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“GOOD OF MY PATIENT”: WHO GETS TO DECIDE?

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ABSTRACT

Physicians play a crucial role in helping patients make life or death decisions. However, all healthcare professionals have personal beliefs and biases that influence these decisions. This paper explores how physicians are able to uphold the Hippocratic ideal of doing what is in the best interest of the patient while taking into account their personal beliefs and biases. The paper begins by analyzing existing schools of thought around how to do what is best for the patient. While there are many different views, this paper looks at the main three: the bioethical movement, the paternalistic approach to medicine, and the religiously-inspired ideals of medicine. Upon exploring these approaches, the paper suggests that physicians adopt the subjective Health Belief Model (HBM) when helping patients make life-altering decisions. The paper applies the model to in vitro genetic testing to show the model's positive impact on the physician-patient relationship. The paper concludes by addressing other uses for the HBM and limitations of the model.

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INTRODUCTION

Physicians play an important role in helping patients make life or death decisions. Patients trust their doctors to guide them towards the “right” decision. Thus, it is crucial for physicians to give quality medical care and advice without having personal beliefs tainting the care they provide to patients. Physicians are humans, so it is expected that their personal beliefs will impact their judgment. However, there are some instances where physicians feel their personal viewpoints or morals prevent them from providing treatment or referring patients to other doctors who are willing and able to provide the necessary treatment. Physicians are supposed to, per the Hippocratic Oath, provide care that is “for the good of my patient;” however, when there are external and internal influences that cause a physician to either withhold care or pertinent information, the doctor-patient relationship ultimately suffers.

Take for instance the following story. A woman walks into an abortion clinic and is denied an abortion because the doctor says it is against his religious beliefs. It sounds like the opening to a bad joke, but this is the sad reality for many girls and women. In the fall of 2017, many pregnant, undocumented immigrant girls were in federal custody and denied their right to have an abortion.¹⁰⁶ Although the minor undocumented girls completed the necessary state medical procedures to get an abortion without parental permission, the government found a way to prevent access to counseling or an abortion.¹⁰⁷ Since the girls are living in a shelter that is operated by the United States Conference of Catholic Bishops and funded by grant money from the Department of Health and Human Services, Office of Refugee Resettlement (“ORR”), the government interfered and upheld the religious principles of the shelter.¹⁰⁸ In one instance, an undocumented girl was given an abortion pill¹⁰⁹ without the ORR approving the procedure.¹¹⁰ Once the ORR knew that the girl was given the pill, the ORR director, Scott Lloyd, wrote to the doctor commanding that the girl not be given the second abortion pill.¹¹¹ The federally funded facility where the girl was living pushed back against this order and brought her to the hospital.¹¹² Lloyd intervened again, telling the hospital not to give her the pill unless death was imminent.¹¹³

¹⁰⁶ See Robert Pear, *Do Migrant Teenagers Have Abortion Rights? Two Volatile Issues Collide in Court*, N.Y. TIMES (Sept. 28, 2018), <https://www.nytimes.com/2018/09/29/us/politics/court-abortion-immigrants.html>.

¹⁰⁷ *Id.*

¹⁰⁸ Kanyakrit Vongkiatkajorn, *The ACLU is Suing to Bring Abortion Rights to Migrant Girls*, MOTHER JONES (July 1, 2016, 10:00 AM), <https://www.motherjones.com/politics/2016/07/aclu-lawsuit-hhs-usccb-abortion-services-unaccompanied-minors/>; See Alison Kodjak, *Civil Rights Chief at HHS Defends the Right to Refuse Care on Religious Grounds*, NPR (Mar. 20, 2018, 3:38 PM), <https://www.npr.org/sections/health-shots/2018/03/20/591833000/civil-rights-chief-at-hhs-defends-the-right-to-refuse-care-on-religious-grounds>.

¹⁰⁹ See *The Abortion Pill*, PLANNED PARENTHOOD, <https://www.plannedparenthood.org/learn/abortion/the-abortion-pill> (last visited May 6, 2018) (defining the abortion pill as a non-surgical abortion in which medication is used to bring about abortion. Typically, women and girls are given the first pill in the clinic, and the second pill will be taken orally within 48 hours. The medicine causes cramping and bleeding to empty the uterus).

¹¹⁰ See Ed Pilkington, *Trump Officials Considered Contentious Method to ‘Reverse’ Undocumented Teen’s Abortion*, THE GUARDIAN (Jan. 31, 2018), <https://www.theguardian.com/us-news/2018/jan/31/scott-lloyd-considered-controversial-method-reverse-abortion> (stating that the abortion procedure is unrecognized by the medical profession as a means of reversing abortion).

¹¹¹ *Id.*

¹¹² *Id.*

¹¹³ *Id.*

The hospital went through the necessary medical tests and pushed back against Lloyd's demands.¹¹⁴ Court documents show that in the end, the ORR did allow the girl to go ahead and take the second pill, which terminated her pregnancy.¹¹⁵ However, prior to the termination, "the ORR had made inquiries about the efficacy of administering progesterone as a means of stopping the abortion."¹¹⁶

While this story seems outlandish, it is not uncommon for women to be turned away or dissuaded from getting an abortion. While the exact number of women who are denied abortions annually does not exist, there is data to suggest that women who are turned away tend to have worse life outcomes including higher rates of poverty and increased prevalence of mental health problems.¹¹⁷ In fact, 67% of "turnaways" were below the poverty line compared to 56% of women who got abortions.¹¹⁸ Additionally, the study found that one week after getting the abortion, 97% of women who obtained an abortion felt that abortion was the right decision, whereas 65% of the women who were turned away still wished they had been able to obtain an abortion.¹¹⁹ All of this is to say that, despite the government intervening to protect the minor's best interest, the data shows that getting the abortion was the best thing she could have done.

"According to the World Health Organization ("WHO"), every year 21.6 million women worldwide have an unsafe abortion."¹²⁰ "Of these unsafe abortions, 18.5 million are in developing countries."¹²¹ "Complications from unsafe abortions kill 47,000 women each year; these women make up nearly 13% of all maternal deaths."¹²² These reasons include doctors turning people away on religious grounds, as well as state laws that deny abortions to women after a certain number of weeks.¹²³ In addition to religious and governmental intervention, people are denied medical care for numerous reasons, and many of these reasons have to do with how physicians comply with societal pressure to not uphold the Hippocratic Oath.¹²⁴

Denying a woman an abortion is not the only instance where women are denied medical care for one reason or another.¹²⁵ For example, women are often denied

¹¹⁴ *Id.*

¹¹⁵ *Id.*

¹¹⁶ *Id.*

¹¹⁷ Tara Culp-Ressler, *Denying Women Abortion Access Increases Their Risk of Falling into Poverty*, THINKPROGRESS (Nov. 13, 2012), <https://thinkprogress.org/denying-women-abortion-access-increases-their-risk-of-falling-into-poverty-6c73c7e75e0e/>.

¹¹⁸ *Id.*

¹¹⁹ *Id.*

¹²⁰ Nathalie Baptiste, *This is What Happens When Abortion is Outlawed*, THE AMERICAN PROSPECT (Jun. 17, 2015), <http://prospect.org/article/what-happens-when-abortion-outlawed>. The article states that the number of unsafe abortions in the United States is "miniscule, for now." *Id.* It goes on to caution that as conservative lawmakers find creative ways to undermine *Roe v. Wade*, such as waiting periods, mandatory ultrasounds, and targeted regulation of Abortion Provider bills that single out abortion clinics and subject them to stricter laws than other medical facilities, there will be an increase in the number of women who are left with few legal methods to end their pregnancies. *Id.*

¹²¹ *Id.*

¹²² *Id.*

¹²³ CTR. FOR REPROD. RIGHTS, *The World's Abortion Laws Map 2013 Update*, https://www.reproductiverights.org/sites/crr.civicactions.net/files/documents/AbortionMap_Factsheet_2013.pdf.

¹²⁴ Mary L. Davenport et al., *Right of Conscience for Health-Care Providers*, 79 LINACRE Q. 169, 171 (2012).

¹²⁵ Alexa Kolbi-Molinas, *The Rising Threat of Religious Hospitals Denying Women Medical Care*, ACLU (Feb. 25, 2016, 11:30 AM), <https://www.aclu.org/blog/religious-liberty/using-religion-discriminate/rising->

prescriptions for contraception, and transgender patients are deprived of hormone therapy.¹²⁶ Additionally, women have been prevented from receiving in vitro fertilization or in vitro genetic testing for a myriad reasons.¹²⁷ The ethical dilemma that physicians face when deciding whether to perform a procedure despite the procedure being against the physician's moral values is one that is not easy to solve. However, for any physician to provide quality care that is in the best interest of the patient, the physician must do their best to put their own personal beliefs to the side.

When determining what information will be provided to a patient, a physician is making judgments that are based on their personal beliefs. No matter how good of a doctor one may be, a doctor is human, which means that they have biases, beliefs, morals, values, etc. which all impact the information they are or are not willing to provide a patient. Given that these beliefs have a substantial impact on a patient's quality of care, the question of whether the physician is acting in the best interest of the patient should be considered.

While considering whether the physician is acting in the best interest of their patient, this paper suggests that it is also imperative to contemplate the following four questions:

1. Who should be deciding what should happen to patients in the first place;
2. Should it be the physician who has undergone four years of medical school plus however many years of residency;
3. Should it be left entirely up to the patient or her family; or,
4. Should there be a way for physicians to help guide the patient and her family to a decision?

If we accept the fourth question as the best one; that we should find a way for physicians to help guide families towards making the best decision, then we are left with the question of how to ensure that the physician's advice is entirely unbiased or the least problematic. Before diving into the three existing solutions to the "who gets to decide" question, it is essential to note that no matter how hard a physician tries, a physician will always carry some bias. Doctors are human. Humans have biases, both conscious and unconscious, which makes it entirely unrealistic to assume that a physician will not bring personal prejudices into these conversations.

In a way, this question is a catch 22. If a physician solely decides, the physician's personal beliefs will undoubtedly have some impact on the decision that is made. Conversely, if the patient chooses, the outcome is tainted by personal beliefs coupled with a lack of medical knowledge. Finally, if we combine a physician's suggestion with the

[threat-religious-hospitals-denying-women](#) (quoting that "The hospital admits you and consults with a specialist who concludes that the only option is to induce labor and complete the miscarriage – either way, the fetus will not survive.").

¹²⁶ Shilpa Phadke, *Rhetoric vs. Reality: Why Access to Contraception Matters to Women*, CTR. AM.

PROGRESS (Nov. 15, 2017, 11:03 AM),

<https://www.americanprogress.org/issues/women/reports/2017/11/15/442808/rhetoric-vs-reality-access-contraception-matters-women/>; Donna Jackel, *For Transgender College Students, Health Care is Far From Guaranteed*, PROGRESSIVE (Jun. 18, 2018), <https://progressive.org/dispatches/for-trans-college-students-health-care-180618/>.

¹²⁷ Melissa E. Fraser, *Gender Inequality in In Vitro Fertilization: Controlling Women's Reproductive Autonomy*, 2 N.Y. CITY L. REV. 183, 194-98 (1998); *Female Veteran Denied In Vitro Fertilization Benefits Because She's Single: "It's Taking Away My Life Dream"*, CBS NEWS (Mar. 29, 2019, 8:09 AM), <https://www.cbsnews.com/news/female-veteran-denied-ivf-benefits-because-shes-single/>.

patient's ultimate decision, bias remains. The physician's partialities will primarily influence the patient's decision since the physician informed the patient about the choices they had, and what the physician chose to disclose or suggest was based on personal judgments of what is best for the patient. Rather than adopt the unrealistic view that physicians should be entirely unbiased, we should acknowledge that biases will always exist and look for ways in which physicians can give unproblematic suggestions. Unproblematic opinions can take many forms and, much like physicians, each patient will have a differing view as to what an unproblematic suggestion looks like. This paper does not set out to take on the impossible task of creating a model that rids physicians of their biases; instead, it seeks to explore options that will enable a physician to make more unproblematic suggestions. In turn, this allows patients to feel empowered and like they are receiving care that is in their best interest and not to further their doctor's underlying agenda.

The first part of this paper will begin by looking at the different definitions that physicians operate under. This paper will look at the bioethics movement, the paternalistic approach, and religiously-inspired approaches to see how different physicians define "good of my patient." Secondly, the paper will explore how physicians have tried to remedy these discrepancies and offer an approach that takes these various viewpoints into account. Finally, the proposed method will be applied to the controversial procedure of in vitro genetic testing to see if this proposed approach addresses the concerns of each of the three primary understandings of the Hippocratic ideal.

I. THE PROBLEM: DIFFERENT VERSIONS OF "GOOD OF MY PATIENT"

The practice of medicine is based on trust, and the expectation is that physicians will care for patients without regard to medically irrelevant personal characteristics.¹²⁸ However, physicians often bring their beliefs into their medical practices, which sometimes means a physician will deny care due to their morals or biases. Additionally, physicians have gone so far as to refuse to refer patients to other sources of care because of their personal beliefs. As mentioned above, there are three main understandings of the Hippocratic ideal of devotion to the notion of "good of my patient."¹²⁹ The first understanding is from the bioethics movement's patient-autonomy-oriented approach, that has been extant, especially in more progressive circles, since the 1970s.¹³⁰ The second is a paternalistic understanding that calls upon physicians to make their best judgment about tests and treatments.¹³¹ The third deals with religiously-inspired understandings. The three perceptions will be discussed in greater detail below.¹³²

¹²⁸ See THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS, 10-A-06, *Physician Participation in Interrogation*, Ethic

al and Judicial Affairs Report, at 7 (June 2006).

¹²⁹ *Evolution of Medical Ethics: The Hippocratic Oath*, RICE UNIVERSITY, <https://owlspace-ccm.rice.edu/access/content/user/ecy1/Nazi%20Human%20Experimentation/Pages/Hippocratic%20Oath-modern.html>.

¹³⁰ ALBERT R. JONSEN, *BIOETHICS BEYOND THE HEADLINES: WHO LIVES? WHO DIES? WHO DECIDES?* 9 (Rowman & Littlefield Publishers, 2005).

¹³¹ Brian C. Drolet & Candace L. White, *Virtual Mentor: Selective Paternalism*, 14 AM. MED. ASS'N J. ETHICS 582, 583 (2012).

¹³² Olga Khazan, *When the Religious Doctor Refuses to Treat You*, THE ATLANTIC (Jan. 23, 2018), <https://www.theatlantic.com/health/archive/2018/01/when-the-religious-doctor-refuses-to-treat-you/551231/>.

A. Bioethics Movement's Patient-Autonomy-Oriented Understanding

The word “bioethics” first appeared in 1969.¹³³ It was invented by a medical researcher, Dr. Van Rensselaer Potter, to describe his idea of a broad field of study that would link human values with biological knowledge.¹³⁴ The *Encyclopedia of Bioethics* defines this concept as “the systematic study of the moral dimensions – including moral vision, decisions, conduct, and policies – of the life science and healthcare, employing a variety of ethical methodologies in an interdisciplinary setting.”¹³⁵

When Potter invented the word “bioethics,” he saw life in its most comprehensive sense.¹³⁶ He placed human experience within this extensive and evolving world.¹³⁷ Potter hoped that the new study would incorporate all living beings within the perspective of human values.¹³⁸ Despite this grand view of what bioethics should include, it was captured only by the biomedical sciences.¹³⁹ However, when bioethicists talk about life, they do not just refer to the physical, but also the conscious, social, and historical experience as we understand it, have feelings about it, and evaluate it.¹⁴⁰ Bioethics addresses questions about whether a human embryo is alive, not just in the biological sense but also in the human sense, meaning that it looks at the rights recognized by morality.¹⁴¹ To further bioethics, Tom Beauchamp and James Childress studied and proposed four principles that embody the bioethics approach to medicine.

The Beauchamp and Childress principles that set the agenda for bioethics are: respect for autonomy, nonmaleficence, beneficence, and justice.¹⁴² Despite other approaches that have been proposed, the Four Principle Method has achieved wide popularity.¹⁴³ The first, respect for autonomy, is defined as “acknowledg[ing] a person’s right to hold views, to make choices, and to take actions based on personal values and beliefs.”¹⁴⁴ “The principles of nonmaleficence and beneficence refer to the moral duty to refrain from harming persons and the obligation, under many circumstances, to contribute to their welfare.”¹⁴⁵ “Justice refers to the complex of ideas that center around the basic moral duty to treat persons equally and fairly, in accord with their needs, efforts, contributions, and merit.”¹⁴⁶ The principles are viewed as a framework of norms within which one can reflect upon and attempt to resolve moral problems.¹⁴⁷ These principles reflect “common morality,” that is, principles that would be accepted by most thoughtful persons in every culture.¹⁴⁸ In order to understand these terms, this paper looks at each in greater detail below.

¹³³ JONSEN, *supra* note 25, at 9.

¹³⁴ *Id.*

¹³⁵ *Id.* at 9–10.

¹³⁶ *Id.* at 10.

¹³⁷ *Id.*

¹³⁸ *Id.*

¹³⁹ *Id.*

¹⁴⁰ *Id.*

¹⁴¹ *Id.*

¹⁴² *Id.* at 17

¹⁴³ *Id.*

¹⁴⁴ *Id.*

¹⁴⁵ *Id.*

¹⁴⁶ *Id.*

¹⁴⁷ *Id.*

¹⁴⁸ *Id.*

The first prong of the Beauchamp and Childress bioethics principles is “respect for autonomy.”¹⁴⁹ The bioethical movement views personal autonomy as “self- rule that is free from both controlling interference by others and limitations that prevent meaningful choice, such as inadequate understanding.”¹⁵⁰ For example, “the autonomous individual acts freely in accordance with a self-chosen plan,” whereas someone with diminished autonomy is controlled, in some capacity, by others.¹⁵¹

Despite the evolution of the word, all theories of autonomy agree that two conditions are essential – liberty and agency.¹⁵² Liberty means that there is “independence from controlling influences.”¹⁵³ Agency refers to a “capacity for intentional action.”¹⁵⁴ When it comes to focusing on autonomous decision-making, the focus shifts from the autonomous person to autonomous choice, which is actual governance rather than capacity for governance.¹⁵⁵ Autonomous action happens when a person makes everyday choices without help.¹⁵⁶ In these instances, the person acts in a way that is intentional, with understanding, and without controlling influences that determine their action.¹⁵⁷ For an individual to have their autonomous choices respected and acknowledged, it is imperative that the individual make decisions in this manner according to the Beauchamp and Childress model.¹⁵⁸ This model begs the question of how a female patient can act in a way that is completely autonomous when it comes to making decisions about her health.¹⁵⁹ Assuming that the girl has seen at least one doctor by the time she has to make a decision about her health, the individual has already had a controlling influence, the doctor, impact her decision.¹⁶⁰ Since it is unlikely that a layperson will be able to make any health-related decision without first seeing a physician, aside from making the decision to go to the doctor, it is impossible for a patient to be fully autonomous when making any decision about their health.¹⁶¹

The second prong of the Beauchamp and Childress principles is “nonmaleficence.”¹⁶² Nonmaleficence asserts an obligation not to inflict harm intentionally.¹⁶³ This principle has been associated with the maxim “Above all [or first] do no harm.”¹⁶⁴ Philosophers tend to treat nonmaleficence and beneficence as the opposite of one another, but Beauchamp and Childress treat these as separate, but not opposite, principles.¹⁶⁵ They distinguish the two principles by stating “[o]bligations of nonmaleficence are usually more stringent than obligations of beneficence, and [in some cases] nonmaleficence may override beneficence, even if the best utilitarian outcome

¹⁴⁹ TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 101 (7th ed. 2012).

¹⁵⁰ *Id.*

¹⁵¹ *Id.* at 101–02.

¹⁵² *Id.* at 102.

¹⁵³ *Id.*

¹⁵⁴ *Id.*

¹⁵⁵ *Id.*

¹⁵⁶ *Id.* at 103.

¹⁵⁷ *Id.* at 104.

¹⁵⁸ *Id.* at 102–06.

¹⁵⁹ *Id.* at 106.

¹⁶⁰ *Id.*

¹⁶¹ *Id.*

¹⁶² *Id.* at 150.

¹⁶³ *Id.*

¹⁶⁴ *Id.*

¹⁶⁵ *Id.* at 151.

would be obtained by acting beneficently.”¹⁶⁶ To further illustrate this point, the authors use the hypothetical, “[i]f a surgeon, for example, could save two innocent lives by killing a prisoner on death row to retrieve his heart and liver for transplantation, this outcome would have the highest net utility, but it is not morally defensible.”¹⁶⁷ Although nonmaleficence carries a stricter standard than beneficence, it is altogether seen as more reasonable, particularly when the alleged benefit involves a question of morality.¹⁶⁸ In a case where there is a conflict between right and wrong, like in the example above, nonmaleficence wins.¹⁶⁹ The principle of nonmaleficence is straightforward since the underlying principle is to do no harm, even if there is a benefit to the harm that is being done.¹⁷⁰ Under the nonmaleficence principle, in instances where a woman goes to the doctor for an abortion, the doctor could deny the patient if the doctor felt like harm would be done to the baby, despite the possible health and economic benefits the mother might receive as a result of the procedure. Similarly, the doctor could turn the woman away should the doctor be morally opposed to abortions and feel as if abortions would do some reprehensible harm to the mother. Even though, nonmaleficence appears to be straightforward on its face and promotes doing good for the patient instead of doing any harm, there are many instances where a physician may justify the refusal of treatment because of the potential for harm to the patient.

The third prong is “beneficence.”¹⁷¹ Doing right by others requires not only that we treat people autonomously and refrain from harming them, but also that we contribute to their overall well-being.¹⁷² Contributing to a person’s well-being is essentially the concept of beneficence.¹⁷³ This third prong takes into account not just positive beneficence but also utility – benefits and drawbacks must be balanced.¹⁷⁴ Most people agree that all morally decent individuals should act in the best “interest of their children, friends, and other parties in special relationships.”¹⁷⁵ However, under the bioethics lens, the concept of general beneficence argues that physicians must act impartially to promote the interests of persons beyond this limited scope of relationships.¹⁷⁶ When it comes to physicians doing what is in the best interest of every patient they interact with, they appear to be engaging in this idea of general beneficence.¹⁷⁷

In theory, this idea of a physician treating everyone who steps into her practice with the same quality of care and amount of concern seems good.¹⁷⁸ We want our physicians to do what is best for us, and we want them to perform in the best possible manner. However, when broken down, much like the above example with nonmaleficence, this prong runs into some problems. By engaging in general beneficence, the physician will be acting impartially to promote the interests of all people.¹⁷⁹ General beneficence means that if a

¹⁶⁶ *Id.*

¹⁶⁷ *Id.*

¹⁶⁸ *Id.* at 151–52.

¹⁶⁹ *Id.* at 152.

¹⁷⁰ *Id.*

¹⁷¹ *Id.* at 202.

¹⁷² *Id.* at 202–03.

¹⁷³ *Id.* at 203.

¹⁷⁴ *Id.*

¹⁷⁵ *Id.* at 205.

¹⁷⁶ *Id.*

¹⁷⁷ *Id.*

¹⁷⁸ *Id.*

¹⁷⁹ *Id.*

physician believes that abortion is morally wrong for all people, then the physician can turn away all patients because he believes it is in everyone's best interest not to get an abortion. The counterargument is that people who went to that one doctor could effortlessly go to another doctor whose moral beliefs align with theirs and go forward with the decision to get an abortion. While that is true in many instances, there are plenty of places, both in the United States and elsewhere, where there is not another doctor for hundreds of miles. It is unfair and unjust for anyone to be forced to seek out another physician just because the first physician believed that her moral compass was superior to the patient's needs. While it is impossible for any physician to be entirely objective, the concept of beneficence, much like nonmaleficence, appears to leave too much room for physician discretion, which increases the likelihood that physicians will make problematic suggestions to patients.

The fourth and final prong is "justice."¹⁸⁰ Inequality plagues the healthcare system in the United States; however, inequality is not necessarily a uniquely moral problem that is specific to healthcare.¹⁸¹ When it comes to trying to fix the inequality that is so openly spoken of, there is often great uncertainty as to how to balance and "reconcile goals such as equal access to health care, the freedom to choose a health plan, health promotion, a free-market economy, social efficiency, and the beneficent state."¹⁸² The principles surrounding justice seem to be impossible to attain since it is increasingly difficult to try to make everything equal for every person.¹⁸³ In an attempt to make the concept of justice seem fair, Beauchamp and Childress break the concept of justice down further into "justice" and "distributive justice."¹⁸⁴ Justice is viewed as "fair, equitable, and appropriate treatment in light of what is due or owed to persons."¹⁸⁵ Comparatively, the term distributive justice refers to "fair, equitable, and appropriate distribution of benefits and burdens determined by norms that structure the terms of social cooperation."¹⁸⁶ Typically, this includes policies that give benefits and burdens such as "property, resources, taxation, privileges, and opportunities."¹⁸⁷ The scope of distributive justice leads to problems that arise due to lack of resources and people fighting over the available resources.¹⁸⁸ Given this, compromise must happen. To further explain the necessary trade-offs, Beauchamp and Childress provide the following example:

An interdisciplinary panel of distinguished physicians, ethicists, and lawyers considered the merits and demerits of using modern technology to produce an artificial heart – the so-called totally implantable artificial heart. The panel narrowed the alternatives to three possibilities: (1) produce no heart because it is too expensive; (2) produce a heart powered by nuclear energy; or (3) produce a heart with an electric motor and rechargeable batteries. Eventually, the panel decided that, on balance, the battery-powered heart posed fewer risks to the recipient, to his or her family, and to other members of society than the nuclear-powered heart. In assessing each alternative, the panel considered its implications for the quality of life of

¹⁸⁰ *Id.* at 249.

¹⁸¹ *Id.*

¹⁸² TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 225 (5th ed. 2001).

¹⁸³ TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 249 (7th ed. 2012).

¹⁸⁴ *Id.*

¹⁸⁵ *Id.* at 250.

¹⁸⁶ *Id.*

¹⁸⁷ *Id.*

¹⁸⁸ *Id.*

recipients, its cost to society, and its relative expense in comparison with other medical needs that could be met instead. The panel concluded that, despite the substantial costs, it would be unjust not to allocate money to develop the artificial heart for those in need of it (on the grounds that distributive justice requires it), but that the nuclear-powered heart would create a greater risk to society than could be justified.¹⁸⁹

Considering the alternatives is typical of distributive justice as it does not look at the aggregate risks, costs, and benefits of various options, but also their distribution throughout society.¹⁹⁰ The principle of justice appears to have the best interest of the patient as well as society in mind. While physicians can have their beliefs influence their concept of justice, the example above shows that there is more of a safeguard in place since these conversations tend to take place when others are present, which means that having one singular person's morals influence the entire outcome is unlikely. While the "justice prong" of Beauchamp and Childress's four-prong test appears to be the most likely to accomplish the goal of doing what is truly in the best interest of patients, the ability to achieve the widespread justice takes time, effort, and resources that many physicians do not have.¹⁹¹ Change takes time, while the story of the artificial heart is only one long paragraph, the amount of time it took for the team to come up with the final verdict was long and tiresome. When it comes to dealing with patients, physicians should keep the idea of distributive justice in mind; however, a more streamlined system would greatly benefit patients and physicians. A more streamlined system, like the proposed Health Belief Model ("HBM"), would allow patients to feel like they are getting the best possible care based on their situation, which would satisfy the "justice prong." Additionally, a model like the HBM would allow physicians to feel as if they are acting in the best interest of their patients without worrying about problematic suggestions impacting the patient's quality of care.

In addition to the criteria that Beauchamp and Childress set out, Jonsen's book mentions feminist and feminine bioethics as two essential styles of bioethics.¹⁹²

These two styles are similar in that they arise from the experience of women as healthcare providers, caretakers, patients, and compassionate observers. They differ in that the former draws on analyses of social and cultural power to show how male hegemony defines moral issues so as to preserve male authority; the latter proposes that a style of moral perception and behavior unique to women inclines them to define moral problems regarding community and connectedness between people, while men define them as problems of rights and contracts. For example, feminist bioethicists may view informed consent as a mechanism of male dominance in which the flow of information from male physicians to women patients predestines the result. Women, in this view, must control the information about their own bodies.¹⁹³

¹⁸⁹ TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 328 (4th ed. 1994)

¹⁹⁰ *Id.*

¹⁹¹ *Id.*

¹⁹² JONSEN, *supra* note 25, at 19.

¹⁹³ *Id.*

Later, this paper proposes the HBM, which allows a patient to control the information she is given about her body and then inform the physician what she would like to do with the information she has been provided. While the feminist bioethics approach tends to apply solely to women, the HBM refers to every person, no matter how they choose to identify. “A feminine bioethics approach may be less skeptical about the very practice of informed consent but will approach disputes over consent to procedures not as clashes between the rights of patients and duties of doctors but as settings for negotiation and conciliation.”¹⁹⁴

“Bioethics’ absorption into medicine brings it into contact with ... medical ethics.”¹⁹⁵ “The rules of professional medical ethics aim to preserve the profession’s reputation and respectability in the eyes of the public.”¹⁹⁶ Generally, the purpose of this form of ethics is to maintain professional competence.¹⁹⁷ For example, “[i]t forbids certain acts, such as sexual contact with patients and exploitation of their vulnerability,” and it promotes generosity.¹⁹⁸ These appear to be ethical codes that refer to the specific professional dos and don’ts in the medical field; however, these are dramatically different from the principles of medical bioethics since bioethics focuses on the four guiding principles that govern professional, ethical conduct between the physician and the patient.

Talking about a person’s quality of life might be a mistake when the person is suffering and precluded from activities she previously enjoyed. Meaning that when a person’s life is prolonged, say by putting the person on a ventilator when she is comatose or permanently unconscious, preserving the quality of life is a futile effort since there is a small chance the person will ever be able to regain “cognitive or sapient life.”¹⁹⁹

A less extreme example of the futility argument can be seen below.

The procedure called cardiopulmonary resuscitation [which] revives a heart that has suddenly stopped by an aggressive combination of chest massage, forced mouth-to-mouth breathing, electric shock to the heart, and heart-stimulating drugs. After it was introduced in the 1950s, it was widely used both in hospitals and by emergency responders. However, it was noticed that in many persons, this strenuous intervention failed, and those that survived soon died of the underlying diseases that had brought on their cardiac arrest. Providers began to ask whether it was possible to determine when cardiac resuscitation might be futile and thus omitted. Today, it is common to designate seriously ill, hospitalized patients as “Do not resuscitate” . . . when doctors judge that resuscitation would be futile, that is, would not serve the patient’s interests.²⁰⁰

This idea begs the question of who gets to decide. Physicians have a better understanding of the data that surrounds the likelihood of a person surviving the cardiac episode. However, leaving it up to a doctor to decide whether or not a person will be given

¹⁹⁴ *Id.*

¹⁹⁵ *Id.*

¹⁹⁶ *Id.*

¹⁹⁷ *Id.*

¹⁹⁸ *Id.*

¹⁹⁹ *Id.* at 36.

²⁰⁰ *Id.* at 37.

a chance to recover, should her heart stop on the operating table, seems cruel and like there is room for error.

The bioethical approach to medicine strives to ensure that patients feel like their wants, needs, and concerns are heard. The autonomy prong of the bioethical model seeks to respect a patient's choice; however, even if the physician adopts a solely autonomous approach and does whatever the patient says he wants to do, predispositions of physicians will find their way into conversations with patients. Using a baseline model, while not perfect, ensures the patient feels like her voice is heard throughout the process and that the physician is not the sole person making the decision.

B. Paternalistic Understanding

The rise in diagnostic and therapeutic options has created the need for more medical decisions. The process of making these decisions remains vague. Many medical decisions are entirely made by the physician whereas others involve hearing the patient's desires. In many instances, the decisions are not straightforward, and the choice the patient makes may not align with the advice of the physician. "Paternalism—choosing a course of action that is in the patient's best interest but without the patient's consent—serves as an integral value in ethical decision making."²⁰¹ It is a balance to other values, and it reflects an ethical obligation to withhold guidance or relinquish professional responsibility to patients.²⁰²

Paternalism is typical in clinical practice and occurs in different degrees and scenarios.²⁰³ The paternalistic approach to medicine should "promote awareness, productive dialogue, and prevention of error in decision-making situations."²⁰⁴ Respect for patient autonomy is imperative; however, medical decisions are often filled with emotions and can "induce distress, confusion, and conflict among patients and families," which can either hinder the patient's ability to make a decision or cause the patient not to want to participate in the decision-making process.²⁰⁵ In an example of a woman on life support whose lone surrogate decision-maker is unwilling to consent to treatment, the paternalistic approach to the Hippocratic ideal of "good of my patient" should apply.²⁰⁶ In these situations, emotions are at an all-time high and choosing to take a loved one off of life support is not an easy decision. Many would argue that the physician or another decision-maker should try to ascertain what the patient would have wanted had she been sufficiently able to opine. However, the situation is so laden with emotions that relying on the physician to help make the decision can be beneficial. Ideally, in a case such as this, patient autonomy is respected, but ultimately the physician makes the decision that is in the best interest of the patient.

²⁰¹ Drolet & White, *supra* note 26, at 583.

²⁰² *Id.* at 583.

²⁰³ *Id.*

²⁰⁴ *Id.* at 583–84.

²⁰⁵ *Id.* at 584. An example of this inability to make a decision is that of a twenty-year-old woman who suffers devastating central neurological injuries from a motor vehicle accident and becomes dependent on a ventilator with poor chances of recovery. In this example, the woman's care team advises that tracheostomy and percutaneous gastrostomy be performed or that life support be withdrawn. Her mother, the lone surrogate decision maker, is unable and unwilling to decide on a plan of care; she does not consent to aggressive intervention or withdrawal of care. Multiple family meetings are unproductive at identifying a plan of care. *Id.*

²⁰⁶ *Id.*

Experts in their respective fields understand the specific nuances that are considered best practice within the profession: “[p]hysicians are obligated to ensure quality and value in health care through education, expertise, and ethical practice patterns.”²⁰⁷ Proponents of this paternalistic approach believe that physicians cannot be forced into a system that relies solely on patient autonomy; autonomy, they hold, should be balanced with the “paternalistic obligation to uphold standards of care.”²⁰⁸ The paternalistic approach to medicine serves a purpose. Doctors know the nuances of medicine, whereas patients, despite their best efforts, are unlikely to know about these intricacies or understand them. However, there are plenty of opportunities for a physician to abuse her power. Doctors who do not balance their paternalistic approach with patient autonomy appear to be more inclined to abuse their power since they are unlikely to take into account why a person may be hesitating to do a procedure. A physician who solely employs the paternalistic approach has the potential to abuse her power by only telling patients about specific procedures. Low-income patients are especially vulnerable because the physician might withhold information about certain procedures because she believes the patient is unable to afford the out-of-pocket costs required.

Despite the benefits this paternalistic approach serves to patients, allowing a physician to have full reign over what he or she will and will not offer patients can lead to physicians providing care without taking into account what might be best for that individual patient. In essence, the paternalistic approach turns the Hippocratic ideal of “good of my patient” towards “I am doing what I think is best for my patient regardless of his wants,” which defeats the purpose.

C. Religiously-Inspired Understandings

Due to religious beliefs, some physicians refuse to provide medical care for patients. For example, doctors, nurses, and even midwives may choose to not prescribe contraception because of religious beliefs.²⁰⁹ The idea of allowing physicians to deny patients necessary treatment because of their religious beliefs goes against the “good of my patient” Hippocratic ideal. Until recently, there were no protections in place for physicians with sincerely held religious beliefs. Some medical providers were denied jobs or precluded from interviews when they disclosed to employers that they had religious beliefs that prevented them from providing certain types of care.²¹⁰

There has been a recent shift in focusing on the religious characteristics of healthcare professionals, which leads to questions about how clinicians’ religious practice and traditions shape their professional practices.²¹¹ Given that medical professionals are in situations where they have to provide care that might go against their religious beliefs, disagreements about morally controversial medical interventions are visible and can impact the physician-patient relationship. In fact, religious differences account for much of the variation in physicians’ practices related to “morally controversial areas such as sexual and

²⁰⁷ *Id.*

²⁰⁸ *Id.* at 584–85.

²⁰⁹ Khazan, *supra* note 27.

²¹⁰ *Id.* (A situation arose where a midwife applied for a job at a federally qualified health center. She was denied the opportunity to continue with the interview process due to the fact that the health center received Title X funding and she was unable to counsel women regarding all forms of contraception due to religious beliefs. The midwife sued.)

²¹¹ Farr A. Curlin, *Commentary: A Case for Studying the Relationship Between Religion and the Practice of Medicine*, 83 ACAD. MED. 1118, 1119 (2008).

reproductive healthcare practices, end-of-life care, prayer, and other forms of interaction with patients regarding spiritual issues, as well as physicians' judgments about their obligations when patients request morally controversial medical interventions."²¹² In light of their religious convictions and these contentious areas of medicine, physicians can and often do make prudential judgments about how to help their patients. When making these decisions, physicians use "the technical means available, taking everything else into account—including the scientific evidence, the patients' wishes, and professional expectations, of course, but also including religious and other moral considerations."²¹³

In January 2018, the Department of Health and Human Services Civil Rights Office ("HHS") unveiled a new regulation as well as a new division that would protect medical professionals who are unable or unwilling to provide specific medical treatments due to religious beliefs.²¹⁴ The new division of HHS – The Conscience and Religious Freedom Division – will oversee medical care providers and will not prevent physicians who have sincerely held religious beliefs from holding high up positions within their hospitals, clinics, etc.²¹⁵ At the national press conference announcing the creation of the Conscience and Religious Freedom Division, Roger Severino, the head of civil-rights enforcement at HHS, said that "the state should not force people to go against their integrated view of humanity."²¹⁶ He also stated "that though there had been just 10 complaints from health-care workers related to religious beliefs during the Obama administration, there have already been 34 in the first year of the Trump presidency."²¹⁷ In addition to the new division, HHS issued "a proposed rule that would affect as many as 745,000 hospitals and doctors' offices" and require them to display announcements of "protections against religious discrimination on their job applications and employee manuals."²¹⁸ The rule will also "allow HHS to enforce protections for religious medical providers."²¹⁹

Groups in support of this new rule believe it will assist the federal government in shielding healthcare employees from being forced into providing care that violates their deeply held moral beliefs.²²⁰ Reproductive-rights advocates oppose this new rule because of its worrisome effects. Advocates fear the new rule will surpass current regulations and enable a majority of health-care workers to refuse to deliver a wide variety of services to the public.²²¹ The new rule does not require physicians to guide patients to other physicians, which is an obvious concern.²²² For example, "a pharmacist could refuse to fill a prescription for birth control, a transgender patient could be denied hormone therapy, or a pediatrician could refuse to treat the child of gay parents."²²³ The rule has not been finalized; however, there are concerns that when it becomes finalized, the proposed fears will materialize in some shape or form.²²⁴ "There are already federal laws that protect

²¹² *Id.*

²¹³ *Id.*

²¹⁴ See Dep't Health & Human Servs., *HHS Announces New Conscience and Religious Freedom Decision*, HHS.gov (Jan. 18, 2018), <https://www.hhs.gov/about/news/2018/01/18/hhs-ocr-announces-new-conscience-and-religious-freedom-division.html>.

²¹⁵ *Id.*

²¹⁶ Khazan, *supra* note 27.

²¹⁷ *Id.*

²¹⁸ *Id.*

²¹⁹ *Id.*

²²⁰ *Id.*

²²¹ *Id.*

²²² *Id.*

²²³ *Id.*

²²⁴ *Id.*

medical personnel from being required to provide abortions.”²²⁵ Additionally, “nearly every state also allows health-care providers to refuse to perform abortions, and 12 states allow them to refuse to provide contraceptives.”²²⁶ Six states extend this right to pharmacists, and allow them to decline to supply birth-control prescriptions.²²⁷

The proposed rule holds that “conscientiously objecting physicians shouldn’t be required to refer patients to willing providers.” The rule defines “referral” as providing ‘any information,’ including a phone number or website on a pamphlet, about a health service that the provider disagrees with.”²²⁸ This new rule begs the question of whether it infringes on a physician’s ethical duty to uphold the Hippocratic ideal of providing care that is in the best interest of her patient. Physicians go through extensive training to practice medicine. In addition to four years of medical school, they then have to apply to residency and pick a specialty, so assumedly, physicians know or should have an inkling of an idea of the types of treatments they will be required to perform. The idea that a physician goes into the field of medicine with the hope of inflicting her religious beliefs onto patients seems absurd; however, with the issuance of this new rule, it appears as if it might not be as far-fetched as one might have believed. One example of an argument is that a physician would not go into the OB/GYN field if she knew she would not be willing to at least refer a patient to another doctor who could provide services for women who wish to prevent pregnancy, terminate their pregnancy, or conceive a child. Conversely, another example argument is that a religious doctor would have gone into the OB/GYN field with the hope of doing “God’s work” and preventing women from getting abortions or having in vitro fertilization. The religious gynecologist might believe that it is immoral to have these procedures and is acting in the best interest of the patient.

The problem with the Hippocratic ideal is that it can be used in any situation. For example, a physician can say that it was “for the good of my patient that I performed in vitro fertilization.” Comparatively, a physician can argue that refusing to perform an in vitro fertilization procedure and not provide a referral was “for the good of my patient because it is immoral for someone to get pregnant in a laboratory and I do not want my patient to suffer the moral consequences.” While people make arguments as to why one justification is better than the other, this Hippocratic ideal is subjective and can help a physician justify her position so that the physician is still ethically aligned with the oath that she took before becoming a physician.

II. THE HEALTH BELIEF MODEL

Despite the different ways that doctors have chosen to apply the Hippocratic ideal of “good of my patient,” the underlying theme of each of these approaches is that physicians are acting in a manner that they believe to be in the best interest of their patient. It is human nature for people to have a set of core values and beliefs. Thus, no matter how hard anybody tries, the advice that is given will be tainted with some form of bias. However, a person can try to minimize the present bias by using different models to analyze solutions more objectively, which in turn reduces the number of problematic opinions that are brought to the conversation. Physicians’ personal views carry over into their professional lives. A physician’s personal views can influence how they interact with

²²⁵ *Id.*

²²⁶ *Id.*

²²⁷ *Id.*

²²⁸ *Id.*

patients and the advice they give to them. Given this, developing an objective model so that physicians can provide the best possible care to patients is imperative. One such model is the Health Belief Model (“HBM”): the HBM “is a psychological model that attempts to explain and predict health behaviors.”²²⁹ The HBM “was developed in the early 1950s by social scientists at the U.S. Public Health Service in order to understand the failure of people to adopt disease prevention strategies or [to obtain] screening tests for the early detection of disease.”²³⁰ Additionally, the HBM has been used “for patients’ responses to symptoms and compliance with medical treatments.”²³¹

The HBM “addresses the individual’s perceptions of the threat posed by a health problem (susceptibility, severity), the benefits of avoiding the threat, and factors influencing the decision to act.”²³² Social psychologists “theorized that people’s beliefs about whether or not they were susceptible to disease, and their perceptions of the benefits of trying to avoid it, influenced their readiness to act.”²³³ The researchers concluded that “six main constructs influence people’s decisions about whether to take action to prevent, screen for, and control illness.”²³⁴ The six constructs are: “perceived susceptibility” (belief that a person is “susceptible to the condition”); “perceived severity” (belief that a person’s “condition has serious consequences”); “perceived benefits” (belief that “taking action would reduce [a person’s] susceptibility to the condition or its severity”); “perceived barriers” (belief that the “costs of taking action are outweighed by the benefits”); “cue to action” (the person is “exposed to factors that prompt action” (like an amniocentesis)); and “self-efficacy” (a person’s confidence in her ability “to successfully perform an action”).²³⁵

By using a subjective model, such as the HBM, the doctor can distance herself from her personal beliefs when it comes to treating patients and, instead, can justify treatment because it is in the best interest of the patient as the patient understands his or her interest. In an ideal world, this allows doctors to treat every patient with the same quality of care that is not based on personal beliefs. While the HBM was created to explain and predict health-related behaviors, particularly the use of health services, when looking at it in conjunction with the Hippocratic ideal of “good of my patient,” the model is beneficial for all physicians to apply when treating patients. As mentioned above, it is impossible to entirely be rid of physician bias, even when using the HBM. However, the test can remove a physician’s reliance on her own bias to give all patients standardized care. Meaning that the physician will state the problem, possible solutions, and outcomes, and will then listen to the patients wants and concerns. From there, the physician and the patient, together, will reach a decision that is in the best interest of the patient. To get a sense of how the HBM works, the next section applies the HBM to the controversial issue of in vitro genetic testing.

²²⁹ *Health Belief Model: Explaining Health Behaviors*, U. TWENTE, https://www.utwente.nl/en/bms/communication-theories/sorted-by-cluster/Health%20Communication/Health_Belief_Model/ (last visited Feb. 28, 2019).

²³⁰ Wayne W. LaMorete, *The Health Belief Model*, B.U. SCH. PUB. HEALTH (Aug. 29, 2018), <http://sphweb.bumc.bu.edu/otlt/MPH-Modules/SB/BehavioralChangeTheories/BehavioralChangeTheories2.html>.

²³¹ *Id.*

²³² NAT’L CANCER INST., *Theory At A Glance: A Guide for Health Promotion Practice*, U.S. DEP’T HEALTH & HUMAN SERVS. 1, 12 (2nd ed., 2005), <https://www.sbccimplementationkits.org/demandrnmch/wp-content/uploads/2014/02/Theory-at-a-Glance-A-Guide-For-Health-Promotion-Practice.pdf>.

²³³ *Id.* at 13.

²³⁴ *Id.*

²³⁵ *Id.*

III. APPLICATION OF THE HEALTH BELIEF MODEL TO IN VITRO GENETIC TESTING

Genetic testing has been around for many years; however, recently more couples are opting to undergo in vitro testing procedures since “methods have improved, and more disease-causing genes have been discovered.”²³⁶ Despite the increase in interest and developments, many people believe that promoting genetic testing will lead to people creating designer babies or aborting embryos that are not considered perfect.²³⁷ When looking at the available research surrounding both prenatal genetic testing,²³⁸ and in vitro or preimplantation genetic testing,²³⁹ it is clear that physicians are instrumental in whether patients decide to undergo this testing.²⁴⁰ Most physicians will only recommend preimplantation genetic testing if there is a known family history of a particular disease.²⁴¹ However, today, prenatal genetic testing has become a routine part of pregnancy care.²⁴² Similar to preimplantation genetic testing, prenatal genetic testing is often only suggested if the pregnancy is deemed to be high risk, meaning the woman is 35 years of age or older, or if blood tests done in women under the age of 35 show that there is a risk that the fetus has a genetic disorder.²⁴³ Since there are risks involved with both procedures, parents have to make a very well thought out decision weighing the pros and cons.

When parents decide to have in vitro genetic testing done, they undergo a similar process that infertile couples go through.²⁴⁴ Namely, the eggs are extracted from the mother and fertilized with the father’s sperm in a petri dish.²⁴⁵ When the embryos from the procedure are three days old, the doctor removes a single cell and analyzes the DNA.²⁴⁶ The embryos that do not have defective genes are then considered for implantation into the mother’s uterus.²⁴⁷ In vitro fertilization and genetic testing are expensive, but they ensure children will not inherit genes that will inhibit their quality of life.²⁴⁸ This testing also

²³⁶ Gina Kolata, *Ethics Questions Arise as Genetic Testing of Embryos Increases*, N.Y. TIMES (Feb. 3, 2014), https://www.nytimes.com/2014/02/04/health/ethics-questions-arise-as-genetic-testing-of-embryos-increases.html?_r=.

²³⁷ *Id.*

²³⁸ Usually done through an amniocentesis during the first trimester of pregnancy. See Cari Nierenberg, *Prenatal Genetic Screening Tests: Benefits & Risks*, LIVE SCIENCE (Mar. 14, 2018), <https://www.livescience.com/45949-prenatal-genetic-testing.html>.

²³⁹ Done through an embryo biopsy of a single blastomere cell. A.R. Thornhill, et al., *Best Practice Guidelines for Clinical Preimplantation Genetic Diagnosis (PGD) and Preimplantation Genetic Screening (PGS)*, 20 HUM. REPROD. 35, 38 (2005).

²⁴⁰ Amy Harmon, *Couples Cull Embryos to Halt Heritage of Cancer*, N.Y. TIMES (Sept. 3, 2006), <http://www.nytimes.com/2006/09/03/health/03gene.web.html?pagewanted=all>.

²⁴¹ Alice Uflacker, et al., *Preimplantation Genetic Diagnosis (PGD) for Genetic Prion Disorder Due to F198S Mutation in the PRNP Gene*, JAMA NEUROLOGY (Sept. 1, 2013), <https://jamanetwork.com/journals/jamaneurology/fullarticle/1817721>.

²⁴² Ellen Garvey, *Pros and Cons of Genetic Screening During Pregnancy*, BATTLEBORO OBGYN, <https://www.bmhvt.org/pros-and-cons-of-genetic-screening-during-pregnancy/> (last visited Feb. 27, 2019).

²⁴³ See Daniel M. Sacks, *Amniocentesis*, MEDLINE PLUS (Sept. 26, 2015), <http://www.nlm.nih.gov/medlineplus/ency/article/003921.htm>; see also Uflacker, et al., *supra* note 136.

²⁴⁴ Harmon, *supra* note 135.

²⁴⁵ *Id.*

²⁴⁶ *Id.*

²⁴⁷ *Id.*

²⁴⁸ Kolata, *supra* note 131.

prevents couples from having to abort a pregnancy if examination of the fetus detects a severe genetic problem, since they will already know their fetus is healthy.²⁴⁹

Parents who are deciding whether they should undergo any genetic testing procedure, whether it is preimplantation or prenatal, rely on their physicians. Often, people feel that physicians impose their views on the patient, which results in the patient making a decision based on what the physician wants, rather than what is actually in the best interest of the patient.²⁵⁰ Genetic counselors are used to minimize the direct influence of healthcare providers.²⁵¹ Genetic counselors are supposed to be as non-directive as possible, while offering support and guidance by informing patients of what is available to them.²⁵²

While there are positives and negatives regarding whether a woman should undergo any genetic testing, the decision ultimately comes down to the relationship patients have with their physician. When using the HBM, a theory that looks at how people form high degrees of self-efficacy, women are more inclined to take preventative action when they are high risk and then to weigh all of the pros and cons surrounding the options available to them.²⁵³

Whether a patient decides to have in vitro or prenatal genetic testing, the information given to her by the physician and the relationship that they form is essential to the decision-making process. The patient-physician relationship is imperative to ensure that the patient feels confident in her decision to undergo the treatment. By applying the HBM, patients feel more confident in their relationship with their physician and in turn, physicians feel as if they are not as conflicted since they will be following an objective model.²⁵⁴ While the HBM is neither perfect nor the only answer to this incredibly complicated problem, it is one way for physicians to attempt to provide the best possible care for their patients regardless of their personal beliefs. Although this paper primarily relates the HBM to in vitro genetic testing, the model can be applied to other situations where patients have to make difficult decisions.

A. HBM Model and In Vitro Genetic Testing

Relating the decision-making process of in vitro or prenatal genetic testing to the HBM is quite easy. When a couple goes into their first prenatal visit, the obstetrician must obtain a detailed medical and obstetric history. At that point, depending on whether or not the pregnancy is deemed to be “high risk,” a term typically used when the mother is over the age of thirty-five or if there is a family history or previous pregnancy with a genetic abnormality, the obstetrician will likely suggest an amniocentesis.²⁵⁵ If the expectant mother is 35 years of age or older or has a history of genetic abnormalities, then she will have a blood test to screen for various genetic abnormalities such as Down Syndrome, Trisomy 13, and Trisomy 18 (perceived susceptibility).²⁵⁶ Once the test results come back, then the parents and the doctors will identify if a condition is present, how serious it is, and

²⁴⁹ *Id.*

²⁵⁰ See Susan Markens, “Is This Something You Want?”: Genetic Counselors’ Accounts of Their Role in Prenatal Decision Making, 28 SOC. FORUM 431, 434 (2013).

²⁵¹ *Id.*

²⁵² *Id.*

²⁵³ *Id.*

²⁵⁴ *Id.*

²⁵⁵ An amniocentesis is when a needle is inserted into the mother’s uterus to obtain amniotic fluid to test for genetic abnormalities or fetal infections. Sacks, *supra* note 138.

²⁵⁶ *Id.*

what some of the implications could be (perceived severity). During the conversation, benefits regarding the “effectiveness of taking action to reduce the risk or seriousness,” which in many instances means medical termination of the pregnancy, will be discussed (perceived benefits).²⁵⁷ Once the information is presented to the couple by the doctor, the couple will discuss the various psychological costs of taking action (perceived barriers). Then the couple will decide whether they will medically terminate the pregnancy by looking at a variety of factors ranging from their moral values to their ability to care for a child with a genetic disability (cues-to-action).²⁵⁸ The couple will also ask themselves whether they have enough information about raising a disabled child, so they can sufficiently weigh the benefits of keeping or ending the pregnancy. The decision that parents make as to whether or not they will terminate the pregnancy is an example of the self-efficacy prong.²⁵⁹ While this example is related to an already pregnant couple who is considering prenatal testing, the same decision-making process can be related to those deciding to undergo in vitro genetic testing.

B. Role of Physician in In Vitro Genetic Testing

Parents-to-be are likely to have some degree of anxiety regarding their pregnancy. For some, it might be the age of the mother, and for others, it might be that it is their first pregnancy and they do not know what they should be expecting over the course of the next nine months. It is therefore up to the physician to ensure that each of her patients is well informed and supported, especially when blood test results come back suggesting that an expectant mother undergo prenatal genetic testing. Doctors and genetic counselors play a pivotal role in helping patients outline the crucial factors that the HBM posits so that they can be self-reliant when it comes to making the final decision. In fact, one study found that patients are most concerned with how physicians put their mind at ease in the initial visit.²⁶⁰ Additionally, the study discovered that low-income and minority patients are often more satisfied and therefore more likely to listen to the suggestions their obstetricians made, which is an important component of any health-related decision.²⁶¹

Another study looked at trait anxiety and the best ways to present information about prenatal genetic testing.²⁶² Genetic testing is not a regular part of maternal care, and there are risks involved.²⁶³ For the couple to make an informed decision about whether to undergo particular genetic tests, they must process a considerable amount of information about “the tests, their risks and benefits, and the possible long-term consequences of their decisions.”²⁶⁴ The goal of the study was to test “the independent and combined roles of information modality and trait anxiety in cognitive responses to information about prenatal genetic testing.”²⁶⁵ The participants in this study “first completed a trait anxiety measure”

²⁵⁷ *Id.*; NAT’L CANCER INST., *supra* note 127, at 14.

²⁵⁸ NAT’L CANCER INST., *supra* note 127, at 14.

²⁵⁹ *Id.*

²⁶⁰ Debra L. Roter, et al., *Effects of Obstetrician Gender on Communication and Patient Satisfaction*, 93 OBSTETRICS & GYNECOLOGY 635, 640 (1999).

²⁶¹ *Id.*

²⁶² Cecile Muller & Linda D. Cameron, *Trait Anxiety, Information Modality, and Responses to Communications About Prenatal Genetic Testing*, 37 J. BEHAV. MED. 988 (2014).

²⁶³ Some risks include loss of pregnancy, premature rupture of membranes, bleeding, infection, and there is a chance that the test will not be accurate or show a false-positive. Garvey, *supra* note 137.

²⁶⁴ Muller & Cameron, *supra* note 157, at 988.

²⁶⁵ *Id.* at 990.

and then received information regarding prenatal testing via one of three formats: audio, video or text.²⁶⁶ The study found that for highly anxious participants, viewing the video led to more distressing test-related thoughts and emotions than did the audio format.²⁶⁷ However, low-anxiety patients had a much more positive response and less distress to the video format than to the audio message.²⁶⁸ One possible reason for the preference of video over audio could be that with video, patients can see nonverbal cues, whereas, audio messages leaves a lot to the imagination.

Trait anxiety and information modalities on distress in response to information about prenatal genetic testing are related. Therefore, it is up to health professionals to ensure that all patients, regardless of trait anxiety levels, are offered the appropriate medium to learn about prenatal genetic testing procedures so they can make the most appropriate and well-educated decision. While all physicians should take the time to account for each patient's individual needs and anxiety levels, male obstetricians will be more inclined to take the time to consider trait anxiety levels since the first study found that male obstetricians have more extended visits with patients.²⁶⁹ Female obstetricians should increase the length of their visits with patients to get a better sense of trait anxiety levels and enhance the physician-patient relationship.

Doctors play a crucial role in informing patients about the risk they have of being carriers of certain genetic disorders. It is up to the doctor to clearly and thoroughly inform the patient of the various benefits and risks involved with in vitro genetic testing. Given the role that doctors play in helping their patients make life-altering decisions, doctors must act in the best interest of their patients. The HBM reduces the personal beliefs that a physician brings to conversations with patients and allows a physician to listen to and better understand what her patients want, which in turn allows her to do what is best for her patients.

C. HBM Applicability to Other Medical Decisions

While this paper applies the HBM specifically to in vitro fertilization, the model can be useful in most situations where a healthcare professional is providing care to patients. When it comes to cases of abortion, the HBM can benefit patients and physicians, since it allows physicians to remove their personal views and lets them listen to why the patient is choosing this option. It also gives the physician an opportunity to address the concerns she has for the patient, while still allowing the patient to have her autonomy. Using the HBM makes the patient's reasoning known to the physician, which allows for her to be more supportive of the patient.

The HBM is applicable to just about any patient population as well as any treatment option. The model can apply to cases involving elderly patients. For example, if an elderly patient asks about a procedure that the physician feels should be done in younger patients, the HBM allows the physician and the patient to have an open dialog, which leads the ultimate decision to be in the best interest of the patient. While the abortion and elder care case are brief examples, the model can and should be applied in situations where a patient bases a medical decision off of the relationship she has with her doctor.

²⁶⁶ *Id.*

²⁶⁷ *Id.* at 992.

²⁶⁸ *Id.* at 994.

²⁶⁹ Roter, *supra* note 155, at 640.

D. Limitations of the HBM

The HBM is not perfect. As stated throughout this paper, doctors and patients are human, which means that bias and opinions will be brought into any relationship. The HBM does not claim to get rid of physician bias; rather, it allows patients and physicians to have an open discussion around their goals and beliefs. The hope is that by engaging in an open conversation, the relationship will be strengthened, and the physician will be more supportive of the patient's decision than she otherwise would have been had she not used the HBM. The HBM branches off of the bioethical model of trying to do what is best for the patient; however, unlike bioethics, it allows physicians to have a concrete model that guides their interactions with their patients.

Using a subjective model, like the HBM, lets physicians act in the best interest of the patient. A physician will continue to give her patients advice; however, patients will have a better understanding as to why the physician is making these suggestions. The HBM allows for better communication and benefits the physician-patient relationship by lessening the unproblematic suggestions that physicians make to patients regarding treatment options.

IV. CONCLUSION

Doctors and other healthcare professionals are human, which means that their personal beliefs will undoubtedly influence the way they interact with patients. Often, this means that patients do not receive the care they need or want. While the bioethics movement, paternalistic approach, and the religiously motivated doctor, all have good intentions, it is crucial for doctors to treat patients without making suggestions that are based on personal beliefs. Doctors who deny care do not do so because they want people to suffer. Rather, they deny care because they genuinely believe that it is in the best interest of their patient to do so. While the HBM is by no means perfect, it is a useful tool because it creates a set of six guiding principles that all physicians can rely on when it comes to deciding the type of care they will provide. The HBM limits the influence of physicians' personal beliefs and allows doctors to rely on a subjective test to discuss different treatment options. The HBM can help physicians justify why they are providing the treatment or referring patients to another physician if they remain morally conflicted and unable to provide adequate care. When it comes to providing controversial procedures, physicians should employ the HBM, so they can uphold the Hippocratic ideal of offering care that is "good" for the patient.