Dalberg, Todd, Elizabeth Jacob-Files, Patricia A. Carney, Jeffrey Meyrowitz, Erik K. Fromme, and Gregory Thomas. 2013. "Pediatric Oncology Providers Perceptions of Barriers and Facilitators to Early Integration of Pediatric Palliative Care." *Pediatric Blood & Cancer* 60 (11): 1878-1879
- ⁷⁷ Dahberg, Todd, et a, *Pediatric Oncology* 878-1879
- ⁷⁸ Gelhaus, Petra. "The Desired Moral Attitude of the Physician: (II) Compassion." *Med Health Care Philos* 15 (4), 397-410.2012, 400
- ⁷⁹ Cassell, Eric J: *The nature of suffering and the goals of medicine*. Oxford University Press, New York/Oxford, 2nd edition, 2004, 289
- ⁸⁰ Wiener et al, *cultural and religious* 48-49
- ⁸¹ Wiener et al, *cultural and religious* 50
- ⁸² Weiner, et al *cultural and religious* 50-51
- ⁸³ Mackler, *Introduction* 103
- ⁸⁴ Mackler, *Introduction* 108-111
- ⁸⁵ Weiner et al *Cultural and Religious* 53.
- ⁸⁶ Hill, Douglas L., Victoria A. Miller, Kari R. Hexem, Karen W. Carroll, Jennifer A. Faerber, Tammy Kang, and Chris Feudtner. 2015. "Problems and Hopes Perceived by Mothers, Fathers and Physicians of Children Receiving Palliative Care." *Health Expectations* 18 (5): 1061
- ⁸⁷ Hill et al, *Problems*, 1062
- ⁸⁸ S. Dekel et al., "Peripartum Depression, Traditional Culture, and Israeli Society," *J Clin Psychol* 72, no. 8 (2016). Greenberg, David, and Witztum, Eliezer. 2001. *Sanity and Sanctity : Mental Health Work Among the Ultra-Orthodox in Jerusalem*. New Haven: Yale University Press. Accessed October 20, 2017. ProQuest Ebook Central.
- ⁸⁹ Greenburg, David et al., "Sanity and Sanctity."
- ⁹⁰ Greenburg, David et al., "Sanity and Sanctity.;" K. Coleman-Brueckheimer and S. Dein, "Health Care Behaviours and Beliefs in Hasidic Jewish Populations: A Systematic Review of the Literature," *J Relig Health* 50, no. 2 (2011).
- ⁹¹ Greenburg, David et al., "Sanity and Sanctity."
- ⁹² Goodman; Greenburg, David et al., "Sanity and Sanctity."
- ⁹³ Feinson and Meir; *ibid.*; T. Vishne, S. Misgav, and M. E. Bunzel, "Psychiatric Disorders Related to Menstrual Bleeding among an Ultra-Orthodox Population: Case Series and Literature Review," *Int J Soc Psychiatry* 54, no. 3 (2008).
- ⁹⁴ Mackler, Aaron. "Introduction to Jewish and Catholic Bioethics. A Comparative Analysis. Georgetown University Press. Washington, DC. 2003. 85-91
- ⁹⁵ Goodman, Yehuda and Eliezer Witztum. "Cross-cultural encounters between careproviders: rabbis' referral letters to a psychiatric clinic in Israel." *Social Science and Medicine*.55 (2002) 1309-1313
- ⁹⁶ Goodman, Yehuda. *Cross-cultural*.1313-1320
- ⁹⁷ Greenburg, David et al., "Sanity and Sanctity." 20-45
- ⁹⁸ Greenburg, David et al., "Sanity and Sanctity." 20-45
- ⁹⁹ Goodman, Yehuda. "Dynamics of Inclusion and Exclusion: Comparing Mental Illness Narratives of Haredi Male Patients and their Rabbis." *Culture, Medicine and Psychiatry*. 25. 2001 169-194
- ¹⁰⁰ Goodman, Yehuda. *Dynamics of Inclusion*. 180-194 ; Greenburg, David et al., "Sanity and Sanctity."
- ¹⁰¹ Greenburg, David et al., "Sanity and Sanctity."20-55
- ¹⁰² Greenburg, David et al., "Sanity and Sanctity."20-55
- ¹⁰³ Greenburg, David et al., "Sanity and Sanctity."20-55
- ¹⁰⁴ Vishne, Tali, Sagit Misgav and Michael E. Bunzel. "Psychiatric Disorders Related to Menstrual Bleeding Among an Ultra-Orthodox Population: Case Series and Literature Review." *International Journal of Social Psychiatry*.54. 3 (2008) 219-222
- ¹⁰⁵ Dekel, Sharon, Varda Stanger, Emily R. Georgakopolous, Caren M. Steuebe. "Peripartum Depression, Traditional Culture and Israeli Society." *Journal of Clinical Psychology: In Session*. 72.8 (2016) 784-794
- ¹⁰⁶ Dekel Sharon, et al. *Peripartum Depression*. 784-794
- ¹⁰⁷ Dekel Sharon, et al. *Peripartum Depression*. 784-794
- ¹⁰⁸ Dekel Sharon, et al. *Peripartum Depression*. 784-794; Posmontier, Bobbie and Kathleen M. Fisher. *Narratology*
- ¹⁰⁹ Weinberger-Litman, Sarah L., Laura A. Rabin, Joshua Fogel, Janell L. Mensinger, Leib Litman. "Psychosocial Mediators of the Relationship Between Religious Orientation and Eating Disorder Risk Factors in Young Jewish Women." *Psychology of Religion and Spirituality*. 8.4 (2016) 265-276; Shafra, Yigal and Joel B. Wolowelsky. "A note on eating disorders and appetite and satiety in the orthodox Jewish meal." *Eat. Weight Disorders*. 18 (2013) 75-78; ; Dancyger, Ida, Victor Fornari, Martin Fisher, Marcie Schneider, Shawn Frank, Willo Wisotsky, Cristina Sison, Marina Charitou. "Cultural factors in orthodox Jewish adolescents treated in a day program for eating disorders." *International Journal of Adolescent Medicine and Health*. 4.4 (2002) 317-328; Latzer, Yael, Sarah L. Weinberger-Litman, Barbara Gerson, Anna Rosch, Rebecca Mischel, Talia Hinden, Jeffrey

- Kilstein, Judith Silver. "Negative Religious Coping Predicts Disordered Eating Pathology Among Orthodox Jewish Adolescent Girls." *J. Religion and Health*. 54. (2015) 1760-177
- ¹¹⁰ Weinberger-Litman, Sarah L., Laura A. Rabin, Joshua Fogel, Janell L. Mensinger, Leib Litman. "Psychosocial Mediators of the Relationship Between Religious Orientation and Eating Disorder Risk Factors in Young Jewish Women." *Psychology of Religion and Spirituality*. 8.4 (2016) 265-276; Shafran, Yigal and Joel B. Wolowelsky. "A note on eating disorders and appetite and satiety in the orthodox Jewish meal." *Eat. Weight Disorders*. 18 (2013) 75-78; ; Dancyger, Ida, Victor Fornari, Martin Fisher, Marcie Schneider, Shawn Frank, Willo Wisotsky, Cristina Sison, Marina Charitou. "Cultural factors in orthodox Jewish adolescents treated in a day program for eating disorders." *International Journal of Adolescent Medicine and Health*. 4.4 (2002) 317-328
- ¹¹¹ Shafran, Yigal and Joel B. Wolowelsky. *A Note*. 75-78
- ¹¹² Dancyger, Ida, et al. *Cultural Factors*. 317-328
- ¹¹³ Stolovy, Tali, Yvan Moses Levy, Adiel Doron, Yuval Melamed. "Culturally sensitive mental health care: A study of contemporary psychiatric treatment for ultra-Orthodox Jews in Israel." *International Journal of Social Psychiatry*. 59.8 (2012) 819-823; Bentacourt, Joseph R., Alexander R. Green, J. Emilio Carrillo and Owusu Annaneh-Firempong II. "Defining Cultural Competence: A Practical Framework for Addressing Racial/Ethnic Disparities in Health and Healthcare." *Public Health Reports*. 118.4 (2003) 293-302; Bentacourt, Joseph R., Alexander R. Green and J. Emilio Carrillo. "Cultural Competence in Health Care: Emerging Frameworks and Practical Approaches. Field Report." *The Commonwealth Fund*. 2002 1-40;
- ¹¹⁴ Bentacourt, Joseph R. *Defining* 293-302; Schnall, Eliezer, Solomon Kalkstein, Ayelet Gottesman, Karyn Feinberg, Charles B. Schaeffer and S. Shalom Feinberg. "Barriers to Mental Health Care: A 25 Year Follow-up Study of the Orthodox Jewish Community." *Journal of Multicultural Counseling and Development*. 42. (2014) 161-172
- ¹¹⁵ Bentacourt, Joseph R. *Defining* 293-302
- ¹¹⁶ Popovsky. *Special Issues*; McEvoy, Phil, et al. *Mental health care* 3-10
- ¹¹⁷ Rina Erez, Stanley Rabin, Louis Shenkman and Eliezer Kitai. "A Family Physician in an Ultraorthodox Jewish Village." *Journal of Religion and Health*. 38.1 (1999) 67-71
- ¹¹⁸ Bentacourt, Joseph R. *Cultural Competence* 1-40
- ¹¹⁹ Rina Erez et al., *Family Physician*. 67-71; Sublette, Elizabeth et al *Cultural Sensitivity*. 122-134
- ¹²⁰ Wing Sue, Derald. "Multidimensional Facets of Cultural Competence." *The Counseling Psychologist*. 28.6 (2001) 790-821
- ¹²¹ Narayan, Mary Curry. "Six Steps Towards Cultural Competence: A Clinician's Guide." *Home Health Care Management and Practice*. 14. 1 2001 40-48
- ¹²² Popovsky. *Special Issues*
- ¹²³ Schnall, Eliezer, et al. *25 year followup*
- ¹²⁴ Popovsky. *Special Issues*;
- ¹²⁵ Heilman, Samuel C., Eliezer Witztum. "Value-Sensitive Therapy: Learning from Ultra-Orthodox Patients." *American Journal of Psychotherapy*. 51.4 (1997) 522-540
- ¹²⁶ Heilman, Samuel C. et al. *Value-Sensitive*. 522-540;
- ¹²⁷ Witztum, Eliezer, Jacob T. Buchbinder. "Strategic culture sensitive therapy with religious Jews." *International Review of Psychiatry*. 13. (2001.) 117-124
- ¹²⁸ Schnall, Eliezer, et al. *25 year followup*
- ¹²⁹ Schnall, Eliezer, et al. *25 year followup*
- ¹³⁰ Paascheorlow, Michael. "The Ethics of Cultural Competence." *Academic Medicine*. 2004 79 (4). 347-9
- ¹³¹ McEvoy, Phil, et al. *Mental health care* 3-10
- ¹³² McEvoy, Phil, et al. *Mental health care* 3-10
- ¹³³ McEvoy, Phil, et al. *Mental health care* 3-10
- ¹³⁴ www.jpost.com
- ¹³⁵ McEvoy, Phil, et al. *Mental health care* 3-10
- ¹³⁶ Yoelit Tikvah Lipinsky. *Hepsed & Bechi: Halakha, Bioethics and Post-Mortem Artificial Insemination*. 2015 650
- ¹³⁷ Babylonian Talmud Tractate Rosh Hashanna 28a-b
- ¹³⁸ Shelton, Rachel C., Anna C. Snively, Maria De Jesus, Megan D. Othus, Jennifer D. Allen. "HPV Vaccine Decision-Making and Acceptance—Does Religion Play a Role?" *Journal of Religion and Health*. 52, 2013. 1121-1123
- ¹³⁹ Shelton, Rachel C. et al, "HPV and Decision Making" 1122-1123
- ¹⁴⁰ Shelton, Rachel C. et al, "HPV and Decision Making" 1123
- ¹⁴¹ Shelton, Rachel C. et al, "HPV and Decision Making" 1122-1128
- ¹⁴² *Jews and Genes: The Genetic Future in Contemporary Jewish Thought*. Ed. Laurie Zoloth and Elliot N. Dorff. The Jewish Publication Society, Philadelphia./ The University of Nebraska Press, Lincoln. 2015
- ¹⁴³ Talmud b. Niddah
- ¹⁴⁴ Talmud b. Niddah
- ¹⁴⁵ *Jews and Genes: The Genetic Future in Contemporary Jewish Thought*. Ed. Laurie Zoloth and Elliot N. Dorff, 323-324
- ¹⁴⁶ *Jews and Genes: The Genetic Future in Contemporary Jewish Thought*. Ed. Laurie Zoloth and Elliot N. Dorff, 324-327
- ¹⁴⁷ Glick, Shimon M. "Some Jewish thoughts on genetic enhancement." *Journal of Medical Ethics*. 37. 2011. 2-4
- ¹⁴⁸ *Jews and Genes: The Genetic Future in Contemporary Jewish Thought*. Ed. Laurie Zoloth and Elliot N. Dorff 324-327
- ¹⁴⁹ Glick, Shimon M. "Some Jewish thoughts on genetic enhancement." *Journal of Medical Ethics*. 37. 2011. 4-5

-
- ¹⁵⁰ Sayers, MB. "Analyzing Risk in Medicine and Surgery: A Traditional Jewish Approach" *Ethics and Medicine*.27.3. 2001.177-180
- ¹⁵¹ Sayers, MB "Analyzing Risk" 177-181
- ¹⁵² Steinberg, Avraham. *Encyclopedia of Jewish Medical Ethics*. Fred Rosner, translator. Feldheim Publishers. Jerusalem. 2003. 272-275
- ¹⁵³ Steinberg, Avraham, *Encyclopedia*. 273-276
- ¹⁵⁴ T Brachot 27a
- ¹⁵⁵ Sayers, MB "Analyzing Risk" 177-181
- ¹⁵⁶ Brand, Yitzchak. "Religious medical ethics: a study of the rulings of Rabbi Waldenberg." *Journal of Religious Ethics*. 38.3. 2010. 495-500
- ¹⁵⁷ Brand Yitzchak. "Religious ethics" 498-505
- ¹⁵⁸ Rosner, Fred. "Plastic and Cosmetic Surgery in Judaism." *The American Journal of Cosmetic Surgery*.17.1 2000. 5-7
- ¹⁵⁹ *Jews and Genes: The Genetic Future in Contemporary Jewish Thought*. Ed. Laurie Zoloth and Elliot N. Dorff
- ¹⁶⁰ Rosner, Fred. "Plastic Surgery" 5-7
- ¹⁶¹ Rosner Fred. "Plastic Surgery" 5-7
- ¹⁶² *Jews and Genes: The Genetic Future in Contemporary Jewish Thought*. Ed. Laurie Zoloth and Elliot N. Dorff, 316-317
- ¹⁶³ *Jews and Genes: The Genetic Future in Contemporary Jewish Thought*. Ed. Laurie Zoloth and Elliot N. Dorff, 317-319
- ¹⁶⁴ Steinberg, Avraham, *Encyclopedia* 442-449
- ¹⁶⁵ Cribbs, Adam P. and Sumeth MW Perrera. "Science and Bioethics of CRISPR-CaS9 Gene Editing: An Analysis Towards Separating Fact and Fiction." *Yale Journal of Biology and Medicine*. 90. 2017 625-634
- ¹⁶⁶ Dillon, Katherine E., Clarisa R. Gracia. "Pediatric and Young Adult Patients and Oncofertility." *Current Treatment Options in Oncology*. (2012) 13:161–173
- ¹⁶⁷ Cohen, Cynthia B. "Ethical Issues Regarding Fertility Preservation in Adolescents and Children." *Pediatric Blood Cancer* .2009;53:249–253
- ¹⁶⁸ Janson, Per Olof. "Possibilities of fertility preservation in children and young adults undergoing treatment for malignancy." *Acta Obstet Gynecol Scandania* 2000; 79; Wallace, W. Hamish B. "Oncofertility and Preservation of Reproductive Capacity in Children and Young Adults." *Cancer*. 2011.
- ¹⁶⁹ Janson, Per Olof. "Possibilities of fertility preservation in children and young adults undergoing treatment for malignancy." *Acta Obstet Gynecol Scandania* 2000; 79; Wallace, W. Hamish B. "Oncofertility and Preservation of Reproductive Capacity in Children and Young Adults." *Cancer*. 2011.; Cohen, Cynthia B. "Ethical Issues Regarding Fertility Preservation in Adolescents and Children." *Pediatric Blood Cancer* .2009;53:249–253
- ¹⁷⁰ Dillon, Katherine E. et al, "Pediatric Oncofertility" 170
- ¹⁷¹ Dillon, Katherine E. et al, "Pediatric Oncofertility" 170
- ¹⁷² Dillon, Katherine E. et al, "Pediatric Oncofertility" 169
- ¹⁷³ Jotkotwitz, A. (2014). The Seminal Contribution of Rabbi Moshe Feinstein to the Development of Modern Jewish Medical Ethics. *Journal of Religious Ethics*. . Journal of Religious Ethics ,142 -143
- ¹⁷⁴ JPS Tanakh: The Holy Scriptures , 1985
- ¹⁷⁵ Jotkotwiz, A. "Seminal Contribution" 838-890
- ¹⁷⁶ Grazi, R. V., & Wolowelsky, J. B. (2001). Parenthood From the Grave. *The Jewish Spectator* ,65 (4), 398
- ¹⁷⁷ Zoloth, Laurie. "Chapter 24, Jewish Perspectives on Oncofertility: The Complexities of Tradition." *Oncofertility, Cancer Treatment and Research*. Springer Science+Business Media, LLC 2010, 295
- ¹⁷⁸ Zoloth, Laurie. "Oncofertility" 298-230
- ¹⁷⁹ Zoloth, Laurie. "Oncofertility", 235
- ¹⁸⁰ Zoloth, Laurie. "Oncofertility" 235
- ¹⁸¹ Zoloth, Laurie. "Oncofertility" 235-243
- ¹⁸² Zoloth, Laurie. "Oncofertility" -303
- ¹⁸³ Zoloth, Laurie. "Oncofertility" 303
- ¹⁸⁴ Festic, E. ME Wilson, O. Gajic, GD Divertie, JT Rabatin. "Perspectives of physicians and nurses regarding end of life care in the intensive care unit." *Journal of Intensive Care Medicine*.(2012.) 27. 47.
- ¹⁸⁵ Festic, E. et al. "Perspectives." 47-50
- ¹⁸⁶ www.gwish.org
- ¹⁸⁷ Silverman, Henry J. , Emily Bellavance, Brian H. Childs. "Ensuring Quality in Clinical Ethics Consultations: Perspectives of Ethicists Regarding Process and Prior Training of Consultants" *Health Care Ethics Consultation*. (2013.) 13/. 29-31; Marcus, Brian S. et al. "Comparison" 31-33
- ¹⁸⁸ Richmond Moeller, Jessica. Et al. "Functions and Outcomes" 100-101
- ¹⁸⁹ Richmond Moeller, Jessica. Et al. "Functions and Outcomes" 100-101
- ¹⁹⁰ Puchalski, Christina M. and Edward O'Donnell. "Religious and spiritual beliefs in end of life care: how major religions view death and dying." *Pain Management*. (2005.) 9 (3) 114-121
- ¹⁹¹ Kelly, David F., Gerald Magill and Hen ten Have. *Contemporary Catholic Health Care Ethics*..Washington DC: Georgetown University Press, 2013, 32-35
- ¹⁹² Kelly, David F. *Catholic Health Ethics*, 34-35

- ¹⁹³ Kelly, David F. *Catholic Health Ethics*, 133; Mackler, Aaron L. *Introduction to Jewish and Catholic Bioethics: A Comparative Analysis*. Washington DC: Georgetown University Press, 2003, 98-101.
- ¹⁹⁴ Mackler, *Introduction*, 101
- ¹⁹⁵ Mackler, *Introduction*, 103
- ¹⁹⁶ Alderson, Priscilla and Virginia Morrow. *The Ethics of Research with Children and Young People*. 102-103
- ¹⁹⁷ Ross, Lainie Friedman. *Children in medical research. Access versus protection*. New York: Oxford University Press, 2006., 97
- ¹⁹⁸ Alderson, et al, *Ethics* 85; Harcourt, Deborah and Jonathon Sargeant. *Doing Ethical Research with Children*. UK. McGraw-Hill Education, 2012, 75-78
- ¹⁹⁹ Harcourt and Sargeant, *Ethical Research* 75-76
- ²⁰⁰ Alderson et al, *Ethics* 86-8
- ²⁰⁰ Beauchamp, Thomas L. and James F. Childress, *Principles of Biomedical Ethics*. New York, Oxford University Press, 2013, 119-20
- ²⁰⁰ Beauchamp, "Principles" 119
- ²⁰⁰ Schmidt, Katharina, et al. "Applying the Analytic Hierarchy Process in healthcare research: a systematic literature review and evaluation of reporting." *BMC Medical informatics and Decisions Making*. (2015)10-12; Greenberger, Chaya. "The hierarchy of values in Jewish bioethics." *Nursing Ethics*.(2011.) 7-10
- ²⁰⁰ Greenberger, Chaya. "The hierarchy of values in Jewish bioethics." *Nursing Ethics*.(2011.) 1-7
- ²⁰⁰ Schmidt, Katharina, et al. "Applying the Analytic Hierarchy Process in healthcare research: a systematic literature review and evaluation of reporting." *BMC Medical informatics and Decisions Making*. (2015) 6-8
- ²⁰⁰ Beauchamp "Principles"
- ²⁰⁰ Birchley, Giles. "Deciding Together? Best Interests and Shared Decision- Making in Pediatric Intensive Care. *Health Care Analysis*. (2013) 22;3), 210-218
- ²⁰⁰ Case Study adapted from Mendola, Anette. "Faith and Futility in the ICU" *Hastings Center Report*. (2015.) 9-11
- ²⁰¹ Beauchamp, "Principles" 119-20
- Beauchamp, "Principles" 119
- ²⁰³ Schmidt, Katharina et al. "AHP" 10-12; Greenberger, Chaya. "The hierarchy" 7-10
- ²⁰⁴ Greenberger, Chaya. "The hierarchy of values in Jewish bioethics." *Nursing Ethics*.(2011.) 1-7
- ²⁰⁵ Beauchamp "Principles" 119-120
- ²⁰⁶ Birchley, Giles. "Deciding Together?" 210-218
- ²⁰⁷ Lecture on Health Policy October 2012, MPA Program, Queen's University, Kingston, ON; Bulow, Hans-Henrik et al. "Are religion and religiosity important to end of life decisions and patient autonomy in the ICU? The Ethicatt Study." *Intensive Care Medicine*. (2012.) 38. 1126-1132; Keshet, Yael. Ido Liberman. "Coping with Illness and Threat: Why Non-religious Jews Choose to Consult Rabbis on Healthcare Issues." *Journal of Religion and Health*. (2014). 53. 1146; Messikomer, Carla M. Renee C. Fox, Judith P. Swazey. "The Presence and Influence of Religion in American Bioethics." *Perspectives in Biology and Medicine*. (2001.) 44. 485-490; Graham, Jesse and Jonathan Haidt. 2010. "Beyond Beliefs: Religions Bind Individuals into Moral Communities." 140;
- ²⁰⁸ Keshet, Yael. Ido Liberman. "Coping with Illness and Threat: Why Non-religious Jews Choose to Consult Rabbis on Healthcare Issues." *Journal of Religion and Health*. (2014). 53. 1146
- ²⁰⁹ Bandini, Julia, et al. "The role of religious beliefs in ethics committee consultations for conflict over life-sustaining treatment." *Journal of Medical Ethics*. (2017.) 43. 353-356
- ²¹⁰ Orr, Robert D. and Leigh B Genesen. "Requests for 'inappropriate treatment' based on religious beliefs." *Journal of Medical Ethics*. 1997. 23 142-147.
- ²¹¹ Daaleman, TP and VanderCreek, L. "Placing religion and spirituality in end -of -life care" *JAMA*. (2000.) 15. 2514-5
- ²¹² Messikomer, Carla M. et al. "American Bioethics." 488
- ²¹³ Keshet, Yael. "Coping." 1147-1150
- ²¹⁴ Bandini, Julia et al. "Role of religion." 353-357
- ²¹⁵ Cohen, Robin. *Magill Quality of Life Questionnaire*. 1997. Given to the author by a supervisor at Hospital for Sick Children.
- ²¹⁶ Buryska, James F. "Assessing the ethical weight of cultural, religious and spiritual claims in the clinical context." *Journal of Medical Ethics*. (2000.) 27. 118-122
- ²¹⁷ Taylor, Charles. *A Secular Age*. Harvard University Press, 2007, 453
- ²¹⁸ Taylor, Charles. *A Secular Age*. Pages 505-800. Harvard University Press, 2007
- ²¹⁹ Veatch, Robert. *Hippocratic, Religious and Secular Medical Ethics. The Points of Conflict*. Georgetown University Press., 2012
- ²²⁰ Messikomer, Carla M. Renee C. Fox, Judith P. Swazey. "The Presence and Influence of Religion in American Bioethics." *Perspectives in Biology and Medicine*. (2001.) 44. 488-489
- ²²¹ Messikomer, Carla M. et al. "American Bioethics." 489
- ²²² Messikomer, Carla M. et al. "American Bioethics." 489
- ²²³ Messikomer, Carla M. et al. "American Bioethics." 489
- ²²⁴ Messikomer, Carla M. et al. "American Bioethics." 487-489
- ²²⁵ Mackler, Aaron L. *Introduction to Jewish and Catholic Bioethics: A Comparative Analysis*. Washington DC: Georgetown University Press, 2003. 101

- 226 Messikomer, Carla M. et al. "American Bioethics." 489
- 227 Durante, Chris. "Indigenous Pluralism." 520
- 228 Health Canada. *Canada Health Act* (R.S.C., 1985, c. C-6). Department of Justice. Assessed online 1
- 229 Lazar, Harvey, et al. *Federal-Provincial Relations and Health Care : Reconstructing the Partnership /*. Saskatoon: Commission on the Future of Health Care in Canada, Commission sur l'avenir des soins de santé au Canada, 2002. Print.
- 230 Berger, B. (2008). Cultural Limits of Legal Tolerance, *The Canadian Journal of Law and Jurisprudence* 21(2), 245-278.; Berger, B. (2015). Belonging to law: Religious difference, secularism, and the conditions of civic inclusion. *Social & Legal Studies*, 24(1), 47-64.
- 231 Health Canada. *Canada Health Act* (R.S.C., 1985, c. C-6). Department of Justice. Assessed online, November 22nd, 2011
- 232 Berger, B. (2010-2011). Key Theoretical Issues in the Interaction of Law and Religion: Guide for the Perplexed. *Constitutional Forum* 19(2), 41-52
- 233 (*Trinity Western University v British Columbia College of Teachers* (1998), *Ontario (Human Rights Commission) v Brockie* (2000)
- 234 (*Eldridge v British Columbia (Attorney General)* (1997)
- 235 (*C.U. v Alberta (Director of Child Welfare)* 2000; (*Hamilton Health Sciences Corp. v D.H.*) 2014.
- 236 Alegratti, J. (1997-1998). Lawyers, Clients, and Covenant: Religious Perspective on Legal Practice and Ethics. *Fordham Law Review* 66(4), 1101-1130.
- 237 Kislowicz, H. (2013, Fall; 2015/12). Sacred laws in earthly courts: Legal pluralism in Canadian religious freedom litigation. 39, 175.; Kislowicz, H. (2015). Law, Religion, and Feeling Included/Excluded: Case Studies in Canadian Religious Freedom Litigation. *Canadian Journal of Law and Society* 30(3), 365-380. Cambridge University Press.
- 238 Filerman, Gary L. Anne E. Mills, Paul M. Schyve, eds. *Managerial Ethics in Healthcare: A New Perspective*. Chicago IL: Health Administration Press, 2014, 68
- 239 Filerman, et al. *Managerial Ethics*, 63
- 240 Filerman et al. *Managerial Ethics* 256
- 241 Schuklenk, Udo. "Conscientious Objection in Medicine: Private Ideological Convictions must not Supersede Public Service Obligations." *Bioethics*. (2015) 29:5.
- 242 Schuklenk, Udo. "Conscientious Objection" 6
- 243 Brody, Howard and Arlene Macdonald. "Religion and bioethics: towards an expanded understanding." (2013.) 34. 140-143
- 244 Brody, Howard. "Religion and bioethics." 131-144
- 245 Brody, Howard. "Religion and bioethics." 140-143
- 246 Schroeder, Donald, N." John Rawls and Contract Theory." *Soundings: An Interdisciplinary Journal*. 56.3, 1973 1-10
- 247 Schroeder Donald, N. "Rawls." 3-6
- 248 Durante, Chris. "Agreeing to Disagree: Indigenous Pluralism from Human Rights to Bioethics." *The Journal of Religious Ethics*. (2009.) 37. 513-529
- 249 Durante, Chris. "Indigenous Pluralism" 520-527
- 250 Durante, Chris. "Indigenous Pluralism." 525-528
- 251 Veatch, Robert M. *Hippocratic, Religious and Secular Medical Ethics: The Points of Conflict*. Washington, DC. Georgetown University Press. 2012. 140-143
- 252 Engelhardt, Tristram H. Jr. "Reason, Reasonableness and Rawls: Some Skeptical Reflections on Bioethics." *The Dialogue. Yearbook of Philosophical Hermeneutics Reason and Reasonableness* . 2004.
- 253 Schroeder, *Rawls* 1-10
- 254 Schroeder, *Rawls* 1-10
- 255 www. eeo.org
- 256 Wilson, Robin Fretwell "The Calculus of Accommodation: Contraception, Abortion, Same-Sex Marriage, and Other Clashes between Religion and the State", *Boston College Law Review*. (2012). 53:4, 1417-1513
- 257 Graham, Jesse and Jonathan Haidt. 2010. "Beyond Beliefs: Religions Bind Individuals into Moral Communities." *Personality and Social Psychology Review*. (2010.) 14:1, 140-150
- 258 McCarthy, Melissa. "Religious influences in Public Schools: The Winding Path Towards Accommodation" *Saint Louis University Public Law Review*. (2004) 23:2. 565-596
- 259 McCarthy, *Public Schools* 570-590
- 260 McCarthy, *Public Schools* 570-590
- 261 McCarthy, *Public Schools* 570-590
- 262 McCarthy, *Public Schools* 570-590
- 263 Greenblum, Jake. "Public Reason and the limited right to conscientious objection: A response to Magelssen." *Journal of Medical Ethics*. (2017) 44:3. 1-5
- 264 Catholic Health Alliance of Canada, *Health Ethics Guide*, 3rd edition, (2013) accessed online, specifically, chapter 3, 4 and 7 www.chac.ca
- 265 Greenblum, Jake. "Public Reason" 1-5
- 266 Shaw, David M. "Justice and the Fetus: Rawls, Children and Abortion." *Cambridge Quarterly of Healthcare Ethics*. (2011.) 20;1. 93-101
- 267 Shaw, David M. "Justice and the Fetus," 93-101

-
- 267 Shaw, David M. "Justice and the Fetus," 93-101
- 268 Durante, Chris. "Indigenous Pluralism" 520-527
- 269 Ontario Human Rights Commission <http://www.ohrc.on.ca/en/policy-preventing-discrimination-based-mental-health-disabilities-and-addictions/14-undue-hardship>
- 270 <https://www.merriam-webster.com/legal/reasonable%20accommodation>
- 271 Ontario Human Rights Commission <http://www.ohrc.on.ca/en/policy-preventing-discrimination-based-mental-health-disabilities-and-addictions/14-undue-hardship>
- 272 https://www.eeoc.gov/eeoc/newsroom/wysk/workplace_religious_accommodation.cfm
- 273 <https://www.natlawreview.com/article/religious-accommodation-and-patient-safety-healthcare-industry>
- 274 *Ethical and Religious Directives for Catholic Health Care Services* Fifth Edition. 2009, 3-5
- 275 Dugdale, Lydia (ed.): *Dying in the twenty-first century. Toward a new ethical framework for the art of dying well.* The MIT Press, Cambridge (MA) and London (England), 2015, 74
- 276 *Ethical and Religious Directives for Catholic Health Care Services* Fifth Edition. 2009, 3-5
- 277 Baron, JH, "Mount Sinai—A Brief History". *Mount Sinai Journal of Medicine* 67 (1) 3-5
- 278 Baron, JH, "Mount Sinai", 3-5
- 279 Rimon-Zarfaty, "The Israeli abortion committees' process of decision making: an ethical analysis" *Journal of Medical Ethics*;38: 26-27
- 280 Mackler, *Introduction*, 25-37; Kelly et al, *Catholic Ethics*, 39-43
- 281 Filerman, Gary L. Anne E. Mills, Paul M. Schyve, eds. *Managerial Ethics in Healthcare: A New Perspective*. Chicago IL: Health Administration Press, 2014, 86
- 282 Graham, Jesse and Jonathan Haidt. 2010. "Beyond Beliefs: Religions Bind Individuals into Moral Communities." 140
- 283 Filerman, Gary L. Anne E. Mills, Paul M. Schyve, eds. *Managerial Ethics in Healthcare: A New Perspective*. Chicago IL: Health Administration Press, 2014 249-259
- 284 Orr, Robert D. 2007. "The Role of Moral Complicity in Issues of Conscience." *The American Journal of Bioethics* 23
- 285 Orr, Moral Complicity 23
- 286 O'Rourke, Kevin. What Happened in Phoenix?: The complicated reasons behind an abortion at a Catholic hospital. *America The Jesuit Review*. June 21, 2010
- 287 Freedman Lori R; Uta Landy; Jody Steinauer "When There's a Heartbeat: Miscarriage Management in Catholic-Owned Hospitals." 2008 *American Journal of Public Health* Volume 98; Issue 10, 1776
- 288 Freedman et al *Heartbeat*, 1776-1777
- 289 Pijnenburg, Martien A. M. and Bert Gordijn. 2005. "Identity and Moral Responsibility of Healthcare Organizations." *Theoretical Medicine and Bioethics* 75-77
- 290 Foster Angel M., et al "Do Religious Restrictions Influence Ectopic Pregnancy Management? A National Qualitative Study." 104-5
- 291 Foster et al, *Religious* 107-8
- 292 Padela, Aasim I., and Farr A. Curlin. "Religion and Disparities: Considering the Influences of Islam on the Health of American Muslims." *Journal of Religion and Health* 707-708
- 293 Padela, Aasim I. *Religion* 704-710
- 294 Wilson, Robin Fretwell "The Calculus of Accommodation: Contraception, Abortion, Same-Sex Marriage, and Other Clashes between Religion and the State", 1417-1419 1420-1445
- 295 Galek, Kathleen, Kevin J. Flannelly, Harold G. Koenig, and Rev. Sarah L. Fogg. "Referrals to chaplains: The role of religion and spirituality in healthcare settings" *Mental Health, Religion & Culture* Vol. 10 :4, 2007, 370-380; Bassett, W.W. "Private religious hospitals: limitations upon autonomous moral choices in reproductive medicine." 2001 *J Contemp Health Law Policy*. 17(2):488.
- 296 Pijnenburg, Martien, Bert Gordijn, Frans Vosman, and Henk Have. 2008. "Catholic Healthcare Organizations and the Articulation of their Identity." *HEC Forum* 20 (1): 75-97 141
- 297 Liaschenko, J. and Peter, E. (2016), Fostering Nurses' Moral Agency and Moral Identity: *The Importance of Moral Community Hastings Center Report*, 46: S18–S21.
- 298 Liaschenko, J *Fostering Nurses* 18
- 299 Filerman, et al *Managerial Ethics* 97-100
- 300 Filerman, et al *Managerial Ethics* 86-88
- 301 Orr, Robert D. 2007. "The Role of Moral Complicity in Issues of Conscience." *The American Journal of Bioethics* 7 (12):23-24
- 302 Orr , Robert D. *Moral Complicity* 23
- 303 Graham, Jesse and Jonathan Haidt. 2010. "Beyond Beliefs: Religions Bind Individuals into Moral Communities." *Personality and Social Psychology Review* 14 (1): 140
- 304 Graham, Jesse *Beyond Beliefs*, 142-143
- 305 Filerman, Gary L. Anne E. Mills, Paul M. Schyve, eds. *Managerial Ethics in Healthcare: A New Perspective*. Chicago IL: Health Administration Press, 2014 97-100
- 306 Weinstock, Daniel. 2014. "Conscientious Refusal and Health Professionals: Does Religion make a Difference?" *Bioethics* 28 (1): 8-15

- ³⁰⁷ Wascher JM, Stulberg DB, Freedman LR. "Restrictions on Reproductive Care at Catholic Hospitals: A Qualitative Study of Patient Experiences and Perspectives." *AJOB Empir Bioeth*. 2020 Oct-Dec;11(4):257-267
- ³⁰⁸ Wascher JM et al. *Restrictions on Reproductive*, 257-260
- ³⁰⁹ Health Canada. *Canada Health Act* (R.S.C., 1985, c. C-6). Department of Justice. Assessed online
- ³¹⁰ Catholic Care Providers of Canada statement website www.ccpcc.ca
- ³¹¹ Hapenny, Sandra S. "Appeal to Conscience Clauses in the Face of Divergent Practice among Catholic Hospitals." PhD diss. Baylor University, 2011.
- ³¹² Rubinstein, Jeffery L. "Can A Goses Survive for More Than Three Days? The History and Definition of Goses". *The Journal of Jewish Ethics* 11-12
- ³¹³ Babylonian Talmud Sanhedrin 37a.
- ³¹⁴ Mackler, Aaron L. *Introduction to Jewish and Catholic Bioethics: A Comparative Analysis*. Washington DC: Georgetown University Press, 2003, 96
- ³¹⁵ Mackler, Aaron L, *Introduction* 96
- ³¹⁶ Barilan, Y. "The New Israeli Law on the Care of the Terminally Ill: conceptual innovations waiting for implementation." 2007 *Perspectives in biology and medicine* , 557-560
- ³¹⁷ Barilan Y *New Israeli* , 563
- ³¹⁸ Rubinstein, Jeffery L. *Goses* 1-5
- ³¹⁹ Barilan, Y *New Israeli* 566
- ³²⁰ Barilan, Y *New Israeli* 566
- ³²¹ Barilan Y *New Israeli* 563
- ³²² www.core.org
- ³²³ Mackler, *Introduction*, 47
- ³²⁴ Mackler, *Introduction* 44-57
- ³²⁵ www.hods.org ; Mackler, Aaron L. "Respecting bodies and saving lives: Jewish perspectives on organ donation and transplantation." *Camb Q Healthc Ethics*. 2001 Fall;10(4):, 451
- ³²⁶ www.hods.org; Mackler, *Respecting Bodies* 451-453
- ³²⁷ www.catholiceducation.org
- ³²⁸ Mackler *Respecting Bodies* ; Schwarz, et al, "Religion and the Catholic Church's View on (Heart) Transplantation: A Recent Statement of Pope Benedict XVI and its Practical Impact." *Journal of Religion and Health*, 1881-1890
- ³²⁹ Mackler *Respecting Bodies*; Schwartz et al *Religion*, 1-10
- ³³⁰ Schwartz et al, *Religion* 1881
- ³³¹ Olick, Robert S. Eli A. Braun, and Joel Potash, "Accommodating Religious and Moral Objections to Neurological Death," *The Journal of Clinical Ethics* 20, no. 2 (2009): 183-91; Schwartz, et al, *Religion* 1881-1882 ;www.core.org
- ³³² Schwartz et al, *Religion* Olick et al *Accommodating Religious*; www. core. org
- ³³³ Olick et al *Accommodating Religious*, et al, 1-3
- ³³⁴ Mackler *Respecting Bodies*, 451-452
- ³³⁵ Mackler, *Respecting Bodies*, 452; Schwartz et al, 1-10
- ³³⁶ Olick et al *Accommodating Religious*, 1-3
- ³³⁷ Olick et al *Accommodating Religious*, 1-3
- ³³⁸ Olick et al *Accommodating Religious*, 1-3
- ³³⁹ Werber, Stephen J. 1996. "Ancient answers to modern questions: death, dying, and organ transplants--a Jewish law perspective" *Journal of Law and Health* 11 (1) 13-18
- ³⁴⁰ Mackler, *Respecting Bodies* 451-453, Weber, *Ancient Answers* 13-18; , Olick et al *Accommodating Religious*, 1-3
- ³⁴¹ Olick et al. *Accommodating Religious*, 1-3
- ³⁴² Schwartz et al, *Religion* 1881-1890
- ³⁴³ Schwartz et al, *Religion* 1881-1890
- ³⁴⁴ Schwartz, et al, *Religion* 1881-1890
- ³⁴⁵ Sperling, Daniel and Gabriel Gurman. 2012. "Factors Encouraging and Inhibiting Organ Donation in Israel." *Journal of Bioethical Inquiry* 9 (4): 479-497
- ³⁴⁶ Sperling , Daniel, *Factors* 479-481
- ³⁴⁷ Sperling, Danile, *Factors* 479-481
- ³⁴⁸ Kinzbrunner, Barry M. "Jewish Medical Ethics and End-of-Life Care" *Journal of Palliative Medicine*.7:4 2004 563-564
- ³⁴⁹ Rubenstein, Jeffery L. Goses 5-6
- ³⁵⁰ Rubenstein , Jeffery L. Goses 5-10
- ³⁵¹ Alan Jotkowitz "Nomos and Narrative in Jewish Law" *Modern Judaism* 33:1 2013 56-58;61-62
- ³⁵² Babylonian Talmud Sanhedrin 37a.
- ³⁵³ Sperling, Daniel and Gabriel Gurman. 2012. "Factors Encouraging and Inhibiting Organ Donation in Israel." *Journal of Bioethical Inquiry* 9 (4): 479-481
- ³⁵⁴ Sperling, Daniel, *Factors*, 481
- ³⁵⁵ Sperling, Daniel, *Factors* 482-485
- ³⁵⁶ Sperling, Daniel *Factors*, 485
- ³⁵⁷ Sperling, Daniel, *Factors*, 485

-
- ³⁵⁸ Craig, David Melville. 2008. "Religious values in the health care market: stories and structures from Catholic and Jewish hospitals." *Journal Of The Society Of Christian Ethics* 28, no. 2: 226-228
- ³⁵⁹ www. hods.org;
- ³⁶⁰ Kelly, David F., Gerald Magill and Henk ten Have. *Contemporary Catholic Health Care Ethics*. Washington DC: Georgetown University Press, 2013, 200-206
- ³⁶¹ Schwartz et al, *Religion* 1881
- ³⁶² Schwartz et al, *Religion* 1881 570-572
- ³⁶³ McDonough, Mary J.. *Can a Healthcare Market be Moral? A Catholic Vision*. Washington, D.C. : Georgetown University Press, 2007, 163-192
- ³⁶⁴ McDonough, *Healthcare Market* ,186-188
- ³⁶⁵ Schwartz et al, *Religion*, 1881 568
- ³⁶⁶ Kelly, David L. *Contemporary Catholic*, 205-206
- ³⁶⁷ Kelly, David L. *Contemporary Catholic* 206
- ³⁶⁸ Schwartz et al, *Religion*, 1881-1887
- ³⁶⁹ Jotkowitz, Alan and Nitzan Rimon-Zarfaty. The Israeli Abortion Committee's process of decision making: an ethical analysis. *Journal of Medical Ethics*. 38. 2012. 26-27
- ³⁷⁰ Jotkowitz, Alan , *Israeli abortion*, 26
- ³⁷¹ Jotkowitz, Alan *Israeli abortion*, 26
- ³⁷² Jotkowitz, Alan, *Israeli abortion*, 28
- ³⁷³ Talmud b Kiddishin
- ³⁷⁴ Mackler, *Respecting Bodies*, 145
- ³⁷⁵ Jotkowitz, Alan *Israeli abortion*, 27-29
- ³⁷⁶ Jotkowitz, Alan, *Israeli abortion*, 28
- ³⁷⁷ Jotkowitz, Alan, *Israeli abortion* 38. .
- ³⁷⁸ Jotkowitz, Alan, *Israeli abortion* 38-40
- ³⁷⁹ Stulberg, Debra B., Rebecca A. Jackson, and Lori R. Freedman. 2016. "Referrals for Services Prohibited in Catholic Health Care Facilities." *Perspectives on Sexual and Reproductive Health* 48 (3): 111-117.
- ³⁸⁰ Stulberg, et al *Referrals* 112-113
- ³⁸¹ Stulberg et al *Referrals* 112, 113-115
- ³⁸² Mackler, Aaron L. "Respecting bodies and saving lives: Jewish perspectives on organ donation and transplantation." *Camb Q Health Ethics*. 2001 Fall;10(4): 142-143
- ³⁸³ Mackler, Aaron L. *Respecting Bodies* 140-141
- ³⁸⁴ Coleman, GD. "Direct and indirect abortion in the Roman Catholic tradition: a review of the Phoenix case." *HEC Forum*, 2013 Jun;25(2): 128
- ³⁸⁵ Coleman, GD *Direct* 128
- ³⁸⁶ Wascher JM, Stulberg DB, Freedman LR. "Restrictions on Reproductive Care at Catholic Hospitals: A Qualitative Study of Patient Experiences and Perspectives." *AJOB Empir Bioeth*. 2020 Oct-Dec;11(4):257-267
- ³⁸⁷ Wachter, Robert M. *Understanding Patient Safety*. New York : McGraw Hill Medical , 2012
- ³⁸⁸ Freedman Lori R; Uta Landy; Jody Steinauer "When There's a Heartbeat: Miscarriage Management in Catholic-Owned Hospitals." 2008 *American Journal of Public Health* Volume 98; Issue 10, 1776
- ³⁸⁹ Freedman et al *Heartbeat*, 1776-1777
- ³⁹⁰ Pijnenburg, Martien A. M. and Bert Gordijn. 2005. "Identity and Moral Responsibility of Healthcare Organizations." *Theoretical Medicine and Bioethics* 75-77
- ³⁹¹ Foster Angel M., et al "Do Religious Restrictions Influence Ectopic Pregnancy Management? A National Qualitative Study." 104-5
- ³⁹² Kelly, David F., Gerald Magill and Henk ten Have. *Contemporary Catholic Health Care Ethics*. Washington DC: Georgetown University Press, 2013
- ³⁹³ Foster et al, *Religious* 107-8
- ³⁹⁴ Magill, HCE lecture ; Zohar, Noam J. 2003. "Co-Operation Despite Disagreement: From Politics to Healthcare." *Bioethics* 135; Bassett, W.W. "Private religious hospitals: limitations upon autonomous moral choices in reproductive medicine." 2001 *J Contemp Health Law Policy*. 441-447
- ³⁹⁵ Magill, Gerard. HCE662 Lecture. February 2017-Personal notes
- ³⁹⁶ Zohar, Noam J. 2003. "Co-Operation Despite Disagreement: From Politics to Healthcare." *Bioethics* 135
- ³⁹⁷ Zohar, *Co-operation* 125-130
- ³⁹⁸ Zohar, *Co-operation* 125-126
- ³⁹⁹ Wilson, Robin Fretwell "The Calculus of Accommodation: Contraception, Abortion, Same-Sex Marriage, and Other Clashes between Religion and the State", 53 B.C.L. Rev. 1417 1418-1421
- ⁴⁰⁰ Bassett, W.W. "Private religious hospitals: limitations upon autonomous moral choices in reproductive medicine." (2001) *J Contemp Health Law Policy*. 441-447
- ⁴⁰¹ Mackler, *Respecting Bodies* 124-126

- 402 Mackler, *Respecting Bodies* 133-139
- 403 Steinfeld, Rebecca. "Wars of the Wombs: Struggles Over Abortion Policies in Israel." *Israel Studies*, 2015, 19-22
- 404 Steinfeld, *War of Wombs* 4-6; 19-22
- 405 Mackler, *Respecting Bodies* 121-124
- 406 Mackler, *Respecting Bodies* 124
- 407 Mackler, *Respecting Bodies* 134-140
- 408 Podcast- Israel Story "The Needle" Episode 46. Accessed via <https://www.tabletmag.com/podcasts/israel-story/israel-story-the-needle>
- 409 Pellegrino, Edmund D. 1993. "Societal Duty and Moral Complicity: The Physician's Dilemma of Divided Loyalty." *International Journal of Law and Psychiatry* 16 (3-4): 371-391
- 410 Pellegrino, *Societal Duty*, 379-381
- 411 Pellegrino *Societal Duty*, 379-381
- 412 Pellegrino *Societal Duty*, 379-381
- 413 Pellegrino, *Societal Duty*, 380-381
- 414 Cassell, Eric J: *The nature of suffering and the goals of medicine*. Oxford University Press, New York/Oxford, 288-289
- 415 Callahan, Daniel: *The Troubled Dream of Life: In Search of a Peaceful Death* (Simon & Schuster, 1993; Georgetown University Press 62-65
- 416 Daaleman, TP and VanderCreek, L. "Placing religion and spirituality in end of life care" *JAMA*. (2000.) 15. 2514-5
- 417 Daaleman, TP and VanderCreek, L. *Placing Religion* 2514-5
- 418 www.gwish.org
- 419 Daaleman, TP and VanderCreek, L. *Placing Religion* 2514-5
- 420 Heyland DK, Frank C, Tranmer J, Paul N, Pichora D, Jiang X, Day AG. "Satisfaction with end-of-life care: a longitudinal study of patients and their family caregivers in the last months of life." *J Palliat Care*. 2009 Winter;25(4):245-56
- 421 Cassell, Eric J: *The nature of suffering and the goals of medicine*. Oxford University Press, New York/Oxford, 2nd edition, 2004, 288
- 422 Cassell, Eric J. *The Nature of Suffering* 288
- 423 Heyland, DK et al. *Satisfaction with end of life*, 245-56
- 424 Aaron Mackler, *Introduction to Jewish and Catholic Bioethics A Comparative Analysis*, 25-37; David F. Kelly, Gerald Magill, and Henk ten Have, *Contemporary Catholic Health Care Ethics*. 142
- 425 J. David Bleich. *Palliation of Pain*, "Tradition" 36:1 2002 89-90
- 426 Kelly, David L. *Contemporary Catholic* 142
- 427 Yoelit Tikvah Lipinsky. *Hepsed & Bechi: Halakha, Bioethics and Post-Mortem Artificial Insemination*. 2015 6
- 428 Mackler *Introduction* 30
- 429 Gill, Robin, *Health Care and Christian Ethics*. 94
- 430 Gill, *Ethics* 121-122
- 431 Cavanaugh, Thomas A. "The ethics of death-hastening or death-causing palliative analgesic administration to the terminally ill" *Journal of Pain and Symptom Management* (4) 1996, 370-371
- 432 Cavanaugh, *Ethics*, 252-261; Sulmasy Daniel P. "Double Effect—Intention is the Solution, Not the Problem" *The Journal of Law, Medicine and Ethics*. 28 2000, 27-28
- 433 Kelly, David L. *Contemporary Catholic* 34-35
- 434 Callahan, Daniel, *Troubled Dream* 44; 59; 64
- 435 Callahan, Daniel, *Troubled Dream* 81
- 436 Dougherty CJ¹, Purtilo R. "Physicians' duty of compassion." *Camb Q Healthc Ethics*. 1995 Fall;4(4):426-33; Gelhaus, Petra. "The Desired Moral Attitude of the Physician: (II) Compassion." *Med Health Care Philos* 15 (4), 2012.
- 437 Gelhaus, Petra, *Desired Moral*, 400
- 438 Cassell, Eric J: *The nature of suffering and the goals of medicine*. Oxford University Press, New York/Oxford, 2nd edition, 2004., 289
- 439 Wiener, Lori, Denice Grady McConnell, Lauren Latella, and Erica Ludi. 2013. "Cultural and Religious Considerations in Pediatric Palliative Care." *Palliative and Supportive Care* 11 (1): 48-49
- 440 Swetz KM, Crowley ME, Maines TD. What makes a Catholic hospital "Catholic" in an age of religious-secular collaboration? The case of the Saint Marys hospital and the Mayo Clinic. *HEC Forum*. 2013 Jun;25(2):95-10
- 441 O'Rourke, Kevin. "What Happened in Phoenix?: The complicated reasons behind an abortion at a Catholic hospital". *America The Jesuit Review*. June 21, 2010
- 442 O'Rourke, Kevin. "What Happened?" 1-5
- 443 *Ethical and Religious Directives for Catholic Health Care Services* Fifth Edition. 2009
- 444 Daaleman, TP and VanderCreek, L. "Placing religion and spirituality in end of life care" *JAMA*. (2000.) 15. 2514-5
- 445 JH Baron, "Mount Sinai—A Brief History". *Mount Sinai Journal of Medicine* 67 (1) 3-5
- 446 Baron, Mount Sinai, 3-5
- 447 Gould, Jillian. "A Nice Piece of Cake and a Kibitz: Reinventing Sabbath Hospitality in an Institutional Home" *Home Cultures: The Journal of Architecture, Design and Domestic Space*. (2013.) 10:2, 189-206
- 448 Gould, Jillian "A Nice Piece of Cake," 200

-
- ⁴⁴⁹ Keshet, Yael, Ido Liberman. "Coping with Illness and Threat: Why Non-religious Jews Choose to Consult Rabbis on Healthcare Issues." *Journal of Religion and Health*. (2014). 53. 1146
- ⁴⁵⁰ Keshet, Yael, Ido Liberman. "Coping with Illness" 1146-150
- ⁴⁵¹ Wiener, Lori, Denice Grady McConnell, Lauren Latella, and Erica Ludi. 2013. "Cultural and Religious Considerations in Pediatric Palliative Care." *Palliative and Supportive Care* 11 (1), 50
- ⁴⁵² Mackler, Aaron L. *Introduction to Jewish and Catholic Bioethics: A Comparative Analysis*. Washington DC: Georgetown University Press, 2003, 108-111
- ⁴⁵³ Ford, K., J. Sankey, and J. Crisp. "Development of Children's Assent Documents Using a Child-Centred Approach." *J Child Health Care* 11.1 (2007): 19-28
- ⁴⁵⁴ Harcourt, Deborah and Jonathon Sargeant. *Doing Ethical Research with Children*. UK. McGraw-Hill Education, 2012, 70-80
- ⁴⁵⁵ Alderson, *Ethics* 85; Harcourt, Deborah and Jonathon Sargeant. *Doing Ethical Research with Children*. UK. McGraw-Hill Education, 2012, 75-78
- ⁴⁵⁶ Alderson, *Ethics* 86-88
- ⁴⁵⁷ Swartling, U., et al. "'My Parents Decide If I Can. I Decide If I Want To.'" Children's Views on Participation in Medical Research." *J Empir Res Hum Res Ethics* 6.4 (2011): 68-75.
- ⁴⁵⁸ American Academy of Pediatrics Policy accessed via <https://www.aap.org/en-us/Documents/Bioethics-InformedConsent.pdf>
- ⁴⁵⁹ American Academy of Pediatrics Policy accessed via <https://www.aap.org/en-us/Documents/Bioethics-InformedConsent.pdf>
- ⁴⁶⁰ Weiner et al *Cultural and Religious* 53.
- ⁴⁶¹ Hill, Douglas L., Victoria A. Miller, Kari R. Hexem, Karen W. Carroll, Jennifer A. Faerber, Tammy Kang, and Chris Feudtner. 2015. "Problems and Hopes Perceived by Mothers, Fathers and Physicians of Children Receiving Palliative Care." *Health Expectations* 18 (5): 1061
- ⁴⁶² Hill et al, *Problems*, 1062
- ⁴⁶³ Aries, Philippe: *Western attitudes towards death: From the Middle Ages to the present*. The Johns Hopkins University Press, Baltimore, 1974. 2-12
- ⁴⁶⁴ Aries, Philippe, *Western* 29-52
- ⁴⁶⁵ Aries, Philippe, *Western* 11-13
- ⁴⁶⁶ Lydia Dugdale (ed.): *Dying in the twenty-first century. Toward a new ethical framework for the art of dying well*. The MIT Press, Cambridge (MA) and London (England), 2015, 69-70
- ⁴⁶⁷ Aries, Philippe, *Western* 14
- ⁴⁶⁸ Aries, Philippe, *Western* 90-91
- ⁴⁶⁹ Gawande, Atul: *Being mortal. Medicine and what matters in the end*. Metropolitan Books, Henry Holt and Company, New York, 2014, 26-27
- ⁴⁷⁰ Gawande, Atul, *Being Mortal* 25-27
- ⁴⁷¹ Callahan, Daniel: *The Troubled Dream of Life: In Search of a Peaceful Death* (Simon & Schuster, 1993; Georgetown University Press, 2004, 65-67
- ⁴⁷² Callahan, Daniel *Troubled Dream* 74-75
- ⁴⁷³ Callahan, Daniel *Troubled Dream* 81-83
- ⁴⁷⁴ Doughty, Charles J. and Ruth Purtilo. "Physicians' Duty of Compassion." *Cambridge Quarterly of Healthcare Ethics* 1995 Fall; 4(4): 426-433; Gelhaus, Petra. "The Desired Moral Attitude of the Physician: (II) Compassion." *Med Health Care Philos* 15 (4), 397-410.2012.
- ⁴⁷⁵ Cassell, Eric J: *The nature of suffering and the goals of medicine*. Oxford University Press, New York/Oxford, 2nd edition, 2004., 288
- ⁴⁷⁶ Cassell, Eric J. *The Nature of Suffering* 289
- ⁴⁷⁷ Cavanaugh, Thomas A. "The ethics of death-hastening or death-causing palliative analgesic administration to the terminally ill" *Journal of Pain and Symptom Management* (4) 1996, 371
- ⁴⁷⁸ Kelly, David F., Gerald Magill and Henk ten Have. *Contemporary Catholic Health Care Ethics*. Washington DC: Georgetown University Press, 2013, 107-108
- ⁴⁷⁹ Fohr Double Effect 321-326s
- ⁴⁸⁰ Kelly, David F. et al, *Contemporary Catholic Ethics*, 113-114
- ⁴⁸¹ Babylonian Talmud, *Yoma 85b*
- ⁴⁸² Jotkowitz, Alan. "Nomos and Narrative in Jewish Law: The Care of the Dying Patient and the Prayer of the Handmaid," *Modern Judaism*. 33 (2013) 66
- ⁴⁸³ Jotkowitz, Alan. *Nomos* 60-71
- ⁴⁸⁴ Gill *Ethics* 160; Bernard Gert, Charles M. Culver, K. Danner Clouser *Bioethics: A Systematic Approach* 21-26
- ⁴⁸⁵ Gill *Ethics* 160
- ⁴⁸⁶ Gert, et al, *Bioethics* 23
- ⁴⁸⁷ Gert et al, *Bioethics* 45-47
- ⁴⁸⁸ Kelly, David F., Gerald Magill and Henk ten Have. *Contemporary Catholic Health Care Ethics*. Washington DC: Georgetown University Press, 2013, 125-126
- ⁴⁸⁹ Moshe Feinstein, Igrot Mosheh, introduction to Orah Hayyim (accessed online)
- ⁴⁹⁰ Babylonian Talmud Eruvin 13b

-
- 491 Babylonian Talmud Eruvin 13b
- 492 R. Yitzhak Colon (d. 1480) Sheelot u-Teshuvot Maharik, Warsaw 1884, no. 163, p. 176
- 493 Mackler, Aaron L. *Introduction to Jewish and Catholic Bioethics: A Comparative Analysis*. Washington DC: Georgetown University Press, 2003, 30
- 494 Robin Gill, *Health Care and Christian Ethics*. 94
- 495 Gill, Robin *Ethics* 121-122
- 496 Susan Anderson Fohr. "The Double Effect of Pain Medication: Separating Myth from Reality" *Journal of Palliative Medicine*. 1:4 1998 315-318
- 497 Fohr, Susan Anderson, *Double Effect* 321-326
- 498 Fohr, Susan Anderson, *Double Effect* 321-326
- 499 Peter Allmark, Mark Cobb, B. Jane Liddle and Angela Mary Tod. "Is the Doctrine of Double Effect Irrelevant in End-of-Life Decision Making?" *Nursing Philosophy*. 11.1 2010 170
- 500 Cavanaugh, Thomas A. "The ethics of death-hastening or death-causing palliative analgesic administration to the terminally ill" *Journal of Pain and Symptom Management* (4) 1996, 252
- 501 Cavanaugh, Thomas A. *The Ethics* 370-371
- 502 Cavanaugh, Thomas A. *The Ethics* 252-261; Sulmasy Daniel P. "Double Effect—Intention is the Solution, Not the Problem" *The Journal of Law, Medicine and Ethics*. 28 2000, 27-28
- 503 Sulmasy, Daniel P. *Double Effect* 28
- 504 Cavanaugh, Thomas A. *The Ethics* 370-371
- 505 Kelly, David F., Gerald Magill and Henk ten Have. *Contemporary Catholic Health Care Ethics*. Washington DC: Georgetown University Press, 2013, 34-35
- 506 Mackler, Aaron L. *Introduction* 70-71
- 507 Kelly, David F. et al *Contemporary Catholic*, 133; Mackler, *Introduction* 98-101.
- 508 Mackler, Aaron L. *Introduction* 101
- 509 Kelly, David F. et al. *Contemporary Catholic* 126-127
- 510 Scott M. Sullivan "The Development and Nature of the Ordinary/Extraordinary Means Distinction in the Roman Catholic Tradition. *Bioethics*. 21:7 2007, 391-393
- 511 Kelly, David F. *Contemporary Catholic*, 134-135
512. Kelly, David F. *Contemporary Catholic*, 133
- 513 Lipinsky, Yoelit, Hepsed, 56
- 514 Albert R. Jonsen *A Short History of Medical Ethics* 22-23; Mackler, Aaron L. *Introduction* 30
- 515 Rubinstein, Jeffery L.. "Can A Goses Survive for More Than Three Days? The History and Definition of Goses". *The Journal of Jewish Ethics*. 2:2 2016, 11-12
- 516 Babylonian Talmud Sanhedrin 37a.
- 517 Babylonian Talmud Sanhedrin 37a.
- 518 Jonsen *Short History* 22-23
- 519 Mackler, *Introduction* 108-111
- 520 Mackler, *Introduction* 96
- 521 Mackler, *Introduction* 96
- 522 Bleich Palliation 90-108
- 523 Mackler, *Introduction* 220-221
- 524 Bleich Palliation 100-105
- 525 Mackler, *Introduction* 89-91
- 526 Mackler, *Introduction* 92-93
- 527 Mackler, *Introduction* 94-95
- 528 Rubinstein, Jeffery L.. "Can A Goses Survive for More Than Three Days? The History and Definition of Goses". *The Journal of Jewish Ethics*. 2:2 2016, 11-15 ; Bleich, Palliation 109-111
- 529 Rubenstein, Jeffery L. Goses 11-15
- 530 Jotkowitz Nomos 60
- 531 Bleich Palliation 109-111
- 532 Barry M. Kinzbrunner "Jewish Medical Ethics and End-of-Life Care" *Journal of Palliative Medicine*. 7:4 2004 563-564
- 533 Jotkowitz, Alan. "Nomos and Narrative in Jewish Law: The Care of the Dying Patient and the Prayer of the Handmaid," *Modern Judaism*. 33 (2013) 56-74 , 56
- 534 Jotkowitz, Alan. *Nomos* 59-60
- 535 Kinzbrunner *Jewish Ethics* 564
- 536 Mackler, *Introduction* 104-109
- 537 Mackler, *Introduction* 108-111
- 538 Mackler, *Introduction* 96
- 539 Mackler, *Introduction* 96
- 540 Bleich Palliation 111
- 541 Lipinsky Hepsed 45
- 542 Lipinsky Hepsed 45

-
- ⁵⁴³ This anecdote is essential. After all, the laws of menstrual purity are foundational to modern Judaism. If a rabbi can be lenient with a foundational system, yes, leniency may be found in other circumstances. Yerushalmi Talmud Tractate Niddah 8c
- ⁵⁴⁴ Lipinsky, Hepsed 50
- ⁵⁴⁵ Babylonian Talmud Tractate Rosh Hashanna 28a-b
- ⁵⁴⁶ Bleich Palliation 103-104
- ⁵⁴⁷ Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*. 118-121
- ⁵⁴⁸ Jotkowitz, Alan. "Nomos and Narrative in Jewish Law: The Care of the Dying Patient and the Prayer of the Handmaid," *Modern Judaism*. 33 (2013) 56-74 , 104
- ⁵⁴⁹ Jotkowitz, Alan. *Nomos* 104
- ⁵⁵⁰ Beauchamp and Childress, *Principles*. 131-136; 133
- ⁵⁵¹ Beauchamp and Childress, *Principles*. 140
- ⁵⁵² Bleich Palliation 104
- ⁵⁵³ Bleich Palliation 105
- ⁵⁵⁴ Bleich Palliation 105-106
- ⁵⁵⁵ Bleich Palliation 106
- ⁵⁵⁶ Bleich Palliation 107-108
- ⁵⁵⁷ Bleich Palliation 107-108
- ⁵⁵⁸ Bleich Palliation 107-108
- ⁵⁵⁹ Rubinstein, Jeffery L.. "Can A Goses Survive for More Than Three Days? The History and Definition of Goses". *The Journal of Jewish Ethics*. 2:2 2016, 5-6
- ⁵⁶⁰ Rubinstein, Jeffery L. Goses 5-10
- ⁵⁶¹ Rubenstein , Jeffery L Goses 5-10
- ⁵⁶² Rubenstein , Jeffery L Goses 7-8
- ⁵⁶³ Rubenstein , Jeffery L Goses 9-10
- ⁵⁶⁴ Rubenstein , Jeffery L Goses 17-19
- ⁵⁶⁵ Jotkowitz, Alan. "Nomos and Narrative in Jewish Law: The Care of the Dying Patient and the Prayer of the Handmaid," *Modern Judaism*. 33 (2013), 60-62
- ⁵⁶⁶ Jotkowitz, Alan *Nomos* 61-62
- ⁵⁶⁷ Jotkowitz, Alan *Nomos* 61-62
- ⁵⁶⁸ Benini, Franca Marco Spizzichino, Manuela Trapanotto, and Anna Ferrante.2008. "Pediatric palliative care" *Italian Journal of Pediatrics*. (34) , 3
- ⁵⁶⁹ Friedrichsdorf, SJ, S Remke, B Symalla, C Gibbon, and J Chrastek. 2007. "Developing a pain and palliative care programme at a US children's hospital." *International Journal Of Palliative Nursing* 13, no. 11: 534
- ⁵⁷⁰ Benini, Franca Marco Spizzichino, et al, *Pediatric palliative* 3; Sahler, Olle Jane Z. Gerri Frager, Marcia Levetown, Felicia G. Cohn, and Michael A. Lipson. *Pediatrics*.2000. "Medical Education About End-of-Life Care in the Pediatric Setting: Principles, Challenges, and Opportunities" 575-576
- ⁵⁷¹ Sahler, Olle Jane Z. *Medical Education*, 576;
- ⁵⁷² Dalberg, Todd, Elizabeth Jacob-Files, Patricia A. Carney, Jeffrey Meyrowitz, Erik K. Fromme, and Gregory Thomas. 2013. "Pediatric Oncology Providers Perceptions of Barriers and Facilitators to Early Integration of Pediatric Palliative Care." *Pediatric Blood & Cancer* 60 (11): 1878-1879
- ⁵⁷³ Dalberg, Todd et al, *Pediatric Oncology* 1878-187
- ⁵⁷⁴ Tan, Gim H. Balagandhar R. Totapally, Dan Torbati, and Jack Wolfsdorf. End-of-Life Decisions and Palliative Care in a Children's Hospital Journal of Palliative Medicine. April 2006, 9(2): 333
- ⁵⁷⁵ Tan, Gim H. et al, *End of Life Decisions* 338
- ⁵⁷⁶ Tan, Gim H. et al, *End of Life Decisions* 339
- ⁵⁷⁷ Gill *Ethics* 121-122
- ⁵⁷⁸ Fohr, Double Effect 318
- ⁵⁷⁹ Tan, Gim H. et al, *End of Life Decisions* 338-339
- ⁵⁸⁰ Cassell, Eric J: *The nature of suffering and the goals of medicine*. Oxford University Press, New York/Oxford, 2nd edition, 2004.269--270
- ⁵⁸¹ Cassell *The Nature of Suffering* 268-271
- ⁵⁸² Cassell, *The Nature of Suffering* 245
- ⁵⁸³ Gelhaus , "Desired Moral," 400
- ⁵⁸⁴ Cassell *The Nature of Suffering* 289
- ⁵⁸⁵ Thomas, Stefanie M. et al. "Not just little adults: a review of 102 pediatric ethics consultations." *Acta Paediatrica*. (2015.) 104. 530-533; Dalberg et al, 1771
- ⁵⁸⁶ Tan, Gim H. Balagandhar R. Totapally, Dan Torbati, and Jack Wolfsdorf. End-of-Life Decisions and Palliative Care in a Children's Hospital Journal of Palliative Medicine. April 2006, 9(2) 333
- ⁵⁸⁷ Thomas, Stefanie M. et al. "Not just little 779-781
- ⁵⁸⁸ Benini, Franca Marco Spizzichino, et al, *Pediatric palliative*, 7
- ⁵⁸⁹ Benini, Franca Marco Spizzichino, et al, *Pediatric palliative*, 7-8

- ⁵⁹⁰ Klick, Jeffery C., Sarah Friebert, Nancy Hutton, Kaci Osenga, Kenneth J. Pituch, Tamara Vesel, Norbert Weidner, Susan D. Block, Laura J. Morrison. "Developing Competencies for Pediatric Hospice and Palliative Medicine". *Pediatrics* Dec 2014, 134 (6) 1670-1671
- ⁵⁹¹ Friedrichsdorf, SJ, S Remke, B Symalla, C Gibbon, and J Chrastek. 2007. "Developing a pain and palliative care programme at a US children's hospital." *International Journal Of Palliative Nursing* 13, no. 11, 534
- ⁵⁹² Friedrichsdorf, SJ et al, *US palliative*, 534
- ⁵⁹³ Friedrichsdorf, SJ et al, *US palliative*, 535
- ⁵⁹⁴ Friedrichsdorf, SJ et al, *US palliative*, 536
- ⁵⁹⁵ Friedrichsdorf, SJ et al, *US palliative*, 536
- ⁵⁹⁶ Friedrichsdorf, SJ et al, *US palliative*, 536-538
- ⁵⁹⁷ Friedrichsdorf, SJ et al, *US palliative*, 38-539
- ⁵⁹⁸ AAP policy accessed online via <https://www.aappublications.org/news/2019/08/02/focus080219>
- ⁵⁹⁹ AAP policy accessed online via <https://www.aappublications.org/news/2019/08/02/focus080219>
- ⁶⁰⁰ Sahler, Olle Jane Z. Gerri Frager, Marcia Levetown, Felicia G. Cohn, and Michael A. Lipson. Pediatrics.2000. "Medical Education About End-of-Life Care in the Pediatric Setting: Principles, Challenges, and Opportunities" 577
- ⁶⁰¹ Williams-Reade, Jackie, Angela L. Lamson, Sharon M. Knight, Mark B. White, Sharon M. Ballard, and Priti P. P. Desai. 2015. "Paediatric Palliative Care: A Review of Needs, Obstacles and the Future." *Journal of Nursing Management* 23 (1): 9
- ⁶⁰² Rogers, Susan, Carlos Gomez, Philip Carpenter, Jean Farley, Debbie Holson, Miriam Markowitz, Brian Rood, Karen Smith, and Peter Nigra. 2011. "Quality of Life for Children with Life-Limiting and Life-Threatening Illnesses: Description and Evaluation of a Regional, Collaborative Model for Pediatric Palliative Care." *American Journal of Hospice and Palliative Medicine* 28 (3): 163-164
- ⁶⁰³ Atwood, Melissa A. Raymond G. Hoffmann, KeYan, , K. Jane Lee. 2013. "Attitudes About Palliative Care." *American Journal of Hospice and Palliative Medicine* 31(6) , 665-667
- ⁶⁰⁴ Klick, Jeffery C., Sarah Friebert, Nancy Hutton, Kaci Osenga, Kenneth J. Pituch, Tamara Vesel, Norbert Weidner, Susan D. Block, Laura J. Morrison. "Developing Competencies for Pediatric Hospice and Palliative Medicine". *Pediatrics* Dec 2014, 134 (6) 1670-1671
- ⁶⁰⁵ Klick, Jeffery C. et al, competencies, 54
- ⁶⁰⁶ Kolarik, Russ C. Gena Walker and Robert M. Arnold. "Pediatric resident education in palliative care: a needs assessment." 2006. *Pediatrics*. (6), 1949
- ⁶⁰⁷ Kolarik, Russ C. et al *Resident Education* 1951-1952
- ⁶⁰⁸ Kolarik, Russ C. et al *Resident Education* 1952
- ⁶⁰⁹ Kolarik, Russ C. et al *Resident Education* 1952
- ⁶¹⁰ Rapoport, Adam. Christopher Obwanga, Giovanna Sirianni, S. Lawrence Librach, and Amna Husain."Not Just Little Adults: Palliative Care Physician Attitudes Toward Pediatric Patients" *Journal of Palliative Medicine*. May 2013, 16(6), 677
- ⁶¹¹ Rapoport Adam et al *Pediatric Palliative* 677
- ⁶¹² Rahimzadeh, Vasiliki Gillian Bartlett, Cristina Longo, Laura Crimi, Mary Ellen Macdonald, Nada Jabado, et al.2015 "Promoting an ethic of engagement in pediatric palliative care research" *BMC Palliative Care*.14, 2
- ⁶¹³ Gawande, Atul, *Being mortal. Medicine and what matters in the end*. Metropolitan Books, Henry Holt and Company, New York, 2014-125
- ⁶¹⁴ Rahimzadeh, Vasiliki, *Promoting Ethics* 4-5
- ⁶¹⁵ Klick, Jeffery C. et al, competencies 1671
- ⁶¹⁶ Klick, Jeffery c. et al, competencies 1674
- ⁶¹⁷ Melin-Johansson, Christina, Inge Axelsson, Marie Jonsson Grundberg, and Frida Hallqvist. 2014. "When a Child Dies: Parents' Experiences of Palliative Care—An Integrative Literature Review." *Journal of Pediatric Nursing* 29 (6): 661
- ⁶¹⁸ Melin-Johansson, Christina. *Parents' Experience* 661- 664
- ⁶¹⁹ Gilmer, Mary Jo , Terrah L. Foster, Cynthia J. Bell, John Mulder, Brian S. Carter. 2012. "Parental Perceptions of Care of Children at End of Life." *American Journal of Hospice and Palliative Medicine* 30(1) , 55-57
- ⁶²⁰ AAP policy accessed online via <https://www.aappublications.org/news/2019/08/02/focus080219>
- ⁶²¹ Gawande, Atul, *Being Mortal* 34-40; Lydia Dugdale (ed.): *Dying in the twenty-first century. Toward a new ethical framework for the art of dying well*. The MIT Press, Cambridge (MA) and London (England), 2015. 59-70
- ⁶²² Beauchamp, Tom L. and Childress, James F. Principles of Biomedical Ethics. Seventh edition. Oxford University Press: Oxford, 2013. 132-133
- ⁶²³ Beauchamp and Childress, *Principles*. 132
- ⁶²⁴ Beauchamp and Childress, *Principles*. 133-134
- ⁶²⁵ Beauchamp and Childress, *Principles*. 134-137
- ⁶²⁶ Beauchamp and Childress, *Principles*. 138-141
- ⁶²⁷ Beauchamp and Childress, *Principles*. 138-139
- ⁶²⁸ Beauchamp and Childress, *Principles*. 139-140
- ⁶²⁹ Wiener, Lori, Denice Grady McConnell, Lauren Latella, and Erica Ludi. 2013. "Cultural and Religious Considerations in Pediatric Palliative Care." *Palliative and Supportive Care* 11 (1): 48-49
- ⁶³⁰ Wiener, Lori et al, *Cultural and Religious* 49-50
- ⁶³¹ Wiener Lori et al, *Cultural and Religious* 50

- 632 Wiener Lori et al, *Cultural and Religious* 50-51
- 633 Wiener Lori et al, *Cultural and Religious* 51
- 634 Wiener Lori et al, *Cultural and Religious* 51
- 635 Wiener Lori et al, *Cultural and Religious* 53-54
- 636 Wiener Lori et al, *Cultural and Religious* 54
- 637 Wiener Lori et al, *Cultural and Religious* 54
- 638 Wiener Lori et al, *Cultural and Religious* 55
- 639 Wiener Lori et al, *Cultural and Religious* 53
- 640 Wiener Lori et al, *Cultural and Religious* 53.
- 641 Hatano, Yutaka, Miwa Yamada, and Kenji Fukui. 2011. "Shades of Truth: Cultural and Psychological Factors Affecting Communication in Pediatric Palliative Care." *Journal of Pain and Symptom Management* 41 (2): 491-495
- 642 Mackler, Aaron L. *Introduction to Jewish and Catholic Bioethics: A Comparative Analysis*. Washington DC: Georgetown University Press, 2003., 104-109
- 643 Young, Anna R., James R. Thobaben, "Pragmatic Moral Problems and the Ethical Interpretation of Pediatric Pain," *Christian bioethics: Non-Ecumenical Studies in Medical Morality*, Volume 17, Issue 3, December 2011, 243–276
- 644 Young, Anna R. *Pragmatic Moral* 243-250
- 645 Young, Anna R. *Pragmatic Moral*
- 646 Lebediger, Israel. "The Minor in Jewish Law." *The Jewish Quarterly Review*, New Series, 6, no. 4 (1916): 459-93.
- 647 Lebediger, Israel, *The Minor* 460-470
- 648 Lebediger, Israel, *The Minor* 460- 470
- 649 Ford, *Development*
- 650 Beauchamp, Tom L. and Childress, James F. *Principles of Biomedical Ethics*. Seventh edition. Oxford University Press: Oxford, 2013. 118-121
- 651 Beauchamp and Childress, *Principles* 116
- 652 Beauchamp and Childress, *Principles* 116-124
- 653 Beauchamp and Childress, *Principles* 116
- 654 Beauchamp and Childress, *Principles* 104-110; 113-116
- 655 Dalberg, Todd, Elizabeth Jacob-Files, Patricia A. Carney, Jeffrey Meyrowitz, Erik K. Fromme, and Gregory Thomas. 2013. "Pediatric Oncology Providers Perceptions of Barriers and Facilitators to Early Integration of Pediatric Palliative Care." *Pediatric Blood & Cancer* 60 (11): 1878; Atwood, Melissa A. Raymond G. Hoffmann, KeYan, , K. Jane Lee. 2013. "Attitudes About Palliative Care." *American Journal of Hospice and Palliative Medicine* 31(6) , 665
- 656 Greenburg, David et al., "Sanity and Sanctity.;" K. Coleman-Brueckheimer and S. Dein, "Health Care Behaviours and Beliefs in Hasidic Jewish Populations: A Systematic Review of the Literature," *J Relig Health* 50, no. 2 (2011).
- 657 Greenburg, David et al., "Sanity and Sanctity."
- 658 Greenburg, David et al., "Sanity and Sanctity.;" K. Coleman-Brueckheimer and S. Dein, "Health Care Behaviours and Beliefs in Hasidic Jewish Populations: A Systematic Review of the Literature," *J Relig Health* 50, no. 2 (2011).
- 659 Greenburg, David et al., "Sanity and Sanctity."
- 660 Goodman; Greenburg, David et al., "Sanity and Sanctity."
- 661 Popovsky, *Special Issues*; Greenburg, David et al., "Sanity and Sanctity."
- 662 Greenburg, David et al., "Sanity and Sanctity.;" Coleman-Brueckheimer and Dein., *Health Care Behaviours*
- 663 K. Coleman-Brueckheimer and S. Dein, "Health Care Behaviours and Beliefs in Hasidic Jewish Populations"
- 664 Greenburg, David et al., "Sanity and Sanctity."
- 665 Elijor, Rachel. "The Origins of Hasidism." *Scripta Judaica Craoviensia*. 10 (2002) 85-90
- 666 Elijor, Rachel. *The Origins*. 90-100
- 667 Elijor, Rachel. *The Origins*. 90-100
- 668 Coleman-Brueckheimer and Dein., *Health Care Behaviours*
- 669 Feinson and Meir; *ibid.*; T. Vishne, S. Misgav, and M. E. Bunzel, "Psychiatric Disorders Related to Menstrual Bleeding among an Ultra-Orthodox Population: Case Series and Literature Review," *Int J Soc Psychiatry* 54, no. 3 (2008).
- 670 Goodman, Yehuda and Eliezer Witztum. "Cross-cultural encounters between careproviders: rabbis' referral letters to a psychiatric clinic in Israel." *Social Science and Medicine*.55 (2002) 1309-1313
- 671 Goodman, Yehuda. *Cross-cultural*.1313-1320
- 672 Goodman, Yehuda. *Cross-cultural*.1313-1321; Greenburg, David et al., "Sanity and Sanctity."
- 673 Feinson, Marjorie C. and Adi Meir. "Disordered Eating and Religious Observance: A focus on Ultra-Orthodox Jews in an Adult Community Study" *International Journal of Eating Disorders* 45 (2012) 101-109; Greenburg, David et al., "Sanity and Sanctity.;" Freund, Anat and Tova Band-Winterstein. "Cultural Psychiatry: A Spotlight on the Experience of Clinical Social Workers' Encounter with Jewish Ultra-Orthodox Mental Health Clients." *Community Mental Health* 53 (2017)
- 674 Rier, David A., Avraham Schwartzbaum and Chaya Heller. "Methodological Issues in Studying an Insular, Traditional Population: A Women's Health Survey Among Israeli Haredi (ultra-Orthodox) Jews." *Women and Health*. 48.4 (2008); Whiteley, Charlotte, Adrian Coyle, and Kate Gleeson. "An idiographic analysis of women's account of living with mental health conditions in Haredi Jewish communities." *Mental Health, Religion & Culture*. 20.3. (2017); Huppert, Jonathan D., Jedidiah Siev,

- and Elyssa S. Kushner. "When Religion and Obsessive-Compulsive Disorder Collide: Treating Scrupulosity in Ultra-Orthodox Jews." *Journal of Clinical Psychology*. 63.10 (2007)
- ⁶⁷⁵ Mackler, Aaron. "Introduction to Jewish and Catholic Bioethics. A Comparative Analysis. Georgetown University Press. Washington, DC. 2003. 85-91
- ⁶⁷⁶ Greenburg, David et al., "Sanity and Sanctity.;" Weiss, Penina and Ron Shor. "Cultural Aspects Within Caregiver Interactions of Ultra-Orthodox Jewish Women and Their Family Members with Mental Illness." *American Journal of Orthopsychiatry*. 83. 4 (2013)
- ⁶⁷⁷ McEvoy, Phil, et al. *Mental health care* 3-10; Goodman, Yehuda. *Cross-cultural*. 1313-1320
- ⁶⁷⁸ www.jpost.com; ⁶⁷⁸ Rier, David A. et al, *Methodological Issues*; Posmontier, Bobbie and Kathleen M. Fisher. "A Narratology of Postpartum Psychosis in an Orthodox Jewish Woman." *Perspectives in Psychiatric Care*. 50 (2014); Marienberg, Evyatar. "Traditional Jewish Sexual Practices and Their Possible Impact on Jewish Fertility and Demography." *Harvard Theological Review*. 106.3 (2013)
- ⁶⁷⁹ Rier, David A. et al, *Methodological Issues*; Posmontier, Bobbie and Kathleen M. Fisher. "A Narratology of Postpartum Psychosis in an Orthodox Jewish Woman." *Perspectives in Psychiatric Care*. 50 (2014); Marienberg, Evyatar. "Traditional Jewish Sexual Practices and Their Possible Impact on Jewish Fertility and Demography." *Harvard Theological Review*. 106.3 (2013)
- ⁶⁸⁰ Greenburg, David et al., "Sanity and Sanctity."
- ⁶⁸¹ Goodman, Yehuda. *Dynamics of Inclusion*. 180-194 ; Greenburg, David et al., "Sanity and Sanctity."
- ⁶⁸² Greenburg, David et al., "Sanity and Sanctity."
- ⁶⁸³ Greenburg, David et al., "Sanity and Sanctity."
- ⁶⁸⁴ Greenburg, David et al., "Sanity and Sanctity."
- ⁶⁸⁵ Greenburg, David et al., "Sanity and Sanctity."
- ⁶⁸⁶ Zoloth, Laurie. *Jewish Oncofertility*. Chapter 24.
- ⁶⁸⁷ Greenburg, David et al., "Sanity and Sanctity."
- ⁶⁸⁸ Weiss, Penina and Ron Shor. *Cultural caregiver*
- ⁶⁸⁹ Weiss, Penina and Ron Shor. *Cultural caregiver*.
- ⁶⁹⁰ Vishne, Tali, Sagit Misgav and Michael E. Bunzel. "Psychiatric Disorders Related to Menstrual Bleeding Among an Ultra-Orthodox Population: Case Series and Literature Review." *International Journal of Social Psychiatry*. 54. 3 (2008) 219-222
- ⁶⁹¹ Dekel, Sharon, Varda Stanger, Emily R. Georgakopolous, Caren M. Steuebe. "Peripartum Depression, Traditional Culture and Israeli Society." *Journal of Clinical Psychology: In Session*. 72.8 (2016) 784-794
- ⁶⁹² Biale , Rachel *Women and Jewish Law*, 137
- ⁶⁹³ Dekel Sharon, et al. *Peripartum Depression*. 784-794; Posmontier, Bobbie and Kathleen M. Fisher. *Narratology*
- ⁶⁹⁴ Weinberger-Litman, Sarah L., Laura A. Rabin, Joshua Fogel, Janell L. Mensinger, Leib Litman. "Psychosocial Mediators of the Relationship Between Religious Orientation and Eating Disorder Risk Factors in Young Jewish Women." *Psychology of Religion and Spirituality*. 8.4 (2016) 265-276; Shafran, Yigal and Joel B. Wolowelsky. "A note on eating disorders and appetite and satiety in the orthodox Jewish meal." *Eat. Weight Disorders*. 18 (2013) 75-78; ; Dancyger, Ida, Victor Fornari, Martin Fisher, Marcie Schneider, Shawn Frank, Willo Wisotsky, Cristina Sison, Marina Charitou. "Cultural factors in orthodox Jewish adolescents treated in a day program for eating disorders." *International Journal of Adolescent Medicine and Health*. 4.4 (2002) 317-328
- ⁶⁹⁵ Shafran, Yigal and Joel B. Wolowelsky. *A Note*. 75-78
- ⁶⁹⁶ Dancyger, Ida, et al. *Cultural Factors*. 317-328
- ⁶⁹⁷ Dancyger, Ida, et al. *Cultural Factors*. 317-328; Feinson, Marjorie C., Tzipi Hornik-Lurie. "Body Dissatisfaction and the Relevance of Religiosity: A Focus on Ultra-Orthodox Jews in a Community Study of Adult Women." *Clin. Social Work*. 44. (2016) 87-97
- ⁶⁹⁸ Dancyger, Ida, et al. *Cultural Factors*. 317-328
- ⁶⁹⁹ Biale , Rachel *Women and Jewish Law* 137
- ⁷⁰⁰ Biale , Rachel *Women and Jewish Law* 160
- ⁷⁰¹ Biale , Rachel *Women and Jewish Law* 151
- ⁷⁰² Talmud Tractate Niddah
- ⁷⁰³ Biale , Rachel *Women and Jewish Law* 173
- ⁷⁰⁴ Haimov-Kochman, Ronit and Chana Adler, Eliana Ein-Mor, Daniel Rosenak, Arye Hurwitz. "Infertility associated with Precoital Ovulation in Observant Jewish couples; Prevalence, treatment, efficacy and side effects." *Israel Medical Association Journal*. 14: 2012. 10; Ganzel, Tova, Deena Rachel Zimmerman. "Hormonal Intervention for Religious Concerns: A Halakhic and Ethical Discussion." *Nashim: A Journal of Jewish Women's Studies and Gender Issues*. 21. (2011) 114-129
- ⁷⁰⁵ Haimov-Kochman, Ronit et al, *Infertility, 10-20*; Ganzel, Tova. *Hormonal Intervention*. 114-129
- ⁷⁰⁶ Haimov-Kochman, Ronit et al, *Infertility, 10-20*; Ganzel, Tova. *Hormonal Intervention*. 114-129
- ⁷⁰⁷ Vishne, Tali, et al. *Psychiatric Disorders*.
- ⁷⁰⁸ Biale , Rachel *Women and Jewish Law* 173
- ⁷⁰⁹ Vishne, Tali, et al. *Psychiatric Disorders*.
- ⁷¹⁰ Ivry, Tsipy. "Kosher medicine and medicalized halacha: An exploration of triadic relations among Israeli rabbis, doctors, and infertility patient" *Journal of the American Ethnological Society*. 37:4, 2010. 663
- ⁷¹¹ Ivry, Tsipy, *Kosher Medicine* 663

- 712 Jotkotwitz, Alan. "The Seminal Contribution of Rabbi Moshe Feinstein to the Development of Modern Jewish Medical Ethics." *Journal of Religious Ethics*. (2014) 285-309
- 713 Jotkotwitz, Alan. *Seminal Contribution*. 285-309
- 714 Jotkotwitz, Alan. *Seminal Contribution*. 285-309
- 715 www.webmd.com
- 716 Haimov-Kochman, Ronit et al, *Infertility*, 10-40
- 717 Haimov-Kochman, Ronit et al, *Infertility*, 10-40
- 718 Kelly, David F., Gerald Magill and Henk ten Have. *Contemporary Catholic Health Care Ethics*. Washington DC: Georgetown University Press, 2013, 124
- 719 Haimov-Kochman, Ronit et al, *Infertility*, 10-40
- 720 Haimov-Kochman, Ronit et al, *Infertility*, 10-40
- 721 www.jpost.com
- 722 McEvoy, Phil, et al. *Mental health care* 3-10
- 723 Yoelit Tikvah Lipinsky. *Hepsed & Bechi: Halakha, Bioethics and Post-Mortem Artificial Insemination*. 2015. 6-5
- 724 Babylonian Talmud Tractate Rosh Hashanna 28a-b
- 725 Michael Paasche-Orlow, The Ethics of Cultural Competency Academic Medicine, 70. 4. 2004; Aaron M. Block, Ezra Gabbay, Samatha F. Knowlton, Joseph J. Fins Psychiatry, Cultural Competency and the Care of Ultra-Orthodox Jews: Achieving Secular and Theocentric Convergence Through Introspection. *Journal of Religion and Health*. 57. 2018
- 726 Mbugua, K. "Respect for Cultural Diversity and the Empirical Turn in Bioethics: A Plea for Caution." *J Med Ethics Hist Med* 5 (2012):
- 727 Racine E. Which Naturalism for Bioethics? A Defense of Moderate (Pragmatic) Naturalism, *Bioethics* 2008; 22(2): 92-100.
- 728 Lauren MacKenzie, Andrew Hatala. Addressing culture within healthcare settings: the limits of cultural competence and the power of humility. *Canadian Medical Education Journal*. 10. 1. 2019
- 729 Albert R. Jonsen *A Short History of Medical Ethics* 22-23; Mackler 30
- 730 Yoelit Tikvah Lipinsky. *Hepsed & Bechi: Halakha, Bioethics and Post-Mortem Artificial Insemination*. 2015 6
- 731 Babylonian **Talmud** Sanhedrin 37a.
- 732 Bleich David, J. "Survey of Recent Halakhic Periodical Literature: Palliation of Pain," *Tradition: A Journal of Orthodox Jewish Thought*. 36 (2002) 105
- 733 Goodman, Yehuda. "Dynamics of Inclusion and Exclusion: Comparing Mental Illness Narratives of Haredi Male Patients and Their Rabbis." *Culture, Medicine and Psychiatry* 25 (2001): Print, 1313-1321
- 734 Shelton RC, Snively AC, De Jesus M, Othus MD, Allen JD. "HPV vaccine decision-making and acceptance: does religion play a role?" *J Relig Health*. 2013 Dec;52(4):1121-1123
- 735 Shelton RC et al *HPV Vaccine* 1122-1123
- 736 Shelton RC et al *HPV Vaccine* 1123
- 737 Shelton RC et al *HPV Vaccine* 1122-1128
- 738 Sas, Daryl F. and Martinlawrencez, Hannah. "CRISPR-CAS9: The Latest Fashion in Designer Babies." *Ethics and Medicine: An International Journal of Bioethics*. 33. 2. 2017. 5-8
- 739 Sas, Daryl F. et a, "CRISPR", 5
- 740 Sas, Daryl F. et a, "CRISPR", 6-7
- 741 Sas, Daryl F. et a, "CRISPR", 7-10
- 742 Schroeder, Donald, N. 'John Rawls and Contract Theory'. *Soundings: An Interdisciplinary Journal*. 338-340
- 743 Schroeder, Donald N. *Rawls*. 338-340
- 744 Glanz, Jason M., Sophia R. Newcomer, Michael L. Jackson, Saad B. Omer, Robert A. Bednarczyk, Jo Ann Shoup, Frank DeStefano, et al. "White Paper on Studying the Safety of the Childhood Immunization Schedule in the Vaccine Safety Datalink." A1
- 745 Macdonald, Geraldine Jody et al. "Immunizing Children" *Current Canadian Health Professional Competencies*. 2-5
- 746 Freed, Gary L. Sarah J. Clark, Amy T. Butchart, Dianne C. Singer, Matthew M. Davis. *Vaccine*. 656-657
- 747 Glanz, Jason M. et al. *White Paper*. A4-A9
- 748 Juliet R. Cuichon, Ian Mitchell, Patricia Buffler, Art Caplan. Citizens intervention in a religious ban on in-school HPV vaccine administration in Calgary, Canada. *Preventative Medicine*. 57. 2014
- 749 Juliet R. Cuichon, Ian Mitchell, Patricia Buffler, Art Caplan. Citizens intervention in a religious ban on in-school HPV vaccine administration in Calgary, Canada. *Preventative Medicine*. 57. 2014
- 750 Catholic Medical Association. Position paper on HPV 2007
- 751 Catholic Medical Association. Position paper on HPV 2007
- 752 Kimberly Schiel Zoberi. A Physician's View of the Ethics of HPV Vaccination. *Healthcare Ethics USA* 2017
- 753 Kimberly Schiel Zoberi. A Physician's View of the Ethics of HPV Vaccination. *Healthcare Ethics USA* 2017
- 754 Fisher et al. Barriers to Human Papillomavirus Vaccine Acceptability in Israel. *Vaccine*. 31S 2013
- 755 Ben Natan et al. Attitude of Israeli Mothers with Vaccination of their Daughters Against Human Papilloma Virus. *Journal of Pediatric Nursing*. 26. (2011); Ben Natan et al. Intention of Mothers in Israel to Vaccinate Their Sons against the Human Papilloma Virus. *Journal of Pediatric Nursing* 2017
- 756 Daniel Gordon et al. "Attitudes to HPV vaccination among mothers in the British Jewish community for accepting or declining the vaccine". *Vaccine* 29. (2011)

- ⁷⁵⁷ Daniel Gordon et al. "Attitudes to HPV vaccination among mothers in the British Jewish community for accepting or declining the vaccine." *Vaccine* 29. (2011)
- ⁷⁵⁸ Bleich, J. David. "Survey of Recent Halakhic Periodical Literature." *Tradition: A Journal of Orthodox Jewish Thought* 26, no. 1 (1991): 53
- ⁷⁵⁹ Bleich, David J. *Vaccines*, 53-55; Daniel Gordon et al. *Attitudes to HPV*, 23
- ⁷⁶⁰ Catholic Health Association of Canada. *Health Ethics Guide*. Ottawa: The Association; 2000. pp. 9–15
- ⁷⁶¹ Kirkwood, Ken. "Catholic bioethical perspectives on Ontario's HPV vaccine." *Open Med.* 2008; 2(4): e111–e113. Published online 2008 Nov 20.
- ⁷⁶² Numbers 25:7-13
- ⁷⁶³ Raz, Aviad E. and Yafa Vizner. "Carrier matching and collective socialization in community genetics: Dor Yeshorim and the reinforcement of stigma."; Ekstein, Josef and Howard Katzenstein. *Advances in Genetics: Chapter 23: The Dor Yeshorim Story: Community-based carrier screening for Tay-Sachs Disease*.
- ⁷⁶⁴ Bahadur, G. (2004). Ethical challenges in reproductive medicine: posthumous reproduction. *International Congress Series*, 295-302.
- ⁷⁶⁵ Zafran, Ruth, "Non-Medical Sex Selection by Preimplantation Genetic Diagnosis: Reflections on Israeli Law and Practice" *North Carolina Journal of Law and Technology*. 9.2. 2008, 200-215
- ⁷⁶⁶ Zafran, Ruth "Non-Medical" 215-217
- ⁷⁶⁷ *Jews and Genes: The Genetic Future in Contemporary Jewish Thought*. Ed. Laurie Zoloth and Elliot N. Dorff 198-199
- ⁷⁶⁸ Sas, Daryl F. and Martinlawrencecz, Hannah. "CRISPR-CAS9: The Latest Fashion in Designer Babies." *Ethics and Medicine: An International Journal of Bioethics*. 33. 2. 2017. 1-3
- ⁷⁶⁹ *Jews and Genes: The Genetic Future in Contemporary Jewish Thought*. Ed. Laurie Zoloth and Elliot N. Dorff, 295
- ⁷⁷⁰ *Jews and Genes: The Genetic Future in Contemporary Jewish Thought*. Ed. Laurie Zoloth and Elliot N. Dorff 195-295
- ⁷⁷¹ *Jews and Genes: The Genetic Future in Contemporary Jewish Thought*. Ed. Laurie Zoloth and Elliot N. Dorff, Mackler 274-275
- ⁷⁷² *Jews and Genes: The Genetic Future in Contemporary Jewish Thought*. Ed. Laurie Zoloth and Elliot N. Dorff Mackler, 275-281
- ⁷⁷³ *Jews and Genes: The Genetic Future in Contemporary Jewish Thought*. Ed. Laurie Zoloth and Elliot N. Dorff 323-324
- ⁷⁷⁴ *Jews and Genes: The Genetic Future in Contemporary Jewish Thought*. Ed. Laurie Zoloth and Elliot N. Dorff 324-327
- ⁷⁷⁵ Ekstein, Josef and Howard Katzenstein. *Advances in Genetics: Chapter 23: The Dor Yeshorim Story: Community-based carrier screening for Tay-Sachs Disease*.
- ⁷⁷⁶ Raz, Aviad E. and Yafa Vizner. "Carrier matching and collective socialization in community genetics: Dor Yeshorim and the reinforcement of stigma."
- ⁷⁷⁷ Raz, Aviad E. and Yafa Vizner. "Carrier matching and collective socialization in community genetics: Dor Yeshorim and the reinforcement of stigma."; Ekstein, Josef and Howard Katzenstein. *Advances in Genetics: Chapter 23: The Dor Yeshorim Story: Community-based carrier screening for Tay-Sachs Disease*.
- ⁷⁷⁸ Jscreen.com (about us)
- ⁷⁷⁹ Ekstein, Josef and Howard Katzenstein. *Advances in Genetics: Chapter 23: The Dor Yeshorim Story: Community-based carrier screening for Tay-Sachs Disease*.
- ⁷⁸⁰ Brand, Yitzchak. "Religious medical ethics: a study of the rulings of Rabbi Waldenberg." *Journal of Religious Ethics*. 38.3. 2010. 495-500
- ⁷⁸¹ Brand, Yitzchak. "Religious ethics" 498-505
- ⁷⁸² Brand Yitzchak. "Religious ethics" 498-505
- ⁷⁸³ *Design and Destiny: Jewish and Christian Perspectives on Human Germline Modification*. Ed. Ronald Cole-Turner. MIT Press. Cambridge, Massachusetts. 2008. 30-39
- ⁷⁸⁴ (Zoloth claims that Jews are seekers of social justice and as a result, would herald the usage of CRISPR since it would create attainable health for all and ease suffering.) *Jews and Genes: The Genetic Future in Contemporary Jewish Thought*. Ed. Laurie Zoloth and Elliot N. Dorff
- ⁷⁸⁵ *Jews and Genes: The Genetic Future in Contemporary Jewish Thought*. Ed. Laurie Zoloth and Elliot N. Dorff 38-50
- ⁷⁸⁶ *Jews and Genes: The Genetic Future in Contemporary Jewish Thought*. Ed. Laurie Zoloth and Elliot N. Dorff 58-64
- ⁷⁸⁷ *Jews and Genes: The Genetic Future in Contemporary Jewish Thought*. Ed. Laurie Zoloth and Elliot N. Dorff 64-65
- ⁷⁸⁸ Sayers, MB. "Analyzing Risk in Medicine and Surgery: A Traditional Jewish Approach" *Ethics and Medicine*. 27.3. 2001. 177-180
- ⁷⁸⁹ Sayers, MB "Analyzing Risk" 177-181
- ⁷⁹⁰ Glick, Shimon M. "Jewish Thoughts" 4-5
- ⁷⁹¹ Steinberg, Avraham. *Encyclopedia of Jewish Medical Ethics*. Fred Rosner, translator. Feldheim Publishers. Jerusalem. 2003. 272-275

- 792 Steinberg, Avraham, *Encyclopaedia*. 273-276
- 793 T Brachot 27a
- 794 Brand Yitzchak. "Religious ethics" 498-505
- 795 Brand Yitzchak. "Religious ethics" 498-505
- 796 Rosner, Fred. "Plastic and Cosmetic Surgery in Judaism." *The American Journal of Cosmetic Surgery*. 17.1 2000. 5-7
- 797 *Jews and Genes: The Genetic Future in Contemporary Jewish Thought*. Ed. Laurie Zoloth and Elliot N. Dorff
- 798 Rosner, Fred. "Plastic and Cosmetic Surgery in Judaism." *The American Journal of Cosmetic Surgery*. 17.1 2000. 5-7
- 799 Rosner Fred. "Plastic Surgery" 5-7
- 800 *Jews and Genes: The Genetic Future in Contemporary Jewish Thought*. Ed. Laurie Zoloth and Elliot N. Dorff 317-319
- 801 Steinberg, Avraham, *Encyclopaedia* 442-449
- 802 Graham, Jesse and Jonathan Haidt. 2010. "Beyond Beliefs: Religions Bind Individuals into Moral Communities." 140
- 803 Cribbs, Adam P. and Sumeth MW Perrera. "Science and Bioethics of CRISPR-Ca9 Gene Editing: An Analysis Towards Separating Fact and Fiction." *Yale Journal of Biology and Medicine*. 90. 2017 625-634
- 804 Cribbs Adam. "Science and Bioethics" 625-634
- 805 Cribbs Adam. "Science and Bioethics" 625-634
- 806 Rosner Fred. "Plastic Surgery" 5-7
- 807 Cribbs Adam. "Science and Bioethics" 625-634
- 808 Loike, John D. "Tampering with Genetic" 42-55; Cribbs Adam. "Science and Bioethics" 625-634
- 809 Bosley, Katrine S. et al. "CRISPR germline engineering—the community speaks." *Nature Biotechnology*. 33.5. 2015. 478-484
- 810 Bosley, Katrine S. et al. "CRISPR" 478-484.
- 811 Pace, Andrew (2004) The Catholic Theology Of Genetic Manipulation, The Linacre Quarterly, 71:3, 254-263,
- 812 Pace, Andrew (2004) The Catholic Theology Of Genetic Manipulation, The Linacre Quarterly, 71:3, 254-263,
- 813 Heavy, Patrick." Synthetic Biology: The Response of the Commission of the (Catholic) Bishops' Conference of the European Community". Special Section: Synthetic Biology: Ethical and Philosophical Challenges. *Cambridge Quarterly of Healthcare Ethics* (2017)
- 814 Heavy, Patrick." Synthetic Biology: The Response of the Commission of the (Catholic) Bishops' Conference of the European Community". Special Section: Synthetic Biology: Ethical and Philosophical Challenges. *Cambridge Quarterly of Healthcare Ethics* (2017)
- 815 Quinn, Gwendolyn P., Devin Murphy, Caprice Knapp, Daniel K. Stearsman, Kathy L. Bradley-Klug, Kelly Sawczyn, and Marla L. Clayman. "Who Decides? Decision Making and Fertility Preservation in Teens With Cancer: A Review of the Literature." *Journal of Adolescent Health*. 49 (2011) 337–34
- 816 Shah, Divya K. , Edward Goldman ' Senait Fisseha. "Medical, ethical, and legal considerations in fertility *International Journal of Gynecology and Obstetrics*. 1115 (2011) 11–15
- 817 Quinn, Gwendolyn P. et al. *Who Decides?*; Shah Divya K. et al *Medical, ethical* 11-15
- 818 Dillon, Katherine E., Clarisa R. Gracia. "Pediatric and Young Adult Patients and Oncofertility." *Current Treatment Options in Oncology*. (2012) 13:161–173
- 819 Zoloth, Laurie. "Chapter 24: Jewish Perspectives on Oncofertility: The Complexities of Tradition." *Oncofertility, Cancer Treatment and Research*. Springer Science+Business Media, LLC 2010
- 820 Dillon, Katherine E. et al. *Pediatric and Young Patients* 165-166.
- 821 Cohn, Felicia. "Chapter 19: Oncofertility and Informed Consent: Addressing Beliefs, Values, and Future Decision Making." *Oncofertility, Cancer Treatment and Research*. Springer Science+Business Media, LLC 2010
- 822 Janson, Per Olof. "Possibilities of fertility preservation in children and young adults undergoing treatment for malignancy." *Acta Obstet Gynecol Scandanavia* 2000; 241
- 823 Janson, Per Olof. "Possibilities of fertility 79; Cohen, Felica, *Oncofertility and Informed Consent*, Wallace, W. Hamish B. "Oncofertility and Preservation of Reproductive Capacity in Children and Young Adults." *Cancer*. 2011
- 824 Janson, Per Olof. "Possibilities of fertility 79; Cohen, Felica, *Oncofertility and Informed Consent*, Wallace, W. Hamish B. "Oncofertility and Preservation of Reproductive Capacity in Children and Young Adults." *Cancer*. 2011
- 825 Wallace, W. Hamish, *Oncofertility* 2308
- 826 Dillon, Katherine E. et al. *Pediatric and Young Patients* 166
- 827 Dillon, Katherine E. et al. *Pediatric and Young Patients* 170
- 828 Dillon, Katherine E. et al. *Pediatric and Young Patients* 169
- 829 Dillon, Katherine E. et al. *Pediatric and Young Patients* 170
- 830 Dillon, Katherine E. et al. *Pediatric and Young Patient* 170
- 831 Jotkowitz, A. The Seminal Contribution of Rabbi Moshe Feinstein to the Development of Modern Jewish Medical Ethics. *Journal of Religious Ethics*. *Journal of Religious Ethics* (2014) 142-143
- 832 Jotkowitz, A. *Seminal Contribution* 143-144.
- 833 Jotkowitz, A. *Seminal Contribution* 295-230
- 834 Zoloth, Laurie *Jewish Oncofertility* 295
- 835 Zoloth, Laurie *Jewish Oncofertility* 298-230
- 836 Pace, Andrew (2004) The Catholic Theology Of Genetic Manipulation, The Linacre Quarterly, 71:3, 254-263,
- 837 Andrew Pace (2004) The Catholic Theology Of Genetic Manipulation, The Linacre Quarterly, 71:3, 254-263,

- 838 Zoloth, Laurie *Jewish Oncofertility* 234
- 839 Zoloth, Laurie *Jewish Oncofertility* 235
- 840 Zoloth, Laurie *Jewish Oncofertility* 235-243
- 841 Zoloth, Laurie *Jewish Oncofertility* 259-303
- 842 Zoloth, Laurie *Jewish Oncofertility* 303
- 843 Zoloth, Laurie *Jewish Oncofertility* 303
- 844 Janson, Per Olof. "Possibilities of fertility
- 845 Andres, Mara M, W.Hamish B Wallace. "Practical and ethical issues for fertility preservation for children and young people with cancer." *Paediatrics and Child Health*. 2009 20:3, 137
- 846 Andres, Mara M et al *Practical and ethical* 137-8
- 847 Stegmann, Barbara J.. "Unique ethical and legal implications of fertility preservation research in the pediatric population." *Fertility and Sterility* Vol. 93, No. 4, March 1, 2010, 1037
- 848 Stegman, Barbara J. *Unique Ethical* 1038
- 849 Janson, Per Olof. "Possibilities of fertility preservation in children and young adults undergoing treatment for malignancy." *Acta Obstet Gynecol Scandanavia* 2000; 7
- 850 Janson, Per Olof. "Possibilities of fertility
- ; Andres Mara M, W.Hamish B Wallace. "Practical and ethical issues for fertility preservation for children and young people with cancer." *Paediatrics and Child Health*. 2009 20:
- 852 Canada Health Act
- 853 Dillon, Katherine E., Clarisa R. Gracia. "Pediatric and Young Adult Patients and Oncofertility." *Current Treatment Options in Oncology*. (2012) 13.; 165
- 854 Dillion, Shelton et al, Zoloth et al
- 855 Zoloth, Laurie. "Chapter 24¹³: Jewish Perspectives on Oncofertility: The Complexities of Tradition." *Oncofertility, Cancer Treatment and Research*. Springer Science+Business Media, LLC 2010, 364-5
- 856 Zoloth, Laurie *Jewish Oncofertility* et al, 365-7
- 857 Zoloth, Laurie *Jewish Oncofertility* 199-203
- 858 Zoloth, Laurie *Jewish Oncofertility* 199-203
- 859 Zoloth, Laurie *Jewish Oncofertility* 203
- 860 Wellesley, Hugo , Ian Jenkins. "Consent in children." *Anesthesia and Intensive Care Medicine*. 2009. 10:4
- 861 Wellesley, Hugo et al. *Consent*, 196-198
- 862 Bird, Sarah. "Consent to medical treatment: the mature minor." *Australia Family Physician*. Vol. 40, No.3, 2011. 158-160;
- Cohen, Cynthia B. "Ethical Issues Regarding Fertility Preservation in Adolescents and Children." *Pediatric Blood Cancer* .2009;53:249-253
- 863 Bird, Sarah *Consent to treatment*, 159-160
- 864 Cohen, Cynthia B. *Ethical Issues*, 252-3;
- 865 Wellesley, Hugo et al. *Consent*, 198
- 866 Wellesley, Hugo et al. *Consent*, 198
- 867 Wellesley, Hugo et al. *Consent*, 198
- 868 Wellesley, Hugo et al. *Consent*, 198
- 869 Hill, Douglas L., Victoria A. Miller, Kari R. Hexem, Karen W. Carroll, Jennifer A. Faerber, Tammy Kang, and Chris Feudtner. 2015. "Problems and Hopes Perceived by Mothers, Fathers and Physicians of Children Receiving Palliative Care." *Health Expectations* 18 (5): 1052-1061
- 870 Hill, Douglas L. et al *Problems and Hopes* 1061-1062
- 871 Hill Douglas L. et al *Problems and Hopes* 1062
- 872 Marcus, Brian S. et al. "Comparison of viewpoint of healthcare professionals with or without involvement with formal ethics processes on the role of ethics committees and hospitals in the resolution of clinical ethical dilemmas." *Clinical Ethics*. (2015.) 10. 22-23
- 873 Marcus, Brian et al. *Comparison*; Savulescu, Julian. "Two worlds apart: religion and ethics." *Journal of Medical Ethics*. (1998) 24 383; Orr, Robert D. and Leigh B. Genesen. "Requests for 'inappropriate' treatment based on religious beliefs." *Journal of Medical Ethics*. (1997.) 23. 142-147
- 874 Savulescu, Julian. *Worlds Apart*. 382-384
- 875 Messikomer, Carla M. Renee C. Fox, Judith P. Swazey. "The Presence and Influence of Religion in American Bioethics." *Perspectives in Biology and Medicine*. (2001.) 44. 485-490
- 876 Orr, Robert D. and Leigh B. Genesen. "Requests for 'inappropriate' treatment based on religious beliefs." *Journal of Medical Ethics*. (1997.) 23. 142-147; Messikomer, Carla M. Renee C. Fox, Judith P. Swazey. "The Presence and Influence of Religion in American Bioethics." *Perspectives in Biology and Medicine*. (2001.) 44. 485-490
- 877 Festic, E. ME Wilson, O. Gajic, GD Divertie, JT Rabatin. "Perspectives of physicians and nurses regarding end of life care in the intensive care unit." *Journal of Intensive Care Medicine*.(2012.) 27. 47.
- 878 Festic, E. et al. "Perspectives." 47-50
- 879 www.gwish.org
- 880 Buryaska, James F. "Assessing the ethical weight of cultural, religious and spiritual claims in the clinical context." *Journal of Medical Ethics*. (2001) 27, 118-122

- ⁸⁸¹ Buryska, James F. "Assessing weight." 120-122
- ⁸⁸² Orr, Robert D. and Leigh B. Genesen. "Requests for 'inappropriate' treatment based on religious beliefs." *Journal of Medical Ethics*. (1997.) 23. 142-147; Messikomer, Carla M. Renee C. Fox, Judith P. Swazey. "The Presence and Influence of Religion in American Bioethics." *Perspectives in Biology and Medicine*. (2001.) 44. 485-490; Marcus, Brian et al. *Comparison*; Savulescu, Julian. "Two worlds apart: religion and ethics." *Journal of Medical Ethics*. (1998); Cadge, Wendy, Elaine Howard Ecklund, Nicholas Short. "Religion and Spirituality: A Barrier and A Bridge in the Everyday Professional Work of Pediatric Physicians." *Social Problems*. (56.) 702-719; ⁸⁸² Carter, Brian, et al. "Why Are There" 98-101; Moskop, John C. "Moral Conflicts and Religious Convictions: What Role for Clinical Ethics Consultants?" *HEC Forum*. (2018.) 3-9
- ⁸⁸³ Richmond, Moeller, Jessica et al. "clinical medical ethics committee" 99-102
- ⁸⁸⁴ Silverman, Henry J. , Emily Bellavance, Brian H. Childs. "Ensuring Quality in Clinical Ethics Consultations: Perspectives of Ethicists Regarding Process and Prior Training of Consultants" *Health Care Ethics Consultation*. (2013.) 13/. 29-31
- ⁸⁸⁵ Silverman, Henry J. , Emily Bellavance, Brian H. Childs. "Ensuring Quality in Clinical Ethics Consultations: Perspectives of Ethicists Regarding Process and Prior Training of Consultants" *Health Care Ethics Consultation*. (2013.) 13/. 29-31; Marcus, Brian S. et al. "Comparison" 31-33
- ⁸⁸⁶ Silverman, Henry J. , Emily Bellavance, Brian H. Childs. "Ensuring Quality in Clinical Ethics Consultations: Perspectives of Ethicists Regarding Process and Prior Training of Consultants" *Health Care Ethics Consultation*. (2013.) 13/. 29-31; Marcus, Brian S. et al. "Comparison" 31-33
- ⁸⁸⁷ Richmond Moeller, Jessica. Et al. "Functions and Outcomes" 100-101
- ⁸⁸⁸ Richmond Moeller, Jessica. Et al. "Functions and Outcomes" 100-101
- ⁸⁸⁹ Henrick Bulow et al Are religion and religiosity important to end-oflife decisions and patient autonomy in the ICU? The Ethicatt study; Bandidni Julia et al. The Role of religious beliefs in ethics committee consultations for conflict over life-sustaining treatment. *Journal of Medical Ethics*; Orr, Robert D. and Leigh B. Genesen. "Requests for 'inappropriate'. 140
- ⁸⁹⁰ Bandidni Julia et al. The Role of religious beliefs in ethics committee consultations for conflict over life-sustaining treatment. *Journal of Medical Ethics*
- ⁸⁹¹ Orr, Robert D. and Leigh B. Genesen. "Requests for 'inappropriate'. 140
- ⁸⁹² Beauchamp, Tom L. and Childress, James F. *Principles of Biomedical Ethics*. Seventh edition. Oxford University Press: Oxford, 2013 113-114; 137
- ⁸⁹³ Orr, Robert D. and Leigh B. Genesen. "Requests for 'inappropriate'. 137-140
- ⁸⁹⁴ Beauchamp and Childress, *Principles* 138-141
- ⁸⁹⁵ Beauchamp and Childress, *Principles* 39-140
- ⁸⁹⁶ Beauchamp and Childress, *Principles*. 138-141
- ⁸⁹⁷ Beauchamp and Childress, *Principles*. 138-139
- ⁸⁹⁸ Beauchamp and Childress, *Principles*. 139-140
- ⁸⁹⁹ Orr, Robert D. and Leigh B. Genesen. "Requests for 'inappropriate'. 140
- ⁹⁰⁰ Henrick Bulow et al Are religion and religiosity important to end-oflife decisions and patient autonomy in the ICU? The Ethicatt study; Bandidni Julia et al. The Role of religious beliefs in ethics committee consultations for conflict over life-sustaining treatment. *Journal of Medical Ethics*
- ⁹⁰¹ Orr, Robert D. and Leigh B. Genesen. "Requests for 'inappropriate'. 138-140
- ⁹⁰² Keshet, Yael. "Coping." 1147-1150
- ⁹⁰³ Keshet, Yael. "Coping." 1147-1150
- ⁹⁰⁴ Maria McDonald, Lecture to University of Toronto Medical Students, Ethics Training, October 2018
- ⁹⁰⁵ Carter, Brian, et al. "Why Are There So Few Ethics Consults in Children's Hospitals?" *HEC Forum*. (2018). 30. 95-100
- ⁹⁰⁶ Carter, Brian, et al. "Why Are There" 98-101; Thomas, Stefanie M. et al. "Not just little adults: a review of 102 pediatric ethics consultations." *Acta Paediatrica*. (2015.) 104. 530-533
- ⁹⁰⁷ Ross, Lainie Friedman. *Children in medical research. Access versus protection*. New York: Oxford University Press, 2006. 95-98
- ⁹⁰⁸ American Academy of Pediatrics Policy via the website.
- ⁹⁰⁹ Bird, Sarah. "Consent to medical treatment: the mature minor." *Australia Family Physician*. (2011.) Vol. 40. 1-5
- ⁹¹⁰ Bird, Sarah. *Consent* 2-6
- ⁹¹¹ Bird, Sarah. *Consent* 2-6
- ⁹¹² Carter, Brian, et al. "Why Are There" 98-101;
- ⁹¹³ Carter, Brian, et al. "Why Are There" 98-101; Moskop, John C. "Moral Conflicts and Religious Convictions: What Role for Clinical Ethics Consultants?" *HEC Forum*. (2018.) 3-9; Thomas, Stefanie M. et al. "Not just little adults" 530-533
- ⁹¹⁴ Thomas, Stefanie M. et al. "Not just little adults" 530-533
- ⁹¹⁵ Haxem, Karen et al. "How Parents of Children Receiving Pediatric Palliative Care Use Religion, Spirituality, or Life Philosophy in Tough Times." *Journal of Palliative Medicine*. Volume 14, Number 1, 2011; Barbara Jones and Sherri Wesisenfluh. "Pediatric Palliative and end of life care. Developmental and spiritual issues of dying children". *Smith College Studies in Social Work*; Lori Wiener et al. "Cultural and religious considerations in pediatric palliative care." *Palliative and Supportive care* 2013
- ⁹¹⁶ Cadge, Wendy, Elaine Howard Ecklund, Nicholas Short. "Religion and Spirituality: A Barrier and A Bridge in the Everyday Professional Work of Pediatric Physicians." *Social Problems*. (56.) 702-719
- ⁹¹⁷ Cadge, Wendy et al. "Barrier and Bridge." 710-715

-
- ⁹¹⁸ Thomas, Stefanie M. et al. "Not just little adults" 530-533
- ⁹¹⁹ Thomas, Stefanie M. et al. "Not just little adults" 530-533
- ⁹²⁰ Thomas, Stefanie M. et al. "Not just little adults" 530-533
- ⁹²¹ Thomas, Stefanie M. et al. "Not just little adults" 530-533; Cadge, Wendy et al. "Barrier and Bridge." 710-715
- ⁹²² Carter, Brian, et al. "Why Are There?" 98-101; Moskop, John C. "Moral Conflicts and Religious Convictions: What Role for Clinical Ethics Consultants?" *HEC Forum*.(2018.) 3-9; Thomas, Stefanie M. et al. "Not just little adults" 530-533
- ⁹²³ Puchalski, O'Donnell, 116.)
- ⁹²⁴ Birchley, Giles. "Deciding Together? Best Interests and Shared Decision-Making in Paediatric Intensive Care." *Health Care Anal.* (2014.) 22. 203-210
- ⁹²⁵ Birchley, Giles. "Deciding Together?" 210-218
- ⁹²⁶ Birchley, Giles. "Deciding Together?" 210-218
- ⁹²⁷ Birchley, Giles. "Deciding Together?" 210-218
- ⁹²⁸ Alderson, Priscilla and Virginia Morrow. *The Ethics of Research with Children and Young People.* 102-103
- ⁹²⁹ Alderson, Priscilla et al *Ethics* 103
- ⁹³⁰ Ross, *Children* 95-98
- ⁹³¹ Alderson, Priscilla, et al *Ethics* 197-108
- ⁹³² Wellesley, Hugo et al. *Consent* 125
- ⁹³³ Bird , Sarah. *Consent*
- ⁹³⁴ Cohen, Cynthia B. "Ethical Issues Regarding Fertility Preservation in Adolescents and Children." *Pediatric Blood Cancer* . 2009;53:249-25
- ⁹³⁵ Harcourt, Deborah and Jonathon Sargeant. *Doing Ethical Research with Children.* UK. McGraw-Hill Education, 2012, 75-78 70-80
- ⁹³⁶ Alderson, Priscilla et al, *Ethics* 85; Sargeant, *Research* 75-78
- ⁹³⁷ Sargeant, *Research* 75-76
- ⁹³⁸ Alderson, Priscilla, et al *Ethics* 86-88
- ⁹³⁹ Ford, K., J. Sankey, and J. Crisp. "Development of Children's Assent Documents Using a Child-Centred Approach." *J Child Health Care* 11.1 (2007): 19-28.
- ⁹⁴⁰ Ford, KJ et al *Development of Assent* 20-28
- ⁹⁴¹ Beauchamp, Thomas L. and James F. Childress, *Principles of Biomedical Ethics.* New York, Oxford University Press, 2013, 116
- ⁹⁴² Beauchamp and Childress, *Principles* 116-124
- ⁹⁴³ Beauchamp and Childress, *Principles* 104-110; 113-116
- ⁹⁴⁴ Brusha, Margherita and Y. Michael Barilan. "Cultural Circumscion in EU Public Hospitals. An Ethical Discussion." *Bioethics.* (2009.) 23. 470-482
- ⁹⁴⁵ Bock, Gregory L. "Making Martyrs of our Children: Religiously Based Requests in Pediatrics." *Ethics and Medicine.*(2012.) 89-96
- ⁹⁴⁶ Bock, Gregory L. "Martyrs" 89-96
- ⁹⁴⁷ Bock, Gregory L. "Martyrs" 89-96
- ⁹⁴⁸ Anderson, Laurie M., et al. "Culturally Competent Healthcare Systems." *American Journal of Preventive Medicine* 24.3 (2003): 68-79. 2273
- ⁹⁴⁹ Alberta Health Services accessed online <https://www.albertahealthservices.ca/assets/programs/ps-1026227-health-care-religious-beliefs.pdf>
- ⁹⁵⁰ Alberta Health Services accessed online <https://www.albertahealthservices.ca/assets/programs/ps-1026227-health-care-religious-beliefs.pdf>
- ⁹⁵¹ Fisher, H. R., C. McKeivitt, and A. Boaz. "Why Do Parents Enroll Their Children in Research: A Narrative Synthesis." *J Med Ethics* 37.9 (2011): 544-51
- ⁹⁵² Fisher, HR, et al, *Why Research?*544-51
- ⁹⁵³ Fisher HR, et al, *Why Research?*544-51?
- ⁹⁵⁴ Fisher, HR, et al, *Why Research?*544-51?
- ⁹⁵⁵ Cherry, *Familial*
- ⁹⁵⁶ Cherry, *Familial*
- ⁹⁵⁷ Will, Jonthan F. "My God My Choice: The Mature Minor Doctrine and Adolescent Refusal of Life-Saving or Sustaining Medical Treatment Based Upon Religious Beliefs. ." *Contemp. Health Law and Policy* 22 (2006). Print.
- ⁹⁵⁸ Hayes, *Resolving*
- ⁹⁵⁹ Hayes, *Resolving*
- ⁹⁶⁰ Young, Anna R., James R. Thobaben, "Pragmatic Moral Problems and the Ethical Interpretation of Pediatric Pain," *Christian bioethics: Non-Ecumenical Studies in Medical Morality*, Volume 17, Issue 3, December 2011, 243-276
- ⁹⁶¹ Young, Anna R. *Pragmatic Morals* 250-270
- ⁹⁶² Puchalski, O'Donnell, 116.)
- ⁹⁶³ Lebediger, Israel. "The Minor in Jewish Law." *The Jewish Quarterly Review*, New Series, 6, no. 4 (1916): 459-93.
- ⁹⁶⁴ Lebenginer, Israel *The Minor* 460-489
- ⁹⁶⁵ Lebenginer, Israel *The Minor* 460-489

- ⁹⁶⁶ Lebeginer, Israel *The Minor* 460-489
- ⁹⁶⁷ Lebeginer, Israel *The Minor* 460-489
- ⁹⁶⁸ Bleich David, J. "Survey of Recent Halakhic Periodical Literature: Palliation of Pain," *Tradition: A Journal of Orthodox Jewish Thought*. 36 (2002) 103-104
- ⁹⁶⁹ Jotkowitz, Alan."Nomos and Narrative in Jewish Law: The Care of the Dying Patient and the Prayer of the Handmaid," *Modern Judaism*. 33 (2013) 104
- ⁹⁷⁰ Jotkowitz, Alan *Nomos* 104
- ⁹⁷¹ Beauchamp, Thomas L. and James F. Childress, *Principles of Biomedical Ethics*. New York, Oxford University Press, 2013 131-136; 133
- ⁹⁷² Bleich, David J. *Palliation* 104
- ⁹⁷³ Bleich, David J. *Palliation* 105
- ⁹⁷⁴ Beauchamp and Childress, *Principles* 139-140
- ⁹⁷⁵ Beauchamp and Childress, *Principles* 140
- ⁹⁷⁶ Hayes, *Resolving*
- ⁹⁷⁷ Fisher, H. R., C. McKeivitt, and A. Boaz. "Why Do Parents Enroll Their Children in Research: A Narrative Synthesis." *J Med Ethics* 37.9 (2011): 544-51?
- ⁹⁷⁸ Wilson, Robin Fretwell "The Calculus of Accommodation: Contraception, Abortion, Same-Sex Marriage, and Other Clashes between Religion and the State", 1417-1419
- ⁹⁷⁹ Bassett, W.W. "Private religious hospitals: limitations upon autonomous moral choices in reproductive medicine." 2001 *J Contemp Health Law Policy*. 441-447
- ⁹⁸⁰ Will, Jonathan F. "My God My Choice: The Mature Minor Doctrine and Adolescent Refusal of Life-Saving or Sustaining Medical Treatment Based Upon Religious Beliefs. ." *Contemp. Health Law and Policy* 22 (2006). Print.
- ⁹⁸¹ Beauchamp, Thomas L. and James F. Childress, *Principles of Biomedical Ethics*. New York, Oxford University Press, 2013, 119
- ⁹⁸² Beauchamp and Childress, *Principles* 119;
- ⁹⁸² Brody, Howard and Arlene Macdonald. "Religion and bioethics: towards an expanded understanding." (2013.) 34. 138-143.;
- ⁹⁸³ Brody, Howard and Arlene Macdonald. "Religion and bioethics: towards an expanded understanding." (2013.) 34. 138-143.
- ⁹⁸⁴ Brody, Howard. "Religion and bioethics." 140-143
- ⁹⁸⁵ Schmidt, Katharina, et al. "Applying the Analytic Hierarchy Process in healthcare research: a systematic literature review and evaluation of reporting." *BMC Medical informatics and Decisions Making*. (2015), 10-12; Greenberger, Chaya. "The hierarchy of values in Jewish bioethics." *Nursing Ethics*.(2011.) 1-Greenberger, Chaya. "The hierarchy" 7-10
- ⁹⁸⁶ Greenberger, Chaya. "The hierarchy of values in Jewish bioethics." *Nursing Ethics*.(2011.) 1-7
- ⁹⁸⁷ Schmidt, Katharina et al. "AHP" 20-27
- ⁹⁸⁸ Beauchamp "Principles"; Drane JF. "Competency to give an informed consent. A model for making clinical assessments." *JAMA*. 1984 Aug 17;252(7):925-7; Jonsen,Albert R. Mark Siegler, and William J. Winslade. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*, Seventh Edition. McGraw Hill Education. 2015
- ⁹⁸⁹ Birchley, Giles. "Deciding Together? Best Interests and Shared Decision-Making in Paediatric Intensive Care." *Health Care Anal.* (2014.) 22. 210-218
- ⁹⁹⁰ Case Study adapted from Mendola, Anette. "Faith and Futility in the ICU" *Hastings Center Report*. (2015.) 9-11
- ⁹⁹⁰ Jonsen,Albert R. Mark Siegler, and William J. Winslade. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*, Seventh Edition. McGraw Hill Education. 2015
- ⁹⁹⁰ Macklin, Ruth "Standard of Care: an evolution in ethical thinking" *The Lancet*. 2008. 372. 284-5
- ⁹⁹⁰ Moffett P, Moore G. The standard of care: legal history and definitions: the bad and good news. *West J Emerg Med*. 2011;12(1):109-112.
- ⁹⁹⁰ Moffett P, Moore G. The standard of care: legal history and definitions: the bad and good news. *West J Emerg Med*. 2011;12(1):109-112.
- ⁹⁹⁰ <https://www.cmpa-acpm.ca/en/site-resources/glossary-of-terms#content-for-s>
- ⁹⁹⁰ Hapenny, Sandra S. "Appeal to Conscience Clauses in the Face of Divergent Practice among Catholic Hospitals." PhD diss. Baylor University, 2011..
- ⁹⁹¹ Jonsen,Albert R. Mark Siegler, and William J. Winslade. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*, Seventh Edition. McGraw Hill Education. 2015
- ⁹⁹² Macklin, Ruth "Standard of Care: an evolution in ethical thinking" *The Lancet*. 2008. 372. 284-5
- ⁹⁹³ Moffett, Moore Standard definition , 284-5
- ⁹⁹⁴ Moffett, Moore Standard definition, 284-5
- ⁹⁹⁵ <https://www.cmpa-acpm.ca/en/site-resources/glossary-of-terms#content-for-s>
- ⁹⁹⁶ Hapenny, Sandra S. "Appeal to Conscience Clauses in the Face of Divergent Practice among Catholic Hospitals." PhD diss. Baylor University, 2011..

BIBLIOGRAPHY

- “Doctors say he’s dead. Jewish law says he’s alive. Can a hospital turn off life support?” CBC News Online, February 15, 2018. . <https://www.cbc.ca/news/canada/toronto/shalom-ouanounou-arguments-1.4536864> accessed Feb. 2019
- “Judge declines to rule in case on Ontario’s definition of death.” CBC News Online , November 13, 2018; <https://www.cbc.ca/news/canada/toronto/shalom-ouanounou-case-moot-decision-1.4904343>; accessed Feb 2019
- Alberta Health Services accessed online <https://www.albertahealthservices.ca/assets/programs/ps-1026227-health-care-religious-beliefs.pdf> Feb. 2016
- Alderson, Priscilla and Virginia Morrow. *The Ethics of Research with Children and Young People*. 102-103
- Allmark, Peter, Mark Cobb, B. Jane Liddle and Angela Mary Tod.”Is the Doctrine of Double Effect Irrelevant in End-of-Life Decision Making?” *Nursing Philosophy*. 11.1 2010 170
- Anderson, Laurie M., et al. "Culturally Competent Healthcare Systems." *American Journal of Preventive Medicine* 24.3 (2003): 68-79.
- American Academy of Pediatrics Policy accessed via <https://www.aap.org/en-us/Documents/Bioethics-InformedConsent.pdf>
- Aries, Philippe: *Western attitudes towards death: From the Middle Ages to the present*. The Johns Hopkins University Press, Baltimore, 1974.
- Atwood, Melissa A. Raymond G. Hoffmann, KeYan, , K. Jane Lee. 2013. “Attitudes About Palliative Care.” *American Journal of Hospice and Palliative Medicine* 31(6) , 665-667
- Babylonian Talmud Brachot online access www.sefira.org
- Babylonian Talmud Eruvin online access www.sefira.org
- Babylonian Talmud Niddah online access www.sefira.org
- Babylonian Talmud Sanhedrin online access www.sefira.org
- Babylonian Talmud, Yoma online access www.sefira.org
- Bahadur, G. (2004). Ethical challenges in reproductive medicine: posthumous reproduction. *International Congress Series* , 295-302.
- Bandini, Julia, et al. “The role of religious beliefs in ethics committee consultations for conflict over life-sustaining treatment.” *Journal of Medical Ethics*. (2017.) 43. 353-356
- Barilan, Y. “The New Israeli Law on the Care of the Terminally Ill: conceptual innovations
- Baron, JH, “Mount Sinai—A Brief History”. *Mount Sinai Journal of Medicine* 67 (1) 3-5
- Baskin, Judith R. “Infertile Wife in Rabbinic Judaism.” *Jewish Women A Comprehensive Historical Encyclopedia*. <http://jwa.org/encyclopedia/article/infertile-wife-in-rabbinic-judaism>
- Bassett, W.W. “Private religious hospitals: limitations upon autonomous moral choices in reproductive medicine.” 2001 *J Contemp Health Law Policy*. 17(2):488.
- Beauchamp, Thomas L. and James F. Childress, *Principles of Biomedical Ethics*. New York, Oxford University Press, 2013, 119-20
- Benini, Franca Marco Spizzichino, Manuela Trapanotto, and Anna Ferrante.2008. “Pediatric palliative care” *Italian Journal of Pediatrics*. (34) , 3
- Bentacourt , Joseph R. *Defining* 293-302; Schnall, Eliezer, Solomon Kalkstein, Ayelet Gottesman, Karyn Feinberg, Charles B. Schaeffer and S. Shalom Feinberg. “Barriers to Mental Health Care: A 25 Year Follow-up Study of the Orthodox Jewish Community.” *Journal of Multicultural Counseling and Development*. 42. (2014) 161-172
- Bentacourt, Joseph R., Alexander R. Green and J. Emilio Carrillo. “Cultural Competence in Health Care: Emerging Frameworks and Practical Approaches. Field Report.” *The Commonwealth Fund*. 2002 1-40;
- Bentacourt, Joseph R., Alexander R. Green, J. Emilio Carrillo and Owusu Annaneh-Firemping II. “Defining Cultural Competence: A Practical Framework for Addressing Racial/Ethnic Disparities in Health and Healthcare.” *Public Health Reports*. 118.4 (2003) 293-302;

- Berger, B. (2008). Cultural Limits of Legal Tolerance, The. *Canadian Journal of Law and Jurisprudence* 21(2), 245-278.;
- Berger, B. (2015). Belonging to law: Religious difference, secularism, and the conditions of civic inclusion. *Social & Legal Studies*, 24(1), 47-64.
- Biale, Rachel. *Women and Jewish Law: The Essential Texts, Their History, and Their Relevance for Today*. Schocken Press, 1995.
- Birchley, Giles. "Deciding Together? Best Interests and Shared Decision- Making in Pediatric Intensive Care. *Health Care Analysis*. (2013) 22;3), 210-218
- Bird, Sarah. "Consent to medical treatment: the mature minor." *Australia Family Physician*. Vol. 40, No.3, 2011.
- Bleich David, J. "Survey of Recent Halakhic Periodical Literature: Palliation of Pain," *Tradition: A Journal of Orthodox Jewish Thought*. 36 (2002) 90-108
- Bleich, David J. . "Palliation of Pain." *Tradition* 36:1 2002 89-90
- Bock, Gregory L. "Making Martyrs of our Children: Religiously Based Requests in Pediatrics." *Ethics*
- Bosley, Katrine S. et al. "CRISPR germline engineering—the community speaks." *Nature Biotechnology*. 33.5. 2015.
- Brafman, Yonathan Yisrael. "Critical Philosophy of Halakha (Jewish law): The Justification of Halakhic Norms of Authority" PhD diss. Columbia University, 2014.
- Brand, Yitzchak. "Religious medical ethics: a study of the rulings of Rabbi Waldenberg." *Journal of Religious Ethics*. 38.3. 2010. 495-500
- Brody, Howard and Arlene Macdonald. "Religion and bioethics: towards an expanded understanding." (2013.) 34. 140-143
- Buchbinder, Eliezer Witztum and Jacob T. "Strategic Culture Sensitive Therapy with Religious Jews." *International Review of Psychiatry* 13 (2001): 117-24. Print.
- Bulow, Hans-Henrik et al. "Are religion and religiosity important to end of life decisions and patient autonomy in the ICU? The Ethicatt Study." *Intensive Care Medicine*. (2012.) 38. 1126-1132
- Buryska, James F. "Assessing the ethical weight of cultural, religious and spiritual claims in the clinical context." *Journal of Medical Ethics*. (2001) 27, 118-122
- Cadge, Wendy, Elaine Howard Ecklund, Nicholas Short. "Religion and Spirituality: A Barrier and A Bridge in the Everyday Professional Work of Pediatric Physicians." *Social Problems*. (56.) 702-719;
- Callahan, Daniel: *The Troubled Dream of Life: In Search of a Peaceful Death* (Simon & Schuster, 1993; Georgetown University Press, 2004), 81
- Carter, Brian, et al. "Why Are There So Few Ethics Consults in Children's Hospitals?" *HEC Forum*. (2018). 30. 95-100
- Canadian Protective Medical Association. <https://www.cmpa-acpm.ca/en/site-resources/glossary-of-terms#content-for-s> accessed October 1st 2020
- Cassell, Eric J: *The nature of suffering and the goals of medicine*. Oxford University Press, New York/Oxford, 2nd edition, 2004
- Catholic Care Providers of Canada statement website www.ccpc.ca
- Catholic Health Alliance of Canada, Health Ethics Guide, 3rd edition, (2013) accessed online, specifically, chapter 3, 4 and 7 www.chac.ca
- Cavanaugh, Thomas A. "The ethics of death-hastening or death-causing palliative analgesic administration to the terminally ill" *Journal of Pain and Symptom Management* (4) 1996 248-254
- Center for Organ Recovery and Education. www.core.org. Accessed August 2020
- Cohen, Cynthia B. "Ethical Issues Regarding Fertility Preservation in Adolescents and Children." *Pediatric Blood Cancer* .2009;53:249–253
- Cohn, Felicia. "Chapter 19- Oncofertility and Informed Consent: Addressing Beliefs, Values, and Future Decision Making." *Oncofertility, Cancer Treatment and Research*. Springer Science+Business Media, LLC 2010

- Coleman-Brueckheimer, K. and S. Dein, "Health Care Behaviours and Beliefs in Hasidic Jewish Populations: A Systematic Review of the Literature," *J Relig Health* 50, no. 2 (2011).
- Coleman-Brueckheimer, K., and S. Dein. "Health Care Behaviours and Beliefs in Hasidic Jewish Populations: A Systematic Review of the Literature." *J Relig Health* 50.2 (2011): 422-36. Print.
- Coleman, GD. "Direct and indirect abortion in the Roman Catholic tradition: a review of the Phoenix case." *HEC Forum*, 2013 Jun;25(2): 128
- Craig, David Melville. 2008. "Religious values in the health care market: stories and structures from Catholic and Jewish hospitals." *Journal Of The Society Of Christian Ethics* 28, no. 2: 226-228
- Cribbs, Adam P. and Sumeth MW Perrera. "Science and Bioethics of CRISPR-CaS9 Gene Editing: An Analysis Towards Separating Fact and Fiction." *Yale Journal of Biology and Medicine*. 90. 2017 625-634
- Cuichon, Juliet R. , Ian Mitchell, Patricia Buffler, Art Caplan. "Citizens intervention in a religious ban on in-school HPV vaccine administration in Calgary, Canada." *Preventative Medicine*. 57. 2014
- Daaleman, TP and VanderCreek, L. "Placing religion and spirituality in end -of -life care" *JAMA*. (2000.) 15. 2514-5
- Dalberg, Todd, Elizabeth Jacob-Files, Patricia A. Carney, Jeffrey Meyrowitz, Erik K. Fromme, and Gregory Thomas. 2013. "Pediatric Oncology Providers Perceptions of Barriers and Facilitators to Early Integration of Pediatric Palliative Care." *Pediatric Blood & Cancer* 60 (11): 1878-1879
- Dancyger, Ida, Victor Fornari, Martin Fisher, Marcie Schneider, Shawn Frank, Willo Wisotsky, Cristina Sison, Marina Charitou. "Cultural factors in orthodox Jewish adolescents treated in a day program for eating disorders." *International Journal of Adolescent Medicine and Health*. 4.4 (2002) 317-328
- Daniel Gordon et al. "Attitudes to HPV vaccination among mothers in the British Jewish community for accepting or declining the vaccine". *Vaccine* 29. (2011)
- Dekel, S., et al. "Peripartum Depression, Traditional Culture, and Israeli Society." *J Clin Psychol* 72.8 (2016): 784-94.
- Design and Destiny: Jewish and Christian Perspectives on Human Germline Modification*. Ed. Ronald Cole-Turner. MIT Press. Cambridge, Massachusetts. 2008.
- Devi, Sharmila. "Mental Health and Religion in Israel's Ultra-Orthodox Jews." *The Lancet* 366.9496 (2005): 1516-17.
- Dillon, Katherine E., Clarisa R. Gracia. "Pediatric and Young Adult Patients and Oncofertility." *Current Treatment Options in Oncology*. (2012) 13:161–173
- Dougherty CJ¹, Purtilo R. "Physicians' duty of compassion." *Camb Q Healthc Ethics*. 1995 Fall;4(4):426-33.;
- Drane JF. "Competency to give an informed consent. A model for making clinical assessments." *JAMA*. 1984 Aug 17;252(7):925-7;
- Dugdale, Lydia (ed.): *Dying in the twenty-first century. Toward a new ethical framework for the art of dying well*. The MIT Press, Cambridge (MA) and London (England), 2015, 74
- Durante, Chris. "Agreeing to Disagree: Indigenous Pluralism from Human Rights to Bioethics" *Journal of Religious Ethics*. (2009) 37(3):513 - 529
- Elior, Rachel. "The Origins of Hasidism." *Scripta Judaica Cracoviensia*.10 (2012): 85-109
- Encyclopedia of Jewish Medical Ethics* Avraham Steinberg; translated Fred Rosner. Feldham Publishers. Jerusalem, Israel. 2003
- Engelhardt, Tristram H. Jr. "Reason, Reasonableness and Rawls: Some Skeptical Reflections on Bioethics." *The Dialogue. Yearbook of Philosophical Hermeneutics Reason and Reasonableness* . 2004.
- Erez, Rina, Stanley Rabin, Louis Shenkman and Eliezer Kitai. "A Family Physician in an Ultraorthodox Jewish Village." *Journal of Religion and Health*. 38.1 (1999) 67-71
- Ethical and Religious Directives for Catholic Health Care Services* Fifth Edition. 2009, 3-5
- Ezekiel J Emanuel et al. (eds.): *The Oxford Textbook of Clinical Research Ethics*. Oxford

- Feinson and Meir; *ibid.*; T. Vishne, S. Misgav, and M. E. Bunzel, "Psychiatric Disorders Related to Menstrual Bleeding among an Ultra-Orthodox Population: Case Series and Literature Review," *Int J Soc Psychiatry* 54, no. 3 (2008)
- Feinson, M. C., and A. Meir. "Disordered Eating and Religious Observance: A Focus on Ultra-Orthodox Jews in an Adult Community Study." *Int J Eat Disord* 45.1 (2012): 101-9.
- Feinson, Marjorie C., and Tzipi Hornik-Lurie. "Body Dissatisfaction and the Relevance of Religiosity: A Focus on Ultra-Orthodox Jews in a Community Study of Adult Women." *Clinical Social Work Journal* 44.1 (2016): 87-97.
- Festic, E. ME Wilson, O. Gajic, GD Divertie, JT Rabatin. "Perspectives of physicians and nurses regarding end of life care in the intensive care unit." *Journal of Intensive Care Medicine*.(2012.) 27. 47
- Filerman, Gary L. Anne E. Mills, Paul M. Schyve, eds. *Managerial Ethics in Healthcare: A New Perspective*. Chicago IL: Health Administration Press, 2014
- Fisher, H. R., C. McKeivitt, and A. Boaz. "Why Do Parents Enroll Their Children in Research: A Narrative Synthesis." *J Med Ethics* 37.9 (2011): 544-51?
- Flannelly, Kevin et al. "A Systematic Review of Religion and Spirituality in Three Palliative Care Journals, 1990-1999." *Journal of Palliative Care* (2004) 20(1):50-6
- Flood, Colleen M. "Just Medicare: The Role of Canadian Courts in Determining Health Care Rights and Access." *Journal of Law, Medicine and Ethics*. Vol. 33. 2005
- Ford, K., J. Sankey, and J. Crisp. "Development of Children's Assent Documents Using a Child-Centred Approach." *J Child Health Care* 11.1 (2007): 19-28.
- Foster Angel M., et al "Do Religious Restrictions Influence Ectopic Pregnancy Management? A National Qualitative Study." *Policy Matters*. (2011.) 21:2, 104-5
- Freedman Lori R; Uta Landy; Jody Steinauer "When There's a Heartbeat: Miscarriage Management in Catholic-Owned Hospitals." 2008 *American Journal of Public Health* Volume 98; Issue 10, 1776
- Freund, A., and T. Band-Winterstein. "Cultural Psychiatry: A Spotlight on the Experience of Clinical Social Workers' Encounter with Jewish Ultra-Orthodox Mental Health Clients." *Community Ment Health J* 53.5 (2017): 613-25.
- Friedrichsdorf, SJ, S Remke, B Symalla, C Gibbon, and J Chrastek. 2007. "Developing a pain and palliative care programme at a US children's hospital." *International Journal Of Palliative Nursing* 13, no. 11: 534
- Galek, Kathleen, Kevin J. Flannelly, Harold G. Koenig, and Rev. Sarah L. Fogg. "Referrals to chaplains: The role of religion and spirituality in healthcare settings" *Mental Health, Religion & Culture* Vol. 10 :4, 2007, 370-380;
- Ganzel, Tova, Deena Rachel Zimmerman. "Hormonal Intervention for Religious Concerns: A Halakhic and Ethical Discussion." *Nashim: A Journal of Jewish Women's Studies & Gender Issues* 21 (2011): 114-29.
- Gawande, Atul: *Being mortal. Medicine and what matters in the end*. Metropolitan Books, Henry Holt and Company, New York, 2014, 26-27
- Gelhaus, Petra. "The Desired Moral Attitude of the Physician: (II) Compassion." *Med Health Care Philos* 15 (4), 397-410.2012, 400
- Genesen, Leigh and Robert Orr, . "Requests for 'inappropriate' treatment based on religious beliefs." *Journal of Medical Ethics*. (1997.) 23. 142-147
- Gill, Robin. *Health Care and Christian Ethics* Cambridge University Press: New York. 2006
- Gilmer, Mary Jo , Terrah L. Foster, Cynthia J. Bell, John Mulder, Brian S. Carter. 2012. "Parental Perceptions of Care of Children at End of Life." *American Journal of Hospice and Palliative Medicine* 30(1) , 55-57
- Glick, Shimon M. "Some Jewish thoughts on genetic enhancement." *Journal of Medical Ethics*. 37. 2011.
- Goldstein, David B. *Jacob's Legacy: A Genetic View on Jewish History*. New Haven: Yale 2008
- Goodman, Yehuda. "Dynamics of Inclusion and Exclusion: Comparing Mental Illness Narratives of Haredi Male Patients and Their Rabbis." *Culture, Medicine and Psychiatry* 25 (2001): 169-94.

- Gould, Jillian. "A Nice Piece of Cake and a Kibitz: Reinventing Sabbath Hospitality in an Institutional Home" *Home Cultures: The Journal of Architecture, Design and Domestic Space*.(2013.) 10:2, 189-206
- Grazi, R. V., & Wolowelsky, J. B. (2001). Parenthood From the Grave. *The Jewish Spectator* ,65 (4), 398
- Festic, E. ME Wilson, O. Gajic, GD Divertie, JT Rabatin. "Perspectives of physicians and nurses regarding end of life care in the intensive care unit." *Journal of Intensive Care Medicine*.(2012.) 27. 47
- Greenberg, David, and Witztum, Eliezer. 2001. *Sanity and Sanctity : Mental Health Work Among the Ultra-Orthodox in Jerusalem*. New Haven: Yale University Press. Accessed October 20, 2017. ProQuest Ebook Central.
- Greenberger, Chaya. "The hierarchy of values in Jewish bioethics." *Nursing Ethics*.(2011.) 1-11
- Greenblum, Jake. "Public reason and the limited right to conscientious objection: a response to Magelssen." *Journal of Medical Ethics*. (2018). 44:3. 206-208
- GW Institute for Spirituality and Health. www.gwish.org Accessed March 2018
- Haimov-Kochman, R., et al. "Infertility Counseling for Orthodox Jewish Couples." *Fertil Steril* 93.6 (2010): 1816-9.
- Halakhic Organ Donor Society. www.hods.org Accessed March 2018
- Halakhic Realities: Collected Essays on Brain Death*. Ed Zev Farber. Maggid Press. New York,
- Halakhic Realities: Collected Essays on Organ Donation*. Ed Zev Farber. Maggid Press. New
- Hapenny, Sandra S. "Appeal to Conscience Clauses in the Face of Divergent Practice among Catholic Hospitals." PhD diss. Baylor University, 2011.
- Harcourt, Deborah and Jonathon Sargeant. *Doing Ethical Research with Children*. UK. McGraw-Hill Education, 2012,
- Hatano, Yutaka, Miwa Yamada, and Kenji Fukui. 2011. "Shades of Truth: Cultural and Psychological Factors Affecting Communication in Pediatric Palliative Care." *Journal of Pain and Symptom Management* 41 (2): 491-495
- Haxem, Karen et al. "How Parents of Children Receiving Pediatric Palliative Care Use Religion, Spirituality, or Life Philosophy in Tough Times." *Journal of Palliative Medicine*. Volume 14, Number 1, 2011;
- Health Canada. *Canada Health Act* (R.S.C., 1985, c. C-6). Department of Justice. Assessed online, November 22nd, 2011
- Heavy, Patrick." Synthetic Biology: The Response of the Commission of the (Catholic) Bishops' Conference of the European Community". Special Section: Synthetic Biology: Ethical and Philosophical Challenges. *Cambridge Quarterly of Healthcare Ethics* (2017)
- Heilman, Samuel C., Eliezer Witztum. "Value-Sensitive Therapy: Learning from Ultra-Orthodox Patients." *American Journal of Psychotherapy*. 51.4 (1997) 522-540
- Heyland DK, Frank C, Tranmer J, Paul N, Pichora D, Jiang X, Day AG. "Satisfaction with end-of-life care: a longitudinal study of patients and their family caregivers in the last months of life." *J Palliat Care*. 2009 Winter;25(4):245-56
- Hill, Douglas L., Victoria A. Miller, Kari R. Hexem, Karen W. Carroll, Jennifer A. Faerber, Tammy Kang, and Chris Feudtner. 2015. "Problems and Hopes Perceived by Mothers, Fathers and Physicians of Children Receiving Palliative Care." *Health Expectations* 18 (5): 1061
<https://www.natlawreview.com/article/religious-accommodation-and-patient-safety-healthcare-industry>
- Huppert, Jonathan D., Jedidiah Siev, and Elyssa S. Kushner. "When Religion and Obsessive-Compulsive Disorder Collide: Treating Scrupulosity in Ultra-Orthodox Jews." *Journal of Clinical Psychology*. 63.10 (2007)
- Ida Dancyger, Victor Fornari, Martin Fisher, Marcie Schneider, Shawn Frank, Willo Wisotsky, Cristina Sison, Marina Charitou. "Cultural Factors in Orthodox Jewish Adolescents Treated in a Day Program for Eating Disorders " *Int. J. Adolesc. Med. Health* 14.4 (2002): 317-28.
- Ivry, T., E. Teman, and A. Frumkin. "God-Sent Ordeals and Their Discontents: Ultra-Orthodox Jewish Women Negotiate Prenatal Testing." *Soc Sci Med* 72.9 (2011): 1527-33.

-
- Ivry, Tsipy. "Kosher Medicine and Medicalized Halacha: An Exploration of Triadic Relations among Israeli Rabbis, Doctors, and Infertility Patients." *American Ethnologist* 37.4 (2010): 662-80. Print.
- Janson, Per Olof. "Possibilities of fertility preservation in children and young adults undergoing treatment." *Jews and Genes: The Genetic Future in Contemporary Jewish Thought*. Ed. Laurie Zoloth and Elliot N. Dorff.
- Jones, Barbara and Sherri Wesisenfluh. "Pediatric Palliative and end of life care. Developmental and spiritual issues of dying children". *Smith College Studies in Social Work* (2003) 73:3, 423-443
- Jonsen Albert R *A Short History of Medical Ethics* New York Oxford University Press 2000
- Jonsen, Albert R. Mark Siegler, and William J. Winslade. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*, Seventh Edition. McGraw Hill Education. 2015
- Joseph R. Betancourt, Alexander R. Green, J. Emilio Carrillo, Owusu Ananeh-Firempong II. "Defining Cultural Competence: A Practical Framework for Addressing Racial/Ethnic disparities in Health and Health Care." *Public Health Reports* 118.4 (2003): 293-302.
- Joseph R. Betancourt, Alexander R. Green, J. Emilio Carrillo. "Cultural Competence in Health Care: Emerging Frameworks and Practical Approaches Field Report " *The Commonwealth Fund* (2002): 1-40.
- Jotkotwitz, A. (2014). The Seminal Contribution of Rabbi Moshe Feinstein to the Development of Modern Jewish Medical Ethics. *Journal of Religious Ethics*. . *Journal of Religious Ethics* , 142 - 143
- Jotkowitz, Alan. "Nomos and Narrative in Jewish Law" *Modern Judaism* 33:1 2013 56-5861-62
- JPS Tanakh: The Holy Scriptures , 1985
- Swazey, Judith P.. "The Presence and Influence of Religion in American Bioethics." *Perspectives in Biology and Medicine*. (2001.) 44. 485-490
- Kelly, David F., Gerald Magill and Henk ten Have. *Contemporary Catholic Health Care Ethics*.. Washington DC: Georgetown University Press, 2013, 134-135
- Keshet, Yael. Ido Liberman. "Coping with Illness and Threat: Why Non-religious Jews Choose to Consult Rabbis on Healthcare Issues." *Journal of Religion and Health*. (2014). 53. 1146;
- Schiel Zoberi, Kimberly. "A Physician's View of the Ethics of HPV Vaccination." *Healthcare Ethics USA* 201
- Kinzbrunner, Barry M. "Jewish Medical Ethics and End-of-Life Care" *Journal of Palliative Medicine*. 7:4 2004 563-564
- Kirkwood, Ken. " Catholic bioethical perspectives on Ontario's HPV vaccine." *Open Med*. 2008; 2(4) 111-113.
- Kislowicz, H. (2013, Fall; 2015/12). "Sacred laws in earthly courts: Legal pluralism in Canadian religious freedom litigation" *Canadian Journal of Law and Society*. (2013) Fall 2015 12.
- Kislowicz, H. (2015). Law, Religion, and Feeling Included/Excluded: Case Studies in Canadian Religious Freedom Litigation. *Canadian Journal of Law and Society* 30(3), 365-380. Cambridge University Press.
- Klick, Jeffery C., Sarah Friebert, Nancy Hutton, Kaci Osenga, Kenneth J. Pituch, Tamara Vesel, Norbert Weidner, Susan D. Block, Laura J. Morrison. "Developing Competencies for Pediatric Hospice and Palliative Medicine". *Pediatrics* Dec 2014, 134 (6) 1670-1671
- Kolarik, Russ C. Gena Walker and Robert M. Arnold. "Pediatric resident education in palliative care: a needs assessment." 2006. *Pediatrics*. (6), 1949
- Latzer, Yael, Sarah L. Weinberger-Litman, Barbara Gerson, Anna Rosch, Rebecca Mischel, Talia Hinden, Jeffrey Kilstein, Judith Silver. "Negative Religious Coping Predicts Disordered Eating Pathology Among Orthodox Jewish Adolescent Girls." *J. Religion and Health*. 54. (2015) 1760-177
- Lebendiger, Israel. "The Minor in Jewish Law." *The Jewish Quarterly Review*, New Series, 6, no. 4 (1916): 459-93.

- Liaschenko, J. and Peter, E. (2016), Fostering Nurses' Moral Agency and Moral Identity: *The Importance of Moral Community Hastings Center Report*, 46: S18–S1
- Lipinsky, Yoelit Tikvah. *Hepsed & Bechi: Halakha, Bioethics and Post-Mortem Artificial Insemination*. 2016 Unpublished MA thesis. University of Toronto. Department of Religion. Joint Centre for Bioethics. Centre for Jewish Studies. Supervised by Dr. David Novak and Dr. Tirzah Meacham.
- Lutz, S (2011). "The history of hospice and palliative care". *Current problems in Cancer*, 35 304-30
- MacKenzie, Laura, Andrew Hatala. Addressing culture within healthcare settings: the limits of cultural competence and the power of humility. *Canadian Medical Education Journal*. 10. 1. 2019
- Mackler, Aaron L. *Introduction to Jewish and Catholic Bioethics: A Comparative Analysis*. Georgetown University Press. Washington, DC. 2003.
- Mackler, Aaron L. "Respecting bodies and saving lives: Jewish perspectives on organ donation and transplantation." (2001) *Camb Q Healthc Ethics*. Fall;10(4):420
- Macklin, Ruth "Standard of Care: an evolution in ethical thinking" *The Lancet*. 2008. 372. 284-5
- Marienberg, Evyatar. "Traditional Jewish Sexual Practice and Their Possible Impact on Jewish Fertility and Demography." *Harvard Theological Review* 106.3 (2013): 243-86.
- Mbugua, K. "Respect for Cultural Diversity and the Empirical Turn in Bioethics: A Plea for Caution." *J Med Ethics Hist Med* 5 (2012):
- McCarthy, Melissa. "Religious influences in Public Schools: The Winding Path Towards Accommodation" *Saint Louis University Public Law Review*. (2004) 23:2. 565-596
- McDonough, Mary J.. *Can a Healthcare Market be Moral? A Catholic Vision*. Washington, D.C. : Georgetown University Press, 2007,
- McEvoy, P., et al. "Improving Access to Mental Health Care in an Orthodox Jewish Community: A Critical Reflection Upon the Accommodation of Otherness." *BMC Health Serv Res* 17.1 (2017): 557. Print.
- Melin-Johansson, Christina, Inge Axelsson, Marie Jonsson Grundberg, and Frida Hallqvist. 2014. "When a Child Dies: Parents' Experiences of Palliative Care—An Integrative Literature Review." *Journal of Pediatric Nursing* 29 (6): 661
- Mendola, Anette. "Faith and Futility in the ICU" *Hastings Center Report*. (2015.) 9-11
- Messikomer, Carla M. Renee C. Fox, Judith P. Swazey. "The Presence and Influence of Religion in American Bioethics." *Perspectives in Biology and Medicine*. (2001.) 44. 485-490;
- Merriam Webster Legal Dictionary.
<https://www.merriam-webster.com/legal/reasonable%20accommodation> . Accessed August 2020
- Miller, Victoria A., William W. Reynolds, and Robert M. Nelson. "Parent–Child Roles in minors?" *Journal of Medical Ethics*. (2013) 456
- Moffett P, Moore G. The standard of care: legal history and definitions: the bad and good news. *West J Emerg Med*. 2011;12(1):109-112.
- Moskop, John C. "Moral Conflicts and Religious Convictions: What Role for Clinical Ethics Consultants?" *HEC Forum*.(2018.) 3-9
- Narayan, Mary Curry. "Six Steps Towards Cultural Competence: A Clinician's Guide." *Home Health Care Management and Practice* 14.1 (2001): 40-48.
- O'Rourke, Kevin. What Happened in Phoenix?: The complicated reasons behind an abortion at a Catholic hospital. *America The Jesuit Review*. June 21, 2010
- Olick, Robert S. Eli A. Braun, and Joel Potash, "Accommodating Religious and Moral Objections to Neurological Death," *The Journal of Clinical Ethics* 20, no. 2 (2009): 183-91.
- Ontario Human Rights Commission Undue Hardship Policy <http://www.ohrc.on.ca/en/policy-preventing-discrimination-based-mental-health-disabilities-and-addictions/14-undue-hardship>. Accessed August 2020
- Ontario Human Rights Commission. Discrimination (mental health) Policy
<http://www.ohrc.on.ca/en/policy-preventing-discrimination-based-mental-health-disabilities-and-addictions>. Accessed August 2020

-
- Orr, Robert D. "The Role of Moral Complicity in Issues of Conscience." *The American Journal of Bioethics* (2007) 7 (12): 23-24
- Paascheorlow, Michael. "The Ethics of Cultural Competence." *Academic Medicine*. 2004 79 (4). 347-9
- Pace, Andrew "The Catholic Theology Of Genetic Manipulation," *The Linacre Quarterly*, (2004) 71:3,
- Padela, Aasim I., and Farr A. Curlin. "Religion and Disparities: Considering the Influences of Islam on the Health of American Muslims." *Journal of Religion and Health Partnership* /. Saskatoon: Commission on the Future of Health Care in Canada, Commission sur l'avenir des soins de santé au Canada, 2002. Print.
- Pellegrino, Edmund D. 1993. "Societal Duty and Moral Complicity: The Physician's Dilemma of Divided Loyalty." *International Journal of Law and Psychiatry* 16 (3-4): 371-391
- Pijnenburg, Martien A. M. and Bert Gordijn. 2005. "Identity and Moral Responsibility of Healthcare Organizations." *Theoretical Medicine and Bioethics* 75-77
- Podcast- *Israel Story* "The Needle" Episode 46. Accessed via <https://www.tabletmag.com/podcasts/israel-story/israel-story-the-needle>
- Popovsky, R. M. "Special Issues in the Care of Ultra-Orthodox Jewish Psychiatric in-Patients." *Transcult Psychiatry* 47.4 (2010): 647-72.
- Posmontier, B., and K. M. Fisher. "A Narratology of Postpartum Psychosis in an Orthodox Jewish Woman." *Perspect Psychiatr Care* 50.3 (2014): 167-77.
- Puchalski, Christina M. and Edward O'Donnell. "Religious and spiritual beliefs in end of life care: how major religions view death and dying." *Pain Management*. (2005.) 9 (3) 114-121
- Quinn, Gwendolyn P., Devin Murphy, Caprice Knapp, Daniel K. Stearsman, Kathy L. Bradley-Klug, Kelly Sawczyn, and Marla L. Clayman. "Who Decides? Decision Making and Fertility Preservation in Teens With Cancer: A Review of the Literature." *Journal of Adolescent Health*. 49 (2011) 337-346
- Racine E. "Which Naturalism for Bioethics? A Defense of Moderate (Pragmatic) Naturalism", *Bioethics* 2008; 22(2): 92-100.
- Rahimzadeh, Vasiliki Gillian Bartlett, Cristina Longo, Laura Crimi, Mary Ellen Macdonald, Nada Jabado, et al. 2015 "Promoting an ethic of engagement in pediatric palliative care research" *BMC Palliative Care*. 14, 2
- Rapoport, Adam. Christopher Obwanga, Giovanna Sirianni, S. Lawrence Librach, and Amna Husain. "Not Just Little Adults: Palliative Care Physician Attitudes Toward Pediatric Patients" *Journal of Palliative Medicine*. May 2013, 16(6), 677
- Raz, Aviad E. and Yafa Vizner. "Carrier matching and collective socialization in community genetics: Dor Yeshorim and the reinforcement of stigma.";
- Ekstein, Josef and Howard Katzenstein. *Advances in Genetics: Chapter 23: The Dor Yeshorim Story: Community-based carrier screening for Tay-Sachs Disease*.
- Reichman, D. E., et al. "In Vitro Fertilization for Orthodox Jewish Couples: Antagonist Cycle Modifications Allowing for Mikveh Attendance before Oocyte Retrieval." *Fertil Steril* 99.5 (2013): 1408-12.
- Rier, D. A., A. Schwartzbaum, and C. Heller. "Methodological Issues in Studying an Insular, Traditional Population: A Women's Health Survey among Israeli Haredi (Ultra-Orthodox) Jews." *Women Health* 48.4 (2008): 363-81.
- Rimon-Zarfaty, Nitzan. "The Israeli abortion committees' process of decision making: an ethical analysis" *Journal of Medical Ethics*; (2012) 38:26 26-27
- Rina Erez, Stanely Rabin, Louis Shenkman and Eliezer Kital. "A Family Physician in an Ultraorthodox Jewish Village." *Journal of Religion and Health* 38.1 (1999): 67-71.
- Rogers, Susan, Carlos Gomez, Philip Carpenter, Jean Farley, Debbie Holson, Miriam Markowitz, Brian Rood, Karen Smith, and Peter Nigra. 2011. "Quality of Life for Children with Life-Limiting and Life-Threatening Illnesses: Description and Evaluation of a Regional, Collaborative Model for Pediatric Palliative Care." *American Journal of Hospice and Palliative Medicine* 28 (3): 163-164

-
- Rosen, Daniel D., et al. "Stigma of Mental Illness, Religious Change, and Explanatory Models of Mental Illness among Jewish Patients at a Mental-Health Clinic in North Jerusalem." *Mental Health, Religion & Culture* 11.2 (2008): 193-209.
- Rosner, Fred. "Plastic and Cosmetic Surgery in Judaism." *The American Journal of Cosmetic Surgery*. 17.1 2000. 5-7
- Ross, Lainie Friedman. *Children in medical research. Access versus protection*. New York:
- Rubinstein, Jeffery L.. "Can A Goses Survive for More Than Three Days? The History and Definition of Goses". *The Journal of Jewish Ethics*. 2:2 2016 5-6
- Russell-Meyer, Richard. "Cultural Competence and End-of-Life Care: Religion, Spirituality and Health Care Decision Making." MA diss. Wake Forest University. 2016
- Russo, Charles J. "Religious and Public Schools: A Forty Year Retrospective." *Religion & Education*. (2003) 31:2. 1-22
- Sahler, Olle Jane Z. Gerri Frager, Marcia Levetown, Felicia G. Cohn, and Michael A. Lipson. Pediatrics. 2000. "Medical Education About End-of-Life Care in the Pediatric Setting: Principles, Challenges, and Opportunities" 575-576
- Savage, John. "Can children consent to medical treatment?" *Irish Medical Times*; Oct 14, 2011; 45, 40; ProQuest Central pg. 38
- Savulescu, Julian. "Two worlds apart: religion and ethics." *Journal of Medical Ethics*. (1998) 24 383;
- Sayers, MB. "Analyzing Risk in Medicine and Surgery: A Traditional Jewish Approach" *Ethics and Medicine*. 27.3. 2001. 177-180
- Schmidt, Katharina, et al. "Applying the Analytic Hierarchy Process in healthcare research: a systematic literature review and evaluation of reporting." *BMC Medical informatics and Decisions Making*. (2015)
- Schnall, Eliezer, et al. "Barriers to Mental Health Care: A 25-Year Follow-up Study of the Orthodox Jewish Community." *Journal of Multicultural Counseling and Development* 42.3 (2014):161-73
- Schroeder, Donald, N." John Rawls and Contract Theory." *Soundings: An Interdisciplinary*
- Schuklenk, Udo. "Conscientious Objection in Medicine: Private Ideological Convictions must not Supersede Public Service Obligations." *Bioethics*. (2015) 29:5.
- Schwarz, Ernst and Salvatore Rosanio. 2011. "Religion and the Catholic Church's View on (Heart) Transplantation: A Recent Statement of Pope Benedict XVI and its Practical Impact." *Journal of Religion and Health* 50 (3): 564-574;
- Sullivan, Scott M. "The Development and Nature of the Ordinary/Extraordinary Means Distinction in the Roman Catholic Tradition. *Bioethics*. 21:7 2007, 391-393
- Shafran, Yigal and Joel B. Wolowelsky. "A note on eating disorders and appetite and satiety in the orthodox Jewish meal." *Eat. Weight Disorders*. 18 (2013) 75-78; ;
- Shah, Divya K. , Edward Goldman ' Senait Fisseha. "Medical, ethical, and legal considerations in fertility preservation." *International Journal of Gynecology and Obstetrics*. 1115 (2011) 11–15
- Shaw, David M. "Justice and the Fetus: Rawls, Children and Abortion." *Cambridge Quarterly of Healthcare Ethics*. (2011) 20: 93-101
- Shelton, Rachel C., Anna C. Snaveley, Maria De Jesus, Megan D. Othus, Jennifer D. Allen. "HPV Vaccine Decision-Making and Acceptance—Does Religion Play a Role?" *Journal of Religion and Health*. 52, 2013. 1121-1123
- Silverman, Henry J. , Emily Bellavance, Brian H. Childs. "Ensuring Quality in Clinical Ethics Consultations: Perspectives of Ethicists Regarding Process and Prior Training of Consultants" *Health Care Ethics Consultation*. (2013.) 13/. 29-31
- Sperling, Daniel and Gabriel Gurman. 2012. "Factors Encouraging and Inhibiting Organ Donation in Israel." *Journal of Bioethical Inquiry* 9 (4): 479-497
- Spitz, Elie. "Through Her I Shall Too Bear A Child: Birth Surrogates in Jewish Law." *The Journal of Religious Ethics*. 1996. 24:4
- Stegmann, Barbara J.. "Unique ethical and legal implications of fertility preservation research in the

-
- pediatric population.” *Fertility and Sterility* Vol. 93, No. 4, March 1, 2010
- Steinberg, Avraham. *Encyclopedia of Jewish Medical Ethics*. Fred Rosner, translator. Feldheim Steinfeld, Rebecca. “Wars of the Wombs: Struggles Over Abortion Policies in Israel.” *Israel Studies*, 2015, 19-22
- Stolovy, Tali, Yvan Moses Levy, Adiel Doron, Yuval Melamed. “Culturally sensitive mental health care: A study of contemporary psychiatric treatment for ultra-Orthodox Jews in Israel.” *International Journal of Social Psychiatry*. 59.8 (2012)
- Stulberg, Debra B. et al. “Religious Hospitals and Primary Care Physicians: Conflicts over Policies for Patient Care.” (2010.) 25:7. 725-730
- Stulberg, Debra B., Rebecca A. Jackson, and Lori R. Freedman. 2016. "Referrals for Services Prohibited in Catholic Health Care Facilities." *Perspectives on Sexual and Reproductive Health* (2016) 48 (3): 111-117
- Sulmasy Daniel P. “Double Effect—Intention is the Solution, Not the Problem” *The Journal of Law, Medicine and Ethics*. 28 2000 27-28
- Fohr, Susan Anderson. “The Double Effect of Pain Medication: Separating Myth from Reality” *Journal of Palliative Medicine*. 1:4 1998 315-318
- Swetz KM, Crowley ME, Maines TD. “What makes a Catholic hospital "Catholic" in an age of religious-secular collaboration? The case of the Saint Marys hospital and the Mayo Clinic” . *HEC Forum*. 2013 Jun;25(2):95-10
- Tan, Gim H. Balagangadhar R. Totapally, Dan Torbati, and Jack Wolfsdorf. End-of-Life Decisions and Palliative Care in a Children's Hospital *Journal of Palliative Medicine*. April 2006, 9(2): 333
- Taylor, Charles. *A Secular Age*. Harvard University Press, 2007
- Teman, E., T. Ivry, and H. Goren. "Obligatory Effort [Hishtadlut] as an Explanatory Model: A Critique of Reproductive Choice and Control." *Cult Med Psychiatry* 40.2 (2016): 268-88.
- The Torah. *JPS Publication Book of Numbers*. Online access
- Thomas, Stefanie M. et al. “Not just little adults: a review of 102 pediatric ethics consultations.” *Acta Paediatrica*. (2015.) 104. 530-533;
- Trappler, Elizabeth Sublette and Brian. "Cultural Sensitivity Training in Mental Health: Treatment of Orthodox Jewish Psychiatric Patients." *International Journal of Social Psychiatry* 46.2 (2000): 122-34. Print.
- Turner, Leigh. “Medical ethics in a multicultural society.” *Journal of the Royal Society of Medicine*.(2001)
- U.S. Equal Employment Opportunity Commission
https://www.eeoc.gov/eeoc/newsroom/wysk/workplace_religious_accommodation.cfm Accessed September 2020
- Veatch, Robert. *Hippocratic, Religious and Secular Medical Ethics. The Points of Conflict*. Georgetown University Press., 2012
- Vishne, T., S. Misgav, and M. E. Bunzel. "Psychiatric Disorders Related to Menstrual Bleeding among an Ultra-Orthodox Population: Case Series and Literature Review." *Int J Soc Psychiatry* 54.3 (2008): 219-24.
- Wachter, Robert M. *Understanding Patient Safety*. New York : McGraw Hill Medical , 2012
- Wallace, W. Hamish B. “Oncofertility and Preservation of Reproductive Capacity in Children and Young Adults.” *Cancer*. 2011.
- Wascher JM, Stulberg DB, Freedman LR. “Restrictions on Reproductive Care at Catholic Hospitals: A Qualitative Study of Patient Experiences and Perspectives.” *AJOB Empir Bioeth*. 2020 Oct-Dec;11(4):257-267
- Weinberger-Litman, Sarah L., et al. "Psychosocial Mediators of the Relationship between Religious Orientation and Eating Disorder Risk Factors in Young Jewish Women." *Psychology of Religion and Spirituality* 8.4 (2016): 265-76.
- Weiner, Lori et al. “Cultural and Religious Considerations in Pediatric Palliative Care.” *Palliative and Supportive Care*. 11. (2013) 47

-
- Weinstock, Daniel. 2014. "Conscientious Refusal and Health Professionals: Does Religion make a Difference?" *Bioethics* 28 (1): 8-15
- Weiss, P., R. Shor, and N. Hadas-Lidor. "Cultural Aspects within Caregiver Interactions of Ultra-Orthodox Jewish Women and Their Family Members with Mental Illness." *Am J Orthopsychiatry* 83.4 (2013): 520-7.
- Wellesley, Hugo , Ian Jenkins. "Consent in children." *Anesthesia and Intensive Care Medicine*. 2009. 10:4
- Werber, Stephen J. 1996. "Ancient answers to modern questions: death, dying, and organ transplants--a Jewish law perspective" *Journal of Law and Health* 11 (1) 13-18
- Whiteley, Charlotte, Adrian Coyle, and Kate Gleeson. "An Idiographic Analysis of Women's Accounts of Living with Mental Health Conditions in Haredi Jewish Communities." *Mental Health, Religion & Culture* 20.3 (2017): 277-93.
- Wiener, Lori, Denice Grady McConnell, Lauren Latella, and Erica Ludi. 2013. "Cultural and Religious Considerations in Pediatric Palliative Care." *Palliative and Supportive Care* 11 (1), 50
- Williams-Reade, Jackie, Angela L. Lamson, Sharon M. Knight, Mark B. White, Sharon M. Ballard, and Priti P. P. Desai. 2015. "Paediatric Palliative Care: A Review of Needs, Obstacles and the Future." *Journal of Nursing Management* 23 (1): 9
- Wilson, Robin Fretwell "The Calculus of Accommodation: Contraception, Abortion, Same-Sex Marriage, and Other Clashes between Religion and the State", *Boston College Law Review*. (2012). 53:4, 1417-1513
- Witztum, Eliezer, David Greenberg and Jacob T. Buchbinder. "'A Very Narrow Bridge:' Diagnosis and Management of Mental Illness among Bratslav Hasidim." *Psychotherapy* 27 (1990): 124-31. Print.
- Witztum, Samuel C. Heilman and Eliezer. "Value-Sensitive Therapy: Learning from Ultra-Orthodox Patients." *American Journal of Psychotherapy* 51.4 (1997): 522-41.
- Witztum, Yehuda Goodman and Eliezer. "Cross-Cultural Encounters between Careproviders: Rabbis' Young, Anna R., James R. Thobaben, "Pragmatic Moral Problems and the Ethical Interpretation of Pediatric Pain," *Christian bioethics: Non-Ecumenical Studies in Medical Morality*, Volume 17, Issue 3, December 2011, 243-276
- Zafran, Ruth, " Non-Medical Sex Selection by Preimplantation Genetic Diagnosis: Reflections on Israeli Law and Practice" *North Carolina Journal of Law and Technology*. 9.2. 2008, 200-215
- Zohar, Noam J. 2003. "Co-Operation Despite Disagreement: From Politics to Healthcare." *Bioethics*
- Zoloth, Laurie. "Chapter 24-Jewish Perspectives on Oncofertility: The Complexities of Tradition." *Oncofertility, Cancer Treatment and Research*. Springer Science+Busi