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Assisted Reproductive Technologies and Genetic Disease: Two Theologically-based Ethical Perspectives: Protective Ethics and Proleptic Ethics

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Abstract

Assisted Reproductive Technologies and Genetic Disease: Two Theologically-based Ethical Perspectives: Protective Ethics and Proleptic Ethics

By Donald Y. Miller

Huntington's disease (HD) is a late-onset genetic and degenerative neuropsychiatric disease characterized by involuntary movements, depression and cognitive impairment. There is no cure for HD. A person with the genetic mutation for HD has a 50-50 chance of passing the genetic mutation to their children. With predictive genetic testing, a person at-risk for HD can confirm whether they carry the gene for HD. The related ethical questions include the rationale for accessing genetic confirmation for a terminal disease, offering predictive genetic testing to a minor whose parent has HD, a person's right not to know their genetic status and the use of assisted reproductive technologies.

Philosophical ethics such as consequentialism, deontology and principlism provide structures to assist people at-risk for HD in making healthcare and reproductive choices. For those seeking an ethic that speaks with a religious voice Roman Catholic and Lutheran ethics are well defined. Roman Catholic moral teaching offers clear and unambiguous guidance regarding procreation that applies to every member of the Catholic Church believing that actions have eternal significance.

In contrast, the Evangelical Lutheran Church in America (ELCA) social ethics does not offer clear and unambiguous dictates to its members. Rather, these social statements provide space for dialogue and discernment guided by justice, wisdom and concern for community. Lutheran social ethics encourages responsible deliberation of complex ethical questions that is respectful of an individual's narrative and life experience.

Each religious tradition approaches its relationship with society as well as with the individual. Catholic moral teaching and Lutheran social ethics both encourage engagement in public policy advocacy but take significantly different approaches to church and state relationships.

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Table of Contents

Introduction 1

Chapter 1: The Ethical Dilemmas for Those Living with Huntingtin's Disease 4

Chapter 2: Roman Catholic Moral Teaching 21

Chapter 3: Lutheran Social Ethics 40

Chapter 4: Theological Ethics and Its Role in Public and Private Life 61

Chapter 5: Faith, Ethics and Genetics: Companions not Competitors 77

References 90

Introduction

In this project, I explore the ethical and religious concerns of those living with Huntington's disease (HD) and those struggling with the menacing possibility of developing this horrific disease. Huntington's disease, named after George Huntington, the physician who described this hereditary form of chorea in 1872, is a devastating degenerative neuropsychiatric disorder characterized by involuntary movements (chorea), personality changes, cognitive impairment, and depression (Dufranse et al., 2011). It is an autosomal dominant disorder; the genetic cause is an expansion of the CAG trinucleotide repeat in the IT-15 gene on the short arm of chromosome 4 (Ciammola et al., 2009). A person with 40 or more CAG repeats will eventually develop HD; research has shown that a higher the number of CAG repeats correlates with an earlier onset of symptoms (Kromberg and Wessels, 2013). A child of a person with HD has a 50-50 chance of inheriting the genetic mutation for HD (Carlozzi and Tulsky, 2012). The onset of symptoms is typically between the ages of 35 and 45, but symptoms have been observed as early as 2 years of age and reported as late as 80 years old (Krukenberg et al., 2013). HD is fatal; the average lifespan after diagnosis is 15-20 years (Ho et al., 2001). Despite the identification of the gene mutation that causes HD there has been little progress in developing a cure (Imarisio et al., 2008) therefore treatments are palliative in nature seeking to mitigate the motor and cognitive symptoms (Asscher and Koops, 2009).

Families impacted by HD must wrestle with many difficult decisions, facing questions that have few easy answers.

A) What is the rationale for genetic testing since HD is both a terminal and a late-onset genetic disease?

B) What are the arguments for and against age limitations on predictive genetic testing?

C) Is there a moral and ethical duty to determine HD status while asymptomatic and of child-bearing age?

D) Does respect for autonomy justify a right not to know their genetic information for person at-risk for carrying the gene for HD?

E) Does moral duty compel an individual with the HD gene to prevent its perpetuation?

F) How are conflicts between religious doctrine and medical advances adjudicated?

A case study illustrates the issues facing the fictitious "Jones" family. I examine some of the ethical questions and more importantly the related religious assumptions one faces either directly or indirectly through family and culture.

Chapter 1 addresses the ethical issues that have arisen over the last few decades related to predictive genetic testing, the right not to know one's genetic information and assisted reproductive technologies (ART). Because church teachings have the potential to exert powerful pressure on moral decision making, I introduce the "Jones" family and their religious backgrounds, the Episcopal Church, the Roman Catholic Church, the Evangelical Lutheran Church in America (ECLA) and those with no religious affiliation. I base the "Jones" Family on my experience working with a woman I met in 1998 through my work with hospice in North Carolina, her father had just been diagnosed with HD and she had returned home to North Carolina to serve as his primary care-giver. I met with her as she wrestled with whether or not to learn her HD status. She eventually decided to forgo genetic testing and focus on caring for her father.

Chapter 2 explores the moral teachings of the Roman Catholic Church on genetics and procreation, noting how Natural Law Theory, Deontology, Consequentialism and the *Imago Dei* shape their position as expressed in Pope Paul's 1968 Encyclical *Humanae Vitae*, the

Congregation for The Doctrine of the Faith's 1987 *Instructions on Respect for Human Life in Its Origins and on the Dignity of Procreation (Donum Vitae)* and the 2008 *Instruction Dignitas Personae, On Certain Ethical Questions*.

Chapter 3 analyzes the ELCA's social statements, *Genetics, Faith and Responsibility, Human Sexuality, Gift and Trust,* and *Church in Society: A Lutheran Perspective* whose ethical foundations are responsibility, deliberative justice and respect.

Chapter 4 discusses the role religious moral teaching plays in healthcare practice and the making of public policy in the areas of reproduction, stem cell research and genetic innovation.

Chapter 5 produces a dialogue between a Roman Catholic and a Lutheran (ELCA) theologian as they both look to the future of genetics, healthcare and human progress.

Chapter 1: The Ethical Dilemmas for Those Living with Huntingtin's Disease

The Discovery of the HD Gene

The genetic markers linked to the HD gene were first identified in 1983, enabling individuals at-risk for developing HD to establish their carrier status through a process called linkage analysis. Linkage analysis requires blood samples from both affected and unaffected family members, sometimes from as many as three generations, to trace the line of inheritance in a family. (Quaid et al., 2010). Fortunately, in 1993, the discovery of the CAG trinucleotide repeats permitted direct mutation testing of a single individual without family involvement, removing a potential obstacle to genetic testing. This advancement in predictive genetic technology increased the sensitivity and specificity of the test to virtually 100% while improving the protections for patient autonomy and privacy (Dufrasne, 2011, Quaid et al., 2010). Even with the advances in the accuracy of the genetic tests and increased focus on protecting patient confidentiality the number of people at-risk for HD who confirm their status remains alarmingly low.

Dufrasne et al. (2011) performed a retrospective analysis of the participants who underwent predictive genetic testing for HD in Montreal, Canada from January 1994 to June 2008. They estimate that only 9.2% of the at-risk population in greater Montreal requested predictive genetic testing. Kessler et al. (1987) surveyed individuals at-risk for developing HD to determine the likelihood they would pursue predictive genetic testing. Their results show, 79% said they would use a pre-symptomatic test if available, 66% responded that they would test for prenatal diagnosis and 71% would consider terminating the pregnancy if HD is present. In a follow-up study, Creighton et al. (2003) estimate that only 5-20% of people at-risk for HD seek predictive genetic testing. The discrepancy between reported willingness and follow through can be explained by a variety of reasons.

Reasons people seek or forego Predictive Genetic Testing

People at-risk for developing HD voice many concerns that impact their willingness to pursue predictive genetic testing: stigma, fear of discrimination at work or from insurance companies, an overall sense of hopelessness and becoming a burden to their families (Klitzman, 2010). Another contributing factor is the anxiety and emotional stress related to whether a subtle symptom could be indicative of HD onset (Dufrasne, 2011). Carlozzi and Tulsky (2012) surveyed the health-related quality of life (HRQOL) concerns within the HD community using four focus groups consisting of people symptomatic for HD, individuals at-risk for developing HD, non-clinical HD caregivers, and HD clinicians across the domains of emotional, physical, cognitive and social health. For purposes of this paper I focus on the at-risk group. The following quotes from members of this group express the complexity of deciding to undergo predictive genetic testing.

- “If I get tested now, what good will it do?”
- "There is no hope."
- “When I was growing up we didn’t talk about it. I mean, it was not talked about. We were not supposed to tell anyone.”
- “I might as well do away with myself.”

When these quotes are read through an ethical lens they appear to be based on utilitarianism. A utilitarian asks, of what good are these tests, if they provide information that does not benefit me at the cost of increased anxiety and stress? “The right act in any circumstance is the act that produces the best overall results as determined by the theory’s account of value…Utilitarianism accepts one, and only one, basic principle of ethics: the principle of utility” (Beauchamp and Childress, 2013, p. 354-355). “Of what good” is the basic construct of utilitarian thought. What values or utility might drive a person at-risk of HD to forgo genetic testing? Happiness, success in their chosen career and a desire to live without the stress of unwanted genetic information are all sufficient reasons based on utilitarianism. However, utility can also be the rationale for others at-risk for developing HD in deciding to proceed with genetic testing. They determine that testing offers them valuable information, it empowers them to make decisions regarding healthcare, reproductive choices and managing long-term relationships.

For those at-risk for developing HD that seek predictive genetic testing, the reasons are as compelling as the arguments against testing. Participants in the Montreal Predictive Testing Program (Defrasne et al., 2011) reported that relieving their uncertainty, planning for their future, providing their children with a precise estimate of their own risk and enabling them to make informed decisions about family planning as reasons to seek predictive genetic testing. Doing the right thing for one's children is a frequently cited motivator for someone at-risk for developing HD to proceed with predictive genetic testing. Smith et al. (2013) conducted a qualitative examination of individual's decision-making about predictive genetic testing for HD. One of their subjects, Angela, a woman in her 50's with a daughter who already has children and a son who does not, explained her reason for seeking clarification of her HD status,

> "If you're given the knowledge that you have got a choice whereas… we didn't have any knowledge; we didn't have any choice… If I didn't take it (the test), I would be taking on the whole of that power onto me… it's not allowing other people any choice… I think that's quite selfish" (p. 419).

Clarification of one's HD status can be a tool in reproductive planning for those who have children and for those who would like to have children. For individuals with the mutated HD gene who have already had children, being able to assist their children in making reproductive choices in the future may be a way of coping with the guilt they feel for potentially passing the HD gene to their children. Eleanor, a 30-year-old woman with two daughters aged 12 and 9, based her decision to seek confirmation of her HD status on a hypothetical conversation with one of her daughters. She feared her daughter saying, “Why didn’t you have the test? You could have stopped me getting pregnant…you could have stopped it in our line" (Smith et al., 2013, p. 418). Emotions like fear and guilt play a role in HD because of the late onset of the disease. Many people with HD are diagnosed after they have children and the guilt is a response to not being able to do anything to protect their children from the devastating effects of the disease (Carlozzi and Tulsky, 2012). Others, like Eleanor, may feel they have a moral imperative to seek genetic testing and to encourage their children to seek testing as a way of coping with the uncomfortable feelings associated with unknowingly passing a genetic disease to their children (Smith et al., 2013). Does a person with a history of HD in their family have a duty to clarify their HD status or can they decide to forgo learning their HD status?

The Ethics of Genetic Testing

Predictive genetic testing for individuals at-risk for HD raises ethical issues that are also practical. Ensuring data security, designing necessary protocols for the sharing of genetic information and thinking about the implications genetic data can have on employment and access to health/life insurance are issues that have practical application. Other issues that demand ethical consideration are: Does providing an individual with information about a genetic disease that will impact their future health, when a cure does not exist, violate the ethical principles of respect for autonomy and non-maleficence? Is the confirmation of one's HD status more harmful that not knowing? Can a person at-risk for developing HD claim their right not to know their genetic information and live in what Tuija Takala refers to as "genetic ignorance"?

The availability of predictive genetic tests has expanded over the last two decades; there are tests for a host of adult-onset conditions including cancer, heart disease, and specific neurological disorders. These tests can provide some answers to genetic questions as well as benefits to people as they determine the need for additional testing, make healthcare decisions, and make reproductive choices. Predictive genetic testing has the potential to cause psychological harm and change how a person views themselves as an autonomous individual, therefore many people decide not to learn their HD status.

To address some of the concerns people have regarding predictive genetic testing a protocol developed at the Montreal Predictive Testing Program begins with five inclusion criteria for a person seeking confirmation of their HD status:

1) A family history of at least one confirmed case of HD from either a parent or grandparent.
2) Be at least 18 years of age.
3) Have the capacity to give informed consent.
4) Show no evidence of external pressure or coercion for testing.
5) Be willing to follow the protocol.

This program also includes three exclusion criteria:

1) Presence of neurological symptoms consistent with HD.
2) Suicidal ideation.
3) Current mental illness.

The protocol begins with a phone interview with a psychologist to explore the person's knowledge of HD and reasons for seeking genetic testing. The interviewer gathers appropriate demographic information about the person asking about genetic testing and provides information about the protocol. Following the phone interview, a face to face meeting with a psychologist, the person seeking to test is encouraged to bring a support person with them for each step of the process. This session is designed to identify any psychological issues needing attention before the testing procedure. Participants are invited to discuss their experiences with HD, their hopes and fears about their HD status and identify their coping skills and strategies. The second face to face visit is an interview with a psychologist and a physician; this meeting is scheduled about a month later to assess the person’s family medical history and provide the participant with an opportunity to express any concerns they have about HD.

The third face to face visit is scheduled a month later with a genetic counselor. The focus of this meeting is an explanation of the reliability of DNA testing and nondirective exploration of reproductive options if having children is a goal of the participant. The participant is invited to discuss issues related to psychological harm as well as insurance, social and job discrimination. The participant signs an informed consent document and provides a blood sample. At each step of this protocol, the participant has the option to stop the process and withdrawal from the testing. The results of the blood work are available in four to six weeks. In Montreal the results are always delivered face to face with a physician and psychologist present as well as any support person or persons. If the test reveals that the participant is a carrier of HD, they are referred to a neurologist for assessment. A follow-up phone interview is conducted a week after disclosure by the psychologist to assess the emotional state of the participant and additional sessions with the psychologist are arranged if needed (Dufrasne et al., 2011).

The Montreal protocol seeks to protect the autonomy of the participant throughout the process, by allowing them to opt out of the program at any point. The participant’s psychological and emotional health is of paramount importance, the presence of a psychologist at every step of the process ensures that any psychological injury to the participant is addressed as quickly as possible and the participant is encouraged to bring supportive people with them. These actions show that the program in Montreal is a model for maintaining and protecting the autonomy of the participant throughout the process and their commitment to upholding the ethical principles of beneficence and non-maleficence.

Predictive Genetic Testing and Minors

Predictive genetic testing when offered in conjunction with ethically sound genetic counseling is an established and accepted plan of care for adults at-risk for developing HD.

Conversely, there is controversy about providing predictive genetic testing to minors for conditions, that rarely manifest before adulthood and for which there are limited treatment options. Cara Mand and her colleagues (2013) conducted a review of fifty-three theoretical papers published between 1990 and 2010 on the issue of offering predictive genetic testing to individuals under the age of 18. They concluded that the arguments for and against have remained relatively unchanged over the decades and for the most part are mirror images of each other. The arguments for and against allowing predictive genetic testing of minors use the same categories and make either positive or negative predictions regarding: 1) psychological harm, 2) adverse effects on the family system, 3) the potential for discrimination and 4) diminished personal autonomy.

Mand and her colleagues, concluded that the debate about predictive genetic testing for minors has reached an irreconcilable impasse. “Working from the same set of ethical principles and concerns (e.g. harm, benefit and autonomy) the commentators on either side of the debate have reached opposing conclusions and this sticking point is the position we remain in” (p. 522). They point out that the writers on either side of the debate have set up a "binary analysis," which makes it difficult for either side to see the converse of their arguments. To move past this "sticking point," they recommend applying a developmental perspective that considers the trajectory of child and adolescent development when applying each argument to a given case. Are there positive aspects of a gene-positive test result? Are there negative impacts of a gene-negative result? Is it possible to have both positive and negative implications for either testing and not testing? To bridge the chasm in this debate, Mand and her colleagues advocate for the collection of empirical evidence to verify the claims regarding the negative or positive consequences of allowing predictive genetic testing for minors. Clinical practice has evolved over the last two decades towards a more flexible patient-centered approach to healthcare decision-making, many believe it is time to revisit offering predictive genetic testing to minors. I concur, allowing the option of predictive genetic testing to children on a case by case basis, is a prudent approach that provides them a context to better understand their family and the responsibility of potentially inheriting and passing on the genetic mutation for HD. Before allowing the option for genetic testing for minors, their age, maturity level and presence of a supportive structure like a family or community of faith should be considered. Allowing the option for genetic testing for minors provides for the collection of data and the expansion of our current understanding of human development, in addition it supports individual minors exercising their personal autonomy, encouraging them to make informed decisions regarding their reproductive choices.

The Right Not to Know and The Duty to Inform

Do individuals at-risk for developing HD have a right not to know their HD status or do they have a duty to learn their genetic information and share this information with those closest to them? The right not to know is recognized in recent ethical and legal statements relating to bioethics and genetics. Two examples are the European *Convention on Human Rights and Biomedicine* and UNESCO’s *Universal Declaration on the Human Genome and Human Rights*. The European Convention states, "Everyone is entitled to know any information collected about his or her health. However, the wishes of individuals to not be informed shall be observed." UNESCO's Declaration provides the following, "The right of every individual to decide whether or not to be informed of the results of genetic examination and the resulting consequences should be respected” (Andorno, 2003, p. 436). Andorno argues that a person should be free to make their own decisions regarding genetic information and that the right not to know is an expression of a person’s autonomy, "…the possibility to choose not to know the results of genetic tests may constitute an *enhancement of autonomy* because the decision to know or not to know is not taken out of the hands of the patient by the doctor" (2003, p. 436). Personal autonomy is the primary justification for the right not to know, but ultimately the decision not to know protects "the psychological integrity of the person" (Andorno, 2003, p. 437). Patients must have the freedom to choose a path that protects themselves from any psychological injury their genetic information may cause. Genetic information is not malevolent, but we must be aware of the unfortunate effects this information can have on someone who does not possess adequate coping skills or emotional strength. While Andorno defends the right not to know, he does not believe this is an absolute right,

> "One has to recognize however that the refusal to be informed about one's genetic status may in some cases be problematic because genetic information is not only an individual but also a family affair" (2003, p. 437).

When discussing a person’s right not to know their genetic status, one must balance respecting an individual's autonomy with looking at the benefits of genetic information for the common good. The adage, “my right to swing my fist ends where your nose begins”, can be helpful when looking at a person’s right not to know.

Critics of the right not to know argue that it is contrary to liberal societies upholding of humanity's thirst for knowledge. Aristotle believed the thirst for knowledge is one of the features that separates humankind from the animal. The Kantian phrase, *"Sapere Aude"* ("Have the courage to use your knowledge") speaks to humanity's quest (Andorno, 2003, p. 436). Asscher and Koops (2010) object to the right not to know because such an exercise may place others in harm’s way, and in the case of HD, the others are any future children that may carry the mutated gene for HD. Another critique sited by Andorno (2003) and Asscher and Koops (2010) is the argument from solidarity, the value that society places on acting in a manner that promotes the common good. Andorno recognizes that a person who refuses to know his or her genetic status places themselves in a position of being unable to disclose vital information to family members, such as siblings, children or intimate partners (2003, p. 436). Asscher and Koops' solidarity objection is based on the perceived injustice the right not to know can cause in a publicly funded health system. They argue that a person who chooses not to know their genetic status may place an undue financial strain on the healthcare system by making use of expensive medical procedures like in vitro fertilization (IVF) and pre-implantation genetic diagnosis (PGD) when they are not a carrier of the HD gene (2010, p. 32).

I hold conditionally, that a person has a right not to know their genetic status based on their autonomy and their wish to avoid the potential psychological or emotional harm caused by learning their HD status. Learning one is a carrier of the HD gene can be a burden that some feel is too heavy for them to bear, knowing one's status could so depress them that the quality, joy, and purpose in their lives could metaphorically evaporate (Andorno, 2003, p. 435). Striking a balance between respecting the right for a person to avoid learning their HD status and the need to do what is necessary to protect those who may be harmed by this decision is a formidable task with few easy, clear-cut answers. One area that is clear cut is reproduction; the right not to know is revoked when matters of reproduction enter the conversation. How is it wrong to produce children who will suffer from genetic defects or diseases is ***the*** question when the right not to know and reproduction come into conflict? In what ways is producing avoidable suffering for the sake of remaining unaware of one's HD status morally acceptable?

Rosamond Rhodes (1998) argues against the right not to know one's genetic information. She asserts that our natural aversion to coercion and the historical commitment within the United

States to personal liberty (respect for autonomy) has led the genetic community to adopt an ethics of genetic counseling which is value-neutral or non-directive counseling, built on a "moral assumption" and constitutes a "misleading philosophical leap of faith" (1998, p. 15). In a clarifying footnote to this comment, she explains her assertion,

> “Again, what follows is not an argument for informing patients/clients who choose not to know genetic information about themselves or their offspring. The argument below has the much more limited scope of merely showing that **there is no patient/client “right not to know.”** There may certainly be excellent policy considerations and personal reasons for not imposing information on someone who does not want it” (1998, p. 27).

Rhodes believes a Kantian understanding of autonomy cannot be used to justify one's right not to learn one's genetic information,

> “Now, if autonomy is the ground for my right to determine my course, it cannot also be the ground for not determining my course. If autonomy justifies my right to knowledge, it cannot also justify my refusing to be informed… I am obligated to make thoughtful and informed decisions without being swayed by irrational emotions, including my fear of knowing significant genetic facts about myself. When I recognize that I am ethically required to be autonomous, I must also see that, since autonomous action requires being informed of what a reasonable person would want to know under the circumstances, I am ethically required to be informed.” (1998, p. 18)

I resonate with Rhodes interpretation of Kantian autonomy, to make an informed decision one needs to gather the information that is required, but I question the utility of her cavalier attitude about the legitimacy of emotions. Dismissing fear as simply “irrational” does not make it go away. Fear can sway how people make decisions. Working in healthcare for twenty years I witnessed the power of fear as a motivator and as a hinderance to decision-making. Fear can unleash our courage to act despite perceived danger or it can paralyze our cognitive functions and render us incapable of taking any action. While being fearful of one’s genetic information is real, this fear is not reason enough to justify living in genetic ignorance and possibly contributing to the continuation of HD in a family.

For those at-risk for developing HD, genetic information can be a powerful tool to guide how they live their lives, however I am also persuaded that such genetic information can lead to unwanted changes in self-image, a reduction in one's ability to exercise self-determination and increase anxiety about the future (Juth, 2014). Living in a free society means we must allow people to make poor decisions regarding their behavior but living in an interdependent community requires that we hold people to a standard of action that avoids placing others at undue risk. A person at-risk for HD can choose not to know their genetic status, but that choice is limited when their actions place another at avoidable risk. A person carrying the HD gene mutation has a 50-50 chance of passing the mutated gene on to their children, this is a known risk. There are reproductive options available that can mitigate the potential of perpetuating an incurable genetic disease to the next generation of a family. Not voluntarily taking advantage of available technology to avoid placing another at risk of harm is an ethically tenuous position to defend.

> “In this case, the utilitarian theory directs one to perform the action having the least amount of negative utility. This point helps make clear the guiding idea behind utilitarianism: one is always permitted, if not required, to bring about the best state of affairs bearing the welfare that one can the particular situation in which one finds oneself. In some situations, the theory will direct us to make the best of a bad situation”. (Timmons, 2013, p. 115).

Persons at-risk for HD can claim a right not to know their genetic status, but once they decide to become sexually active, their right not to know is diminished by the potential harm that may be the result of their actions. Utility directs them to make the best of the situation, which requires them to forgo their perceived right not to know because it is what is best for the welfare of others.

Assisted Reproductive Technologies and HD

Assisted reproductive technologies (ART) were developed during the 1970's to address the issue of infertility and to allow people with a desire to have children of their own, especially children with whom they share a biological link. Louise Brown, born on July 25, 1978, became the first successful birth of a child conceived through in vitro fertilization (May, 2013 p. 90-91). ART is a medically accepted option for couples facing infertility or who cannot reproduce traditionally, such as same-sex couples. In 2015, the Centers for Disease Control and Prevention's (CDC) National Summary of ART reported a total of 231,936 cycles, 74,665 pregnancies, 60,778 deliveries resulting in 72,913 infants. ART may have reached a level of acceptability, but the controversy still rages in certain corners. (Vaughn, 2013, p. 396).

For people at-risk of passing the mutated HD gene along to their children, what reproductive options are available to them? First, not having children, while stopping the perpetuation of HD in their family line it results in the loss of the family line, for those who do not already not have children. Second, adoption, which prevents the continuation of HD, and as with not having children, brings an end to the genetic family line unless there are siblings who have had children. Adoption allows the family name to be carried on, if not their genetic material. Third, in vitro fertilization (IVF) using a donor gamete, either egg or sperm, depending on the gender of the HD affected partner. The donor material and genetic material are combined in a laboratory, producing an embryo, that is transferred into the uterus. This procedure allows for the passing on of half of the couple's genetic material, avoiding the genetic material that contains the mutated HD gene. The advantage of this procedure is that it allows a couple to reproduce without the risk of perpetuating HD, this option may be rejected by a couple seeking a child that shares 100% of their genetic material. Fourth, the couple can decide to reproduce in the traditional unassisted manner or by IVF; if this results in a pregnancy, they can opt for genetic testing of the fetus for signs of HD. If the fetus is positive for HD; the couple as two options carrying the pregnancy to term with the knowledge that the child will be a carrier of the mutated HD gene or selective abortion. This option allows the couple to produce a child that shares 100% of the DNA, but it runs the risk of perpetuating HD in the family. Further, it brings abortion with all the corresponding moral, legal and ethical issues into the conversation. Fifth, IVF with preimplantation genetic diagnosis (PGD). This procedure produces several embryos for implantation in a laboratory, but before being implanted in the female, the embryos are screened for the presence of the HD gene, those with the HD gene are set aside, embryos without the HD gene are implanted. This option allows the couple to reproduce without the fear of passing HD along to their children who share 100% of their genetic material, thus allowing for the continuance of the family line without HD. (Vaughn, 2013, May, 2013 and Asscher and Koops, 2009) These reproductive options offer couples with a history of HD, a means of not passing this devastating genetic disease on to the next generation.

Is there hope on the horizon?

New research has raised hopes in the HD community that IONIS-HTTRx, a drug that lowers the level of huntingtin protein, mat be the first effective treatment for people with HD. Professor Sarah Tabrizi, Director of the Huntington's Disease Center at the University College of London, is quoted in the December 11, 2017, news release,

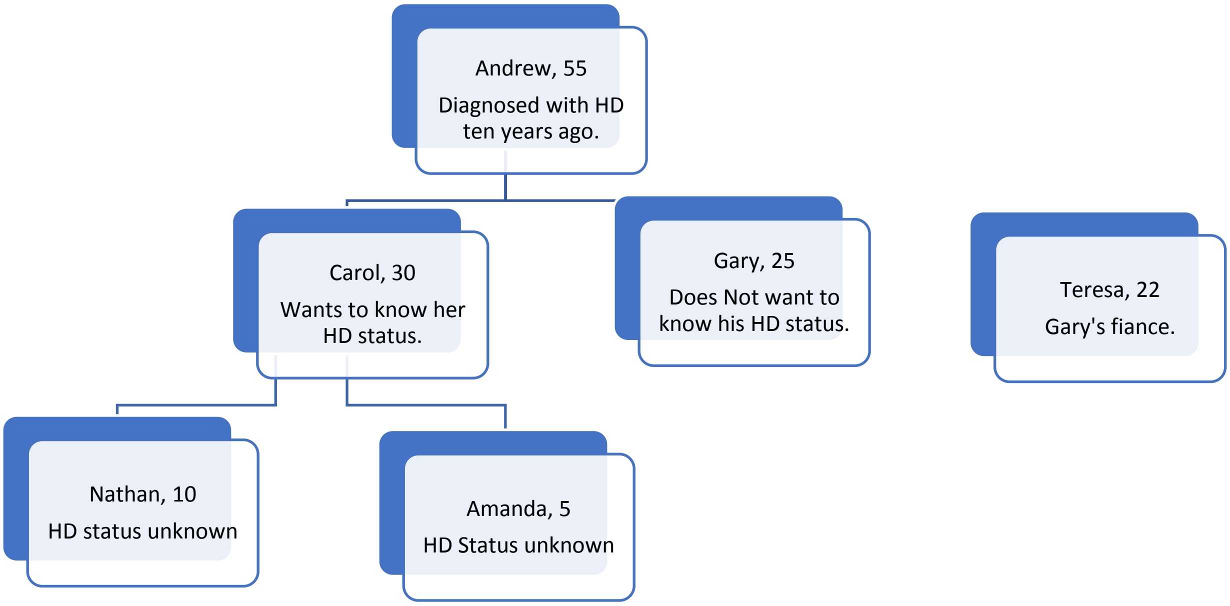
> “The results of this trial are of ground-breaking importance for Huntington’s disease patients and families. For the first time a drug has lowered the level of the toxic disease-causing protein in the nervous system, and the drug was safe and well-tolerated. The key now is to move quickly to a larger trial to test whether the drug slows disease progression” (UCL, 2017).

Other promising research involves sheep GM1 ganglioside, a lipid found in the brain and spinal cord tissues of sheep. Early laboratory studies indicate that sheep GM1 is effective in reducing the symptoms of HD in mice and the hope is that this research will eventually lead to a treatment for HD in humans. (Di Pardoa et al., 2012)

The “Jones” Family

Andrew is a 55-year-old widower diagnosed with HD ten years ago, his motor symptoms have progressed so that he is unable to attend to any of his activities of daily living (ADL's) such as feeding, bathing, and dressing. The chorea or involuntary movement of the extremities has severely limited his mobility, he lives with 24-hour care in a skilled nursing facility (SNF). Andrew experiences bouts of depression and is prone to mood swings. His cognitive abilities continue to deteriorate, some days he can recognize his family, and on other days his affect is flat and mostly unresponsive. Andrew has two children; Carol and Gary.

Carol is 30 years old and has two children, Amanda, 5 and Nathan 10. Carol does not know her HD status and is anxious to be tested; she wants to be as informed as possible about her and her children's future. Gary is 25 years old and engaged to Teresa who is 22 years old. They do not have children, but Teresa has five siblings and wants to start her own family as soon as possible. Gary does not want to know his HD status out of fear of how he might cope with a positive test and how it might affect his relationship with Teresa. Carol believes getting tested is the right thing to do for herself and her children. Gary is adamant that he does not want to know his HD status, saying, “There is nothing we can do about it, so we might as well just live our lives and let things happen as they will.”



The ethical and religious issues faced by the “Jones” family

Can Gary’s desire not to know his HD status be justified using the principle of personal autonomy? Does Gary have a duty to learn his HD status and share this information with Teresa? Are there compelling reasons for Carol to explore the possibility of allowing her children to confirm their HD status as minors? What reproductive options are available for Gary and Teresa and how does their faith influence their moral decision-making regarding reproduction?

Carol wants to do what is best for her children. Therefore, she contacted an HD research center and enrolled in their predictive genetic testing program. Carol wants to ensure her children have access to age-appropriate facts about HD as they frequently visit their grandfather. Additionally, Carol’s HD status will impact her children’s future reproductive choices. While Gary is avoiding the potential emotional stress of learning his HD status, Teresa wants to know. She is anxious about the physical and emotional toll HD might have on her and her pending marriage to Gary. She fears the possibility of having to watch Gary suffer in the same manner as Andrew as well as the possibility of HD being passed to the children she might conceive with Gary.

Carol's results show that she is a carrier of the HD gene but at this point she is asymptomatic. The physician, informs her that the earliest symptoms of HD can begin years before a clinical diagnosis is made. Carol is attentive to any problems with executive functions, fidgeting, apathy, restlessness, depression or uncontrolled movements that could be early signs of chorea (Krukenberg, 2013). Carol informs her children of her HD status and enrolls them in a support group for children with a family history of HD led by a psychologist from the HD research clinic.

Andrew is the most religious person in the family, worshipping weekly in the Episcopal church until his HD symptoms became prohibitive. Carol and her children attend the local Lutheran church (ELCA) because her children participated in the church's preschool program. Gary claims to be agnostic; he is troubled by the hypocrisy he sees in religious people and institutions. Teresa calls herself a lapsed Catholic, she graduated from a Catholic high school and endured years of mandatory Mass attendance. In college, Teresa explored other religious traditions and enjoyed the freedom of not attending worship. While Teresa does not attend Mass regularly, she always imagined raising her future children in a faith community. Claiming her personal autonomy, Teresa rejects the Catholic Church prohibition of contraception. The presence of HD in Gary’s family now raises heretofore unexamined personal values about reproduction and the teachings of the Catholic Church. Gary claims his right not to know his genetic information.

Chapter 2: Roman Catholic Moral Teaching

Life is a continuous process of making moral choices. What makes an action, or a person moral is judged by the values of social and cultural norms, a philosophical framework or the teachings of a religion. The moral teaching of the Roman Catholic Church is more than a set of rules and dictates that the faithful are required to follow,

> "Roman Catholics understand moral theology as the study of the implications of faith for the way people live – both for the sorts of persons we become (virtue) and for the actions we ought (or ought not) to perform. Futhermore, Catholics see such actions as affecting their union with God…Thus Catholics consider their moral actions as having religious significance, affecting their relationship with God" (Nairn, 2001, para. 4).

Possessing ultimate significance, affecting ones' relationship with God raises Catholic moral teaching to an almost threatening level. John P. Langan further explains,

> "The Catholic church in its moral teaching continually looks in two different directions. The first is the look within: to the community of the Catholic faithful who turn to church leadership for moral guidance in a changing world. In addressing this community, the church relies on Scripture and tradition. The second is the look outside: to the larger civil community that sets the legal and cultural context for ethical decisions and that is, at least intermittently, interested in moral issues" (1990, p. 75).

Thus, Catholic moral teaching seeks to influence both the actions of the faithful and the subsequent impact these decisions have in their relationship with God, society and the making of public policy.

Leaders of the Catholic Church offer official moral guidance through papal encyclicals, official letters written by the Pope, and instructions from The Congregation for The Doctrine of The Faith, a body of the church that has existed since 1542 to "judge the offenses in the matter of faith" (www.vatican.va). The church documents impacting the lives of people living with HD are, the Papal Encyclical, *Humanae Vitae,* published in 1968 and two instructions from The Congregation for The Doctrine of The Faith, *Instructions on Respect for Human Life in its Origin and on the Dignity of Procreation, Replies to Certain Questions of the Day (Donum*

Vitae) published in 1987 and *Instruction Dignitas Personae, On Certain Bioethical Questions,* published in 2008. How are members of the Catholic Church to respond official church teaching? Nairn provides the answer,

> "Members of the church are to accept all such teaching with deep respect. Certain moral issues are considered so central to the church's identity and mission that the pope and bishops have stated that Catholics may not adopt a contrary position" (2001, para, 6).

Understanding the foundational point of departure of these teachings may guide the individual who wrestles with total compliance. To better understand the breadth and depth of Catholic moral teaching I explore natural law theory, the concept of the *imago dei,* and moral teachings regarding procreation, conception and contraception in papal encyclicals and documents published by the Vatican.

Natural Law Theory and The Roman Catholic Church

The moral teachings of the Roman Catholic Church are based on natural law theory, not to be confused with the laws of nature that are important to biologist and other scientists. Catholic theologian, John M. Haas describes the difference,

> "The laws of nature are descriptive while the natural law is prescriptive. The laws of nature describe what occurs time after time, while natural law prescribes what ought to be done" (1990, p. 102).

Lewis Vaughn writes,

> "Though natural law theory has religious and non-religious forms, the theistic formulation of theologian-philosopher Thomas Aquinas has been the theory's dominant version…Aquinas believed that God is the originator of natural law and God created humanity with the gift of reason to discern the law and to live accordingly…human beings naturally tend towards—and therefore have a duty of—preserving human life and health, producing and raising children, seeking knowledge and cultivating cooperative relationships" (2013, p. 39).

According to this interpretation of Aquinas' formulation of natural law, humanity has a duty to preserve human life and health and produce children, but what it the child is born with a devesting early-onset genetic condition like Tay-Sachs disease or Duchenne muscular dystrophy? Does this alter the applicability of natural law? Does HD, which is a late-onset genetic disease change the equation?

Mark Timmons discusses the three components of natural law theory. First, *a perfectionist theory of value*, which understands right and wrong conduct to be a process of rational human thought; to act morally is to act rationally and the state of perfection for humanity is located where our God-given rational capacity is fully developed and engaged. Aquinas’ four essential human goods (natural inclinations): *life, procreation, knowledge, and sociability* represent the goods that humanity ought to pursue. The second component is the *principle of double effect,* which engages the problem of an action that produces a hoped for and beneficial effect while also producing an unintended and harmful effect. The matter of intention and foresight are key components to double effect. The third component is *moral absolutism*, the belief that there are actions that are always morally wrong even if the action produces a good result (2013, p. 73-76).

Applying natural law theory to human procreation, the good to be pursued is life itself, which is understood to begin at conception, and the evil that is to be avoided is any action that separates or hinders the unity of the coital act of husband and wife. Catholic moral teaching, based in natural law theory, is interpreted to say, even a couple at-risk for HD has a duty to pursue new life through the procreative act, regardless of the risk of genetic mutation for the child. Speaking of moral goods, May says, “a good that human persons share with other entities…is that of life itself, including bodily life, health and bodily integrity” (2013, p. 67). The question at hand regards “bodily life, health and integrity” for a person living under the shadow of HD. Since HD develops late in life, a person can live a “normal” life until the symptoms manifest. However, I contend that ignoring the possibility of passing the mutated gene for HD to one's offspring violates the moral good of health and bodily integrity, by placing the child at risk of being born with an incurable genetic disease. To possess the knowledge of the possibility of passing the gene for HD to one's child and to decide to ignore this possibility and place the child at risk of developing an incurable disease limits the child's right to an open future. Kirsten Smolensky argues,

> "that parents have a moral obligation to help their children develop the capacities that will allow them to pursue a reasonable array of different life plans available to members of their society. If a parent's genetic choices unreasonably limit the life plans available to their child, the child suffers a moral harm" (Smolensky, 2008, p. 301).

Using this line of thought, a person who willingly ignores their HD status and produces a child who inherits the gene for HD has deliberately caused the child to suffer a "moral harm".

Based on natural law theory, the use of contraception to prevent the passing of the HD gene to one's children may be a prudent choice to avoid causing harm. However, the Catholic Church's opposing interpretation of natural law theory is clear: contraception is immoral, use of assisted reproductive technologies (ART) that replace the coital act is immoral, the destruction of embryos found to carry the HD gene is immoral. Within certain parameters, the use of somatic-cell gene therapy, to treat a disease or correct a genetic defect in an individual is morally acceptable, but germ-line cell therapy that aims to make corrections to genetic defects that can be transmitted to future generations is immoral (May, 2013, p. 229-230). The Catholic Church pronounces that actions, such as the use of contraception that can prevent harm are immoral based solely on their authority, an form of argument that Childress and Macquarrie feel is no longer acceptable,

> "Standards of conduct can no longer be upheld by simple appeal to the authority of the church of the Bible. In modern secular societies, Christian ethicists are agreed that it is

> unreasonable to try and legislate Christian standards for the whole body of citizens…" (1986, p. 49).

The authority of the Catholic Church's moral teachings may be acceptable for members of the Catholic Church, the argument that this authority can and should be expanded to cover the whole of society will be addressed in Chapter 4.

The Dignity of Humanity (*Imago Dei*) in Catholic Moral Teaching

Closely linked to natural theory is the Catholic Church's emphasis on human dignity. Dignity suffers from a peculiar problem, most assume a shared understanding of the meaning of dignity but getting scholars to agree on a consensus definition is a Sisyphean task. Adam Schulman understands dignity as "…the essential and inviolable core of our *humanity*" (2008, p.17). Ruth Macklin spawned much debate with her infamous pronouncement, "Dignity is a useless concept in medical ethics and can be eliminated without loss of content" (2003, p. 1419). Dignity is either the essential kernel of humanity or a useless concept; the Catholic Church would agree with Schulman over Macklin. The Catholic Church utilizes dignity to justify prohibitions on contraception, assisted reproductive technologies, abortion, physician-assisted dying, genetic research and human cloning. Roger Brownsword identifies two contrasting roles dignity can play, "…in support of individual autonomy (human dignity as empowerment) and… as a constraint on autonomy (human dignity as constraint)" (2003, p. 20). The Catholic Church emphasizes dignity as a constraint on personal autonomy, especially when applied to genetics and reproduction. *Dignitas Personae* begins with the statement,

> "The dignity of a person must be recognized in every human being from conception to natural death. This fundamental principle expresses *a great "yes" to human life* and must be at the center of ethical reflection on biomedical research, which has an ever greater importance in today's world" (2008, para. 1).

Genesis 1:27, "*So God created humankind in his image, in the image of God he created them; male and female he created them."* (NRSV) is the scriptural foundation for the *imago dei*. Humanity reflects the image of God; we are the visible representation of the invisible. Norman Ford explains,

> "The Bible shows that human life and its formation are particularly close to God, the Creator…The Bible is the Book of Life *par excellence* about the origin of human life…References to human life in the womb throughout the Bible (Job 10:8-12, Jeremiah 1:4-5, Isaiah 44:24 and Psalm 139:13-16) give ample evidence that God is providently involved in the formation from conception" (2008, p. 39).

While Ford holds that the Bible is authoritative, he admits that the Bible "is not a scientific account of the beginnings of human life or human embryology" (2008, p. 39). Ford may be willing to accept that the Bible is not authoritative in the areas of human genetics, but Pope John Paul II asserts the Catholic Church's position regarding the origins of human life in his Encyclical Letter *Evangelium Vitae*,

> "Some people try to justify abortion claiming that the results of conception, at least up to a certain number of days, cannot be considered a personal human life. But in fact from the time the ovum is fertilized, a life is begun which is neither that of the father nor of the mother; it is rather the new life of a new human being with his own growth. It would never be made human if it were not human already. This has always been clear, and ... modern genetic science offers clear confirmation. It has demonstrated that from the first instant there is established the programme of what this living being will be: a person, this individual person with his characteristic aspects already well determined" (John Paul II, 1995, para. 60).

Thus, Pope John Paul II claims the Catholic Church has primacy over other religious and secular perspectives. Bryan C. Pilkington expresses a less polemic position of the importance of being made in the image of God, "How we think about the dignity of human beings within bioethical situations will affect how we think about persons outside of medicine as well" (2017, p. 312). *Dignitas Personae* reiterates this understanding,

> "The Church, by expressing an ethical judgment on some developments of recent medical research concerning man and his beginnings, does not intervene in the area proper to

> medical science itself, but rather calls everyone to ethical and social responsibility for their actions" (2008, para. 10).

We are called to treat other humans with the respect they deserve within biomedical situations and in the mundane activities of everyday life. "Our human dignity, then, demands we treat each other differently, fundamentally and qualitatively differently than we treat this morning's newspaper or our new puppy" (Brungardt, 2011, p.15). The Catholic Church extends the concept of dignity to human sexuality, genetics and beyond.

The Dignity of Procreation in Catholic Moral Teaching

On procreation, Catholic moral teaching is descriptive and prescriptive asserting that the conjugal act, when done within the bounds of marriage, is both ***unitive and procreative*** and to separate the two is unacceptable,

> "The marital act, therefore, precisely as marital, participates inward in the goods and blessings of marriage. It is inherently love-giving (unitive) and life-giving (procreative). And this is why the Church teaches that 'there is an inseparable connection willed by God and not lawful for man to break of his own initiative…" (May, 2013, p. 85).

For many, sex within marriage is more than a simple act of physical intimacy. May uses the phrase "the marriage act" framing it as an action that renews the covenantal relationship begun when the couple pledged themselves to each other in marriage. John Haas argues for the dignity of procreation,

> "The dignity of procreation is seen in the acts appropriate to it being shared exclusively with only one other person, the spouse. The dignity of procreation is also seen in the fact that these acts take place only within marriage for the child's sake. Should the procreative good be realized through the acts which are apt for its realization it will require a stable, protective environment for its flourishing" (1990, p. 107).

Catholic couples adhering to the moral teaching of the church on procreation are forbidden from using contraception as it separates the unitive and procreative aspects of coitus. A Catholic couple at-risk of passing HD to their future children might question the elevated status given to the unitive and procreative aspects of sex. May believes a Catholic couple at-risk of passing a genetic mutation to their children have a choice,

> "The choice whether to accept the risk and seek to generate life through the conjugal act or to avoid doing so by the practice of periodic countenance is, of course, the responsibility of the couple. The Magisterium of the Church clearly recognizes that the likelihood of generating a child who might suffer from a serious genetic illness provides a *serious* reason for deciding not to have a child for either a certain or indefinite period of time" (2013, p. 242-243).

While the Magisterium acknowledges that couples at-risk for HD have a serious reason to avoid having children, they will not allow the couple to use contraception. Beauchamp and Childress frame this couple's choice like this,

> "This principle (utility) asserts that we ought always to produce the maximal balance of positive value over disvalue—or the least possible disvalue, if only undesirable results can be achieved" (2013, p. 355).

This consequentialist or utilitarian approach to this issue would allow a couple to use contraception to prevent an unwanted event from occurring; the unwanted event in question would be the creation of a child and the potential perpetuation of an incurable genetic disease. By acting to prevent conception, a couple at-risk for HD makes the moral judgment that rejecting church doctrine is a lesser evil than the risk of creating a child who carries the HD gene. Adjudicating conflicts between church doctrine and medical science, begins with choosing between two undesirable outcomes. However, Monsignor Sgreccia is adamantly opposed to such utilitarian arguments,

> "Today utilitarian ethics is fierce and employs many strategies: social utility, evolution of customs and values, proportionalism, and so forth. These theories are very sophisticated, so that a careful analysis is required to expose their pseudo-justifications. All relativist and utilitarian ethics contain the following point: utility is defined by those who can define it, those who have the power to manage consents, to estimate the worth of men and decide their usefulness and destination. Thus the embryo would not be defined for what it is, but for what it can be considered; the quality of the life of the future child, which is necessary in order to have the right to be born, would be decided by those who are

> already adult, on the basis of the results of their diagnosis, of an even distribution of values, social expenses and so forth" (1990, p. 119).

This unwillingness to engage in a dialogue that seeks understanding is disheartening as the voices saying, "NO!" are numerous. The voices within the Catholic Church who reject utilitarian arguments in favor of contraception by members of the Catholic Church to prevent the perpetuation of genetic diseases like HD are saying to these couples that adherence to Catholic moral teaching and potentially conceiving a child who carries a genetic disease is preferable to using contraception.

May, for example, takes exception with a consequentialist or utilitarian line of ethical argument by claiming that it "is plausible only because it redirects the object of choice—contraception—in terms of the hoped-for benefits of contracepting individual acts of sexual union" (2013, p. 133-134). Arguing from a utilitarian construct of moral decision-making shifts the focus of the decision to the outcomes of the action.

The moral absolutism of natural law theory considers the outcomes of an action only after determining whether the action in question is moral. If the action, in this case the use of contraception to prevent the perpetuation of a genetic disease, is morally wrong to begin with, then the outcome, even if it could be perceived as a positive outcome, is secondary to the primary judgment that the act is immoral. "An act morally bad by reason of the object freely chosen can never be made good by reason of any end, no matter how noble, or any circumstance, whatever they may be" (May, 2013, p. 64). A Catholic couple facing the dilemma of genetic disease has no recourse to prevent the spread of the gene, except to practice the only method of birth control acceptable to the Catholic Church, the so-called "rhythm method".

Further, *Humanae Vitae*, presents a "slippery slope" argument against contraception,

> "Responsible men can become more deeply convinced of the truth of the doctrine laid down by the Church on this issue if they reflect on the consequences of methods and plans for artificial birth control. Let them first consider how easily this course of action could open wide the way for *marital infidelity and a general lowering of moral standards*. Not much experience is needed to be fully aware of human weakness and to understand that human beings—and especially the young, who are so exposed to temptation—need incentives to keep the moral law, and *it is an evil thing to make it easy for them to break that law*. Another effect that gives cause for alarm is that a man who grows accustomed to the use of contraceptive methods may forget the reverence due to a woman, and, disregarding her physical and emotional equilibrium, *reduce her to being a mere instrument for the satisfaction of his own desires*, no longer considering her as his partner whom he should surround with care and affection" (1968, para.17).

Slippery slope arguments are merely negative predictions extrapolated from preconceived notions and suppositions. While some will argue that the dire predictions of marital infidelity and the lowering of society's moral standards has in fact become reality, placing blame solely at the feet of contraception is a leap in rhetorical logic. Marital infidelity and the degeneration of moral standards has been part of the human story from the beginning of human existence, the Bible is filled with accounts of infidelity, murder and deceit; see King David's infidelity with Bathsheba (II Samuel 11) and Cain's killing of Abel (Genesis 4).

The Dignity of Human Embryos in Catholic Moral Teaching

Responding to the question, of what respect is due to the human embryo, *Donum Vitae* opens with the acknowledgment that genetic science and medicine have developed interventions that are "diagnostic and therapeutic, scientific and commercial". This admission is followed by a reassertion of the teaching handed down in *Gaudium et Spes*, "Life once conceived, must be protected with the utmost care; abortion and infanticide are abominable crimes" (*Donum Vitae,* I). *Dignitas Personae* expresses the Catholic understanding of what the human embryo represents,

> "The body of a human being, from the very first stages of its existence, can never be reduced merely to a group of cells. The embryonic human body develops progressively

> according to a well-defined program with its proper finality, as is apparent in the birth of every baby" (2008, para. 4).

The embryo is a human person. The Congregation for the Doctrine of the Faith's *Declaration on Procured Abortion* states,

> "The first right of the human person is his life. He has other goods and some are more precious, but this one is fundamental - the condition of all the others. Hence it must be protected above all others. It does not belong to society, nor does it belong to public authority in any form to recognize this right for some and not for others: all discrimination is evil, whether it be founded on race, sex, color or religion. It is not recognition by another that constitutes this right. This right is antecedent to its recognition; it demands recognition and it is strictly unjust to refuse it" (1974, para.11).

The value that the life of the human embryo must be "protected above all others", obviously elevates the embryo above the life of the woman carrying the embryo. The Catholic Church's understanding that the human embryo must be protected and defended has also worked its way into the making of public policy. Nikki Madsen, Executive Director of The Abortion Care Network, says, "Since 2010, state lawmakers have been engaged in a relentless crusade to push abortion out of reach: They've quietly passed more than 334 new restrictions on abortion" (Huss, 2017). Many of the new state-level restrictions do not contain exceptions for the life of the mother or cases of rape or incest. The belief that the unborn child is to be protected above all others, this core teaching of the Catholic Church has been adopted by pro-life movement. The pro-life movement and the Catholic Church are not one-in-the-same, but they share the same ultimate goal, the abolishment of legalized abortion.

Prohibition Against Assisted Reproductive Technologies (ART)

Louise Brown, born on July 25, 1978, to Lesley and John Brown, is now a wife and mother of two sons and she is renowned to this day as the first child born through in vitro fertilization (IVF). Assisted reproductive technologies were developed to treat infertility and have progressed to include procedures that can not only treat infertility, but in some circumstances, halt the spread of genetic disorders and diseases. Haas counters saying,

> "The child is treated as an object, a thing manufactured out of an egg and sperm subject to quality control and dominion by others. Such a manufacture of a person is inappropriate to his innate and unassailable worth. Such a procedure would subject human life to the arbitrary decisions of others and would constitute, in the words of the Instruction *(Donum Vitae)*, a "dynamic of violence and dominion" (1990, p. 111).

A child born as the result of the marital conjugal act is a gift that crowns the act itself and therefore is referred to as "begotten" through the act of conjugal love between a husband and wife, this child is not "made" or simply treated as a product. This distinction is expressed in the Catholic Church's use of the word "procreation" over the word "reproduction" (May, 2013, p. 86). Gilbert Meilaender provides some context to understand this semantic challenge,

> "The shift from "procreation" to "reproduction" is in part a manifestation of human freedom to master and reshape our world. But especially when that mastery extends to the body, the place where we come to know a person, we should be alert to both creative and destructive possibilities in the exercise of our freedom" (2013, p. 11).

Meilaender echoes the thoughts of Leon Kass to explain the shift in language; the Catholic Church has chosen to retain the use of procreation as a way of maintaining the centrality of God the Creator, as an integral aspect of the birth of a child. Modern humanity adopted "the metaphor of the factory" to reduce the role of God and faith in the process of perpetuating the next generation (2013, p. 10).

To prevent the spread of HD, a couple may opt to use IVF in conjunction with pre-implantation genetic diagnosis (PGD). This process, considered immoral by the Catholic Church, produces several embryos in a laboratory using the egg and sperm of the couple with a history of genetic disease. These embryos are screened for the suspected genetic mutation and only those embryos that are mutation free are implanted in the uterus of the prospective mother. The embryos that carry the genetic mutation are usually destroyed (Vaughn, 2013). The destruction of embryos, even one's carrying genetic mutations, is condemned by the Catholic Church. Ford condemns PGD, even if the motive is to reduce the instances of genetic disease, "Clearly, PGD is eugenic since its purpose is to reduce the number of children born with congenital abnormalities" (2008, p. 42).

The Catholic Church's stance against the use of ART can be traced back to an address by Pope Pius XII to the Second World Congress on Fertility and Human Sterility, in 1956.

> "The child is the fruit of the marriage union, when it finds full expression by the placing in action of the functional organs, of the sensible emotions thereto related, and of the spiritual and disinterested love which animates such a union; it is in the unity of this human act that there must be considered the biological condition for procreation" (May, 2013, p. 87-88).

This pronouncement that procreation is to be confined to the conjugal act between a husband and a wife, came twenty-two years before Louise Brown's conception and birth. In the same address Pope Pius XII clarified the Catholic Church's stance, "As regards to experiments of human artificial fecundity 'in vitro,' let it be sufficient to observe that they must be rejected as immoral and absolutely unlawful" (May, 2013, p. 88). An example of the Catholic Church's reliance of arguments based solely on the authority of the Papacy. The rejection of technological progress still exists today even as the Catholic Church acknowledges,

> "Advances in technology have now made it possible to procreate apart from sexual relations through the meeting *in vitro* of the germ-cells previously taken from the man and the woman. But what is technically possible is not for that very reason morally admissible. Rational reflection on the fundamental values of life and of human procreation is therefore indispensable for formulating a moral evaluation of such technological interventions on a human being from the first stages of his development" (*Donum Vitae,* Section 4).

The Catholic Church's view of scientific progress can be summed up in the following statement from Section 2 of *Donum Vitae,*

> "Science and technology are valuable resources for man when placed at his service and when they promote his integral development for the benefit of all; but they cannot of

> themselves show the meaning of existence and of human progress…Thus science and technology require, for their own intrinsic meaning, an unconditional respect for the fundamental criteria of the moral law: that is to say, they must be at the service of the human person, of his inalienable rights and his true and integral good according to the design and will of God. The rapid development of technological discoveries gives greater urgency to this need to respect the criteria just mentioned: science without conscience can only lead to man's ruin. Our era needs such wisdom more than bygone ages if the discoveries made by man are to be further humanized. For the future of the world stands in peril unless wiser people are forthcoming" (1987).

Pope John XXIII adds,

> "The transmission of human life is entrusted by nature to a personal and conscious act and as such is subject to the all-holy laws of God: immutable and inviolable laws which must be recognized and observed. For this reason one cannot use means and follow methods which could be licit in the transmission of the life of plants and animals" (*Mater et Magistra*, 1961, III, para. 193).

Because humans are made in the image of God and have "dominion" over the earth (Genesis 1:26) has led many to place human procreation on a higher plain than that of non-human animals and plants.

Other voices within the Catholic Church are more open to progress and discovery in science and medicine. Specifically, Bruno Schüller and Lisa Sowle Cahill. Schüller, a Professor of Moral Philosophy and a Jesuit, submits these questions in response to *Donum Vitae*,

> "I will admit that the origin of a human person has to be the result of an act of giving, but is there no other act of giving beyond the conjugal act? What disqualifies the intervention of medical techniques as having the character of an act of giving" (Schuller, 1990, p. 87-88)?

I agree with Schüller's question, why is IVF not an act of giving? Schüller asks another significant question, "Is it inconceivable that God provided man with reason and understanding also so that he, by himself may endeavor to find out how to succeed when natural measures prove a failure" (1990, p. 92)? The Catholic Church must find a way to remain faithful to their traditions while embracing openness to struggles of those living with genetic diseases like HD.

Lisa Soule Cahill, Professor of Theology at Boston College, gives this charge to the Catholic Church, “The church needs to look more broadly and more sympathetically at the diverse experiences of those engaged in the “contingent matters” in question” (1990, p. 145). The “contingent matters” to which Cahill refers are reproductive technologies. Schuller and Cahill represent voices calling for the Catholic Church to move ever so slightly towards a more nuanced and humble position when formulating moral guidelines. A Catholic at-risk of passing the gene that causes HD to their children must negotiate the conflict that exists between the teachings of the Catholic Church and the field of genetics.

For Catholic laity, there is less unanimity

For people of any faith, the teachings and guidance of their religious leaders can either comfort or confound as they wrestle with moral decisions. Howard Stone and James Duke articulate how people develop faith,

> “Christians learn what faith is all about from countless daily encounters with their Christianity—formal and informal, planned and unplanned. This understanding of faith, disseminated by the church and assimilated by its members in their daily lives, will be *embedded* theology” (1996, p.12).

When this embedded theology is challenged by the realities of life, a process of theological reflection produces in the person a *deliberative* theology which,

“…questions what had been taken for granted. It inspects a range of alternative understandings in search of that which is most satisfying and seeks to formulate the meaning of faith as clearly and coherently as possible” (1996, p. 17).

When speaking about faith one needs to recognize that some desire to have the teachings of the church be clear and unambiguous, I refer to this group as “externally referent”. While others find comfort in the hard work of hosting nuance and ambiguity, I refer to this group as “internally referent”. These categories are not delineated with solid impregnable lines; while some people exhibit consistency, “What my priest or pastor tells me is always right”, others are more selective, choosing to make their own determination on issues which directly affect them. Catholic couples living with the risk of HD must determine if their decisions about their sexual lives will adhere to the guidance of the church. Will their faith remain an embedded theology or will a deliberative theology lead them to another course of action?

The Guttmacher Institute's (2011) analysis of data from the federal government's National Survey of Family Growth found that "the vast majority of American women of reproductive age (15–44)—including 99% of all sexually experienced women and **98% of those who identify themselves as Catholic**—have used a method of contraception other than natural family planning at some point" (Guttmacher Statistic on Catholic Women's Contraceptive Use, para.1). This data suggests that Catholic women in America are choosing to act from an internally referent position regarding contraception.

Langan recognizes that our modern world makes adherence to the traditional model of marriage and family presented by the Catholic Church more difficult.

> "The number of exceptions, the number of persons who cannot fit the model for many different reasons, is bound to increase. This presents the church with great pastoral problems, and it presents society with increasing numbers of people needing assistance in various ways. But it also challenges the church to think about right and wrong ways to coping with exceptional situations" (1990, p.78).

The "Jones" family is dealing with an exceptional situation. They are compelled to examine what they believe and why. Teresa is coming to terms with her Catholic upbringing and how it affects her relationship with Gary and her desire to become a mother and raise her children in a community of faith. Teresa is doing what the Apostle Paul referred to in Philippians 2:12-13 (NRSV), "Therefore, my beloved, just as you have always obeyed me, not only in my presence, but much more now in my absence, *work out your own salvation with fear and trembling*; for it is God who is at work in you, enabling you both to will and to work for his good pleasure."

Teresa is the youngest daughter of a prominent Catholic family. She was raised to believe that the Catholic Church could do no wrong, their teachings were absolute and to go against church teaching was a mortal sin. Teresa's values reflect much of Catholic teaching, even if she disagrees with the church's stance on contraception. Teresa is conflicted about going against her Catholic upbringing and defying the church's prohibition on assisted reproductive technologies. Teresa is torn between her love for Gary and her need to make informed decisions for herself and their future children.

Gary remains convinced that his decision not to know his HD status is justifiable, even if his decision could end his relationship with Teresa. Gary is adamant, justifying his decisions on his youth and desire to live free of the anxiety of something that may not happen. He also defends his decision on the bases of the lack of effective treatments, "why access information about something I am powerless to change?"

Carol is looking into the potential of gene therapy treatments for HD and is feeling hopeful for the sake of her children should they carry the HD gene. She is pursuing education about HD for her children. Taking a pragmatic approach, she asks, "what do I need to know and how does that information assist me and my children's decision-making?"

Andrew's HD symptoms continue to progress, and he is becoming more and more dependent on others as the months pass. One of his final wishes was to make sure Carol and Gary were clear about his treatment preferences as his disease runs its course. Andrew made sure he had the appropriate paperwork completed and on file. Before his symptoms rendered him completely bed-ridden, he executed an Advance Directive for Healthcare, naming Carol as his healthcare agent and expressed his desire to not be kept alive using artificial means. During an appointment with his neurologist, Andrew requested a Do Not Resuscitate order be written that would follow him to the skilled nursing facility and that his wishes were visible in his electronic medical record.

Life moves moral reasoning from the abstract to the real and in the “Jones” family no one is a set player. They are each employing a multitude of ethical principles and moral teachings to guide their actions in response to the presence of HD. Gary believes that humans have innate dignity, therefore Andrew should take advantage of the life-sustaining measures available. Carol thinks dignity is achieved by allowing life to end without heroic measures. Carol driven by her affection for practical thinking is guided by a utilitarian moral framework with a healthy dose of deontological duty. She believes Gary has a duty to himself and Teresa to learn his HD status. From her research into HD, Carol is aware of the decisions regarding family planning that Gary and Teresa will have to make. The “Jones” family is at an impasse.

Ziva Kunda (1990) discusses the ways people make decisions, the concept of motivated reasoning, can be useful in helping people understand why they believe certain things and how they make decisions. Kunda identifies two categories of motivated reasoning,

> “The motivated reasoning phenomena under review fall into two major categories: those in which the motive is to arrive at an accurate conclusion, whatever it may be, and those in which the motive is to arrive at a particular, directional conclusion” (1990, p. 480).

How does one’s motivation affect one’s decision-making? Kunda asserts that those driven to be accurate in their decisions make use of relevant information and process this information more deeply than a person who is driven to arrive at a certain decision, who may avoid or ignore relevant information that does not support their desired conclusion. Looking at the” Jones” family, Carol and Teresa are driven by a need to arrive at an accurate response to living with HD. Carol is driven to provide her children with accurate information about HD. Teresa is motivated by her desire to have children of her own, her “directional bias”, but her desire to have children is impacted by the presence of HD. Kunda emphasizes that people driven to arrive at a certain goal,

> "…they search memory for those beliefs and rules that could support they desired conclusion. They may also creatively combine accessed knowledge to construct new beliefs that could logically support the desired conclusion. It is this process of memory search and belief construction that is biased by directional goals" (1990, p. 483).

Teresa is biased by her desire to have children, but she is also actively working to overcome her directional bias by doing the hard work of processing her faith to determine if the rules and dictates of Catholic moral teaching assist her as she ponders having children with Gary.

Gary's stated goal is not to know his HD status and he is determined to avoid any information or argument that runs contrary to his stated goal. Gary's bias is that knowing he carries the gene for HD would shatter his self-image and reduce his life to nothing more than a slow, inevitable decline into diminishment and death. By looking at what motivates people the hope is to provide them with tools and strategies to understand and potentially overcome their biases. (1990, p.496).

Chapter 3: Lutheran Social Ethics

We turn now to another religious perspective; the moral teaching of the Evangelical Lutheran Church in America (ELCA). The ELCA was formed in 1988 in a merger of three historic American Lutheran bodies, the Lutheran Church in America (LCA), the American Lutheran Church (ALC) and the Association of Evangelical Lutheran Churches (AELC). Today, the ELCA consists of 10,000 congregations with around 3.5 million members; the member congregations are organized into 65 smaller bodies called synods (ELCA.org).

Both Roman Catholic and Lutheran churches exhibit distinctive elements of a Christian ethic: 1) attention to God's relationship with humanity, 2) an appreciation for human history and experience, 3) a belief that humans are moral agents, capable of making moral decisions, and 4) the interpretation of the moral choices of people, communities and society. Both Roman Catholic and Lutherans use the Bible and historical documents (confessions) of the faith as well as philosophical principles and methods, science and other sources of knowledge and human experience (Childress and Macquarrie Eds., 1986, p. 87-88). A Christian ethic focuses on God's relationship to humanity and humanity's actions within God's creation that are influenced by personal and communal experiences and history.

A brief review of the origin of Protestantism reveals the crucial differences on sources of authority. Taking actions, contrary to the authority of Pope Leo X and the Holy Roman Emperor Charles V, Martin Luther, a Catholic Monk, challenged church practices, especially the selling of indulgences and papal edicts. Luther said the Roman Catholic church was wrong. During an examination at the Diet of Worms, Luther was unrepentant.

> "Since your majesty and your lordships desire a simple reply, I will answer without horn and without teeth. Unless I am convicted by scripture and plain reason—I do not accept the authority of popes and councils for they have contradicted each other—my

> conscience is captive to the Word of God. I cannot and will not recant anything, for to go against conscience is neither right nor safe. (Graves, 2010, para.1).

And whether factual or mythical, “Here I stand, I can do no other, God help me. Amen.”

Only in 1999 with the adoption of *The Joint Declaration on the Doctrine of Justification by The Lutheran World Federation and the Catholic Church* was the mutual name-calling and damning of the Reformation formally addressed. While the Joint Declaration put aside the condemnations leveled against each other in the 16th century and publicly announced an agreement on the “basic truths” regarding the doctrine of justification, this agreement did not erase the differences in how the Catholic Church and Lutheran churches think about and practice social ethics. The shift in focus away from good works as essential for gaining eternal life ushered in a faith focused on the love and service of one’s neighbor. This is a significant shift recalling that Catholics believe their moral decisions and following church dictates are of eternal significance. Protestants are free to follow their conscience, even if their conscience directs them to act in ways that might not be entirely in line with their church’s ethical and theological stance.

While both Lutherans and Roman Catholics practice Christian ethics sharing the same sacred scriptures, believing in the same Trinitarian God represented by the Father, the Son and the Holy Spirit, and believing in eternal life in heaven, they differ significantly in how a person of faith lives a moral life. Lutherans might challenge Roman Catholics as too dependent on the strict rules and dictates handed down by church leaders. Roman Catholics may see Lutherans as too lax because everyone gets to make up their own rules as they see fit (Nairn, 2001, para. 2). This generalization may sound simplistic, but it is consistent in the respective church’s directives, especially as society changes. Reflecting on the differences between Roman Catholic and Lutheran ethics, Nairn writes,

> “Faith in Christ frees people from their own striving for salvation, and in doing so not only relates them to Christ, whose grace is the source of salvation but also enables them to discern the deeper meaning of the structures involved in daily life. These life structures – family, ministry, and secular government – are stations ordained by God. Lutheran ethics emphasizes that it is in these concrete stations that God wants people to live responsible lives. It is therefore not moral actions understood as good works that are religiously significant, but rather justification by grace through faith in Christ that rectifies the relationship between the person and God” (2001, para. 11).

Lutheran ethics calls the faithful to live “responsible lives” within their families, their vocations and society. The word responsible, used repeatedly, is open to interpretation.

John B. Stumme writing in the Introduction to The Promise of Lutheran Ethics says,

> “The Lutheran tradition of theological ethics, it should be recalled, is a changing, diverse, and contentious one…” (1998, p. 2).

This is also true of those who claim the name Lutheran as Lutheran congregations and Lutheran Ethicists exist across the theological and political spectrum; from conservative to liberal. Roger Willer, Director of Theological Ethics for the ELCA, reflects on the development of Lutheran ethics,

> “Responsibility ethics is widely regarded as emerging in the 20th century because of the new contexts of human power, pluralism, complexity, and authority” (2014, para. 16).

Historically, the growth of the Lutheran Church in North America mirrored the different waves of European immigration. Members of Lutheran bodies like the American Lutheran Church (ALC) and the Lutheran Church in America (LCA) trace their heritage back to Germany, the Netherlands, Sweden, Norway, Denmark and Finland. (Wolf, 1965). Thus, historical divisions between Lutherans in America were based on country of origin, while current divisions between Lutherans are more theologically based. For example, in the ELCA, women are ordained ministers of Word and Sacrament, while prohibited from that role in the Lutheran Church-Missouri Synod (LCM).

The ELCA has 12 social statements that are broad, framing documents that cover a wide range of social issues including, abortion, ecology, economics and education. Two ELCA social statements pertinent to people living with HD are Human Sexuality: Gift and Trust (2009) and Genetics, Faith and Responsibility (2011). In contrasts to Catholic Papal Encyclicals and Instructions from the Congregation for the Doctrine of the Faith, an ELCA social statement "…does not bind the conscience of members but it does represent a go to ethic when discerning issues of social ethics" (Willer, 2014, para. 8). Consistent with the ELCA's commitment to encouraging its members to live responsible lives within their families, their vocations and society, the ELCA itself develops a social statement in much the same way. The ELCA seeks to hear from its members on these issues and uses a process that allows for critique throughout.

The development of a social statement begins with the adoption of a social policy resolution. Paul T. Nelson recalls the 2004 ELCA social policy resolution on genetics,

> "The human capacity for genetic manipulation should be understood, in principle, as one of God's gifts in the created order to be pursued for the good of all. As with any such gift, it must be used responsibly and tested for its contribution to justice and stewardship" (2008, para. 2).

The adoption of a social policy resolution leads to the creation of a social statement task force of both clergy and lay members. ECLA Churchwide staff spends considerable time assembling this group with diverse skills and expertise and representative of the various social locations within the ELCA. The members they engage in a multi-year process of learning and conversation (Willer, 2014, para. 21). Early in the task force process, "listening events" are held to gather concerns from ELCA members regarding the issue. The task force produces a draft social statement that is sent out to each member congregation, soliciting responses and concerns. Then, the ELCA Conference of Bishops, the 65 Synodical Bishops and Church Council, an elected body of lay and clergy, review the proposed social statement and offer input. Final adoption of a new social statement requires a super majority (two-thirds) vote at a biennial Churchwide Assembly. This process allows for moral deliberation and invites each ELCA member to exercise their responsibility and make their voice heard (2014, para. 19). The ELCA's social statement, Genetics, Faith and Responsibility was amended and adopted by a vote of 942-34 at the twelfth biennial Churchwide Assembly on August 18, 2011.

Natural Law Theory in Lutheran Ethics

Among contemporary scholars, there is disagreement on Luther's position on the 16th-century interpretations of natural law. Some scholars argue Luther may have favored the Thomistic version, named after Thomas Aquinas, which was the benchmark for the Roman Catholic church. Luther rejected the nominalist version of natural law with its assertion that "any human connection with God is achievable only by means of obedience to the will of God" (Pearson, 2007, para. 22). Presbyterian scholar of the Reformation, J. Daryl Charles says, Luther was Thomistic.

> "Natural-law thinking is firmly embedded in Luther's thoughts…Luther adopts the basic definition of natural law set forth in Romans 2:15, a common judgment to which all men alike assert, and therefore one which God has inscribed upon the soul of each man" (2010, para. 4 and 6).

Luther did not ascribe to the nominalist's belief that natural law was only found in Christian communities,

> "To the contrary, insists Luther, it is borne out by human experience that all nations, cultures and people-groups possess this rudimentary knowledge. The natural law is written in the depth of the heart and cannot be erased" (Charles, 2010, para. 7).

Charles argues that Luther presumed that natural law was at work in the lives of people and should be considered as core to any system of ethics.

Thomas D. Pearson, a Lutheran and Professor of Philosophy and Ethics, argues that Luther did not hold to either the Thomistic or the nominalist's version of natural law, but instead developed his own version. For Luther natural law was,

> "…not a hollow and rational order rightly governing human conduct, but a set of innate instincts that operate merely as a useful instrument for directing our attention toward appropriate actions that serve the neighbor" (Pearson, 2007, para. 42).

Pearson claims Luther rejected the notion that God had inscribed on the hearts of humanity the ability to use reason to discern moral action. Luther believed that humanity's sinful state did not allow natural law to guide human behavior. In a sermon on January 29, 1525, Luther said,

> "But evil lust and sinful love obscure the light of natural law, and blind man, until he fails to perceive the guidebook in his heart and to follow the clear command of reason…he must be reminded of his natural light and have his own heart revealed to him. Yet admonition does not avail; he does not see the light. Evil lust and sinful love blind him" (Pearson, 2014, para. 47).

Scholars will parse Luther's writings and argue for and against their positions on how Luther adhered to or dismissed natural law, but the essential element of this dispute is Luther's understanding of human nature. Luther's vision of humanity is unambiguous; humanity is sinful. Sin renders any version of natural law powerless to assist humankind in living moral lives. Because of humanity's sinful state, Luther understood a different version of natural law.

> "Luther creates a new account of natural law morality: instinctive, not rational; provisional, not ontologically secured; pragmatic, not divinely commanded; chastened by sin, not robust with natural human possibilities" (Pearson, 2014, para. 59).

Luther's understanding of the role of natural law in the developing of a system of ethics can be seen in the following statement by Pearson,

> "It does not go too far to suggest that Luther thinks of ethics as fundamentally local and circumstantial. What is universal in ethics are the natural instincts of human persons. But the rendering of those instincts into a series of practical judgements applied to specific situations in order to realize the goods embedded in those instincts is something for

> Luther that can only take place on the ground, in the midst of the immediate context where the opportunities for right action actually present themselves" (2014, para. 57).

From such an ever-emergent framework, Lutheran ethics begins in deliberative discernment, looking at the situation at hand and working toward a practical judgment rather than relying on a set of predetermined absolutes.

Lutheran ethical deliberation does wear the "situational" or "contextual" ethics label. An influential theologian for many in Lutheran ethics is H. Richard Niebuhr. Niebuhr along with Paul Lehmann spoke of ethics as responding to what God is doing in the world (Childress and Macquarrie Eds., 1986, p. 587). L. Earl Shaw describes Niebuhr's ethics,

> "As a philosopher of the Christian moral life, Niebuhr was more analytical than prescriptive, more interested in preparation for action than application. Thus as an ethicist, he was less practically oriented than his brother (Reinhold Niebuhr). He seeks to lay bare the roots and critically inquire into the fundamental perspectives underlying Christians' moral lives. Niebuhr focuses more on the deciding than the decision" (1977, p. 68).

Shaw continues his explanation of Niebuhr's responsibility ethics by summarizing the way Niebuhr differentiated between utilitarian, deontological ethics and responsibility ethics. Niebuhr viewed utilitarian ethics, what he referred to as teleological ethics as concerned with ideals and deontological ethics with obedience. Niebuhr believed responsibility ethics provided for more "fitting" ethical responses, "…the one (action) that fits into a total interaction as response and anticipation of further response is alone conducive to the good and alone is right. (Niebuhr, 1963, p. 61). Niebuhr's theme of responsibility ethics runs throughout the social statements of the ELCA. The ELCA's first social statement, *Church in Society: A Lutheran Perspective* (1991) states,

> "The witness of this church in society flows from its identity as a community that lives from and for the Gospel. It is in grateful response to God's grace in Jesus Christ that this

> church carries out its responsibility for the well-being of society and the environment" (1991).

The ELCA's 2009 social statement *Human Sexuality: Gift and Trust* continues the theme of the faithful's response to God's work in the world,

> "Our vocation of service leads us to live out our responsibilities primarily in light of and in response to the neighbor's needs, often in complex and sometimes tragic situations" (2009, p. 4).

Lutheran ethics understands that life is complicated and sometimes tragic, and these tragic situations require a thoughtful response that takes the needs of the neighbor into consideration. For people living with the challenges of HD, the ELCA offers an ethical position that begins by hearing their story and then responds to their context with compassion and love. This is not to say that the ELCA social ethic lacks constraining language,

> "Genetic knowledge and its applications are not morally neutral. They require diligent and sustained attention in order to direct their potential good and to limit potential harm…The moral imperative commensurate with contemporary human power is to respect and promote the community of life through the exercise of justice and wisdom" (2011, p. 2-3).

Lutheran ethics as expressed by the ELCA is responsive to what God is doing in creation, is concerned with the complexity and tragic struggles of life in the modern world and guided by the principles of justice and wisdom.

The *Imago Dei* in Lutheran Ethics

Section 3.2 God: Creator of the community of life, in the ELCA's social statement, *Genetics, Faith and Responsibility* contains this commentary on Genesis 1:26-28,

> "God creates human beings as interdependent with the whole of creation and as responsible to provide oversight as stewards who care for that creation. It is a vocation, a calling to continue what God is already doing for the earth—a calling to respect and promote the creation's flourishing. In this sense, Genesis understands the human species as being created 'in the image of God'" (2011, p. 10).

Humanity is made in the image of God and has a vocational calling to tend to God's creation. Genetics and the acquisition of genetic knowledge is part of humanity's vocation, "The ELCA values genetic science as an expression of human responsibility to learn and predict, imagine and invent for the sake of stewarding (human) creation" (2011, p. 40).

Lutherans look to the creation accounts in Genesis 1 and 2 and see a God who is intimately involved in the beginnings of life. So how does the *imago dei* affect Lutheran ethics in genetics and assisted reproductive technologies? Humanity has a thirst for knowledge; we are curious creatures. We want to know how human life works, how it begins, how it develops and how to improve it. The hope of developing treatments for disease drives the medical research community. Watch television for an hour and count the number of advertisements for new medications for cancer, heart disease, diabetes and depression; it appears there is a new drug promising longer life and better health coming out every week or two. Human progress is an astounding testament to the power of human reason and ingenuity. Of course, humanity has not been on an upward trajectory since the day Adam and Eve exited the garden. We must be mindful of the suffering and death left in the wake of human progress. The human capacity for thought landed a man on the moon also wages war and exploits our fellow humans for profit and pleasure. Humanity has, that is to say, *we* have stripped the planet of precious natural resources to quench our thirst for fuel and raw materials. While Luther believed we were made in the image of God, he struggled with the sinful nature of humanity. Indeed, humans can be compassionate and altruistic, but we can also be evil and violent. We are the quintessential both/and. Luther understood the both/and of the human condition in his Treatise on Christian Liberty he writes, "A Christian is a perfectly free lord of all, subject to none. The Christian is a perfectly dutiful servant of all, subject to all" (Lull, ed., 1989, p. 596). Luther believed that these two affirmations were the key to living a moral life in a complex world.

The ethics of ELCA's Social Statement: *Genetics, Faith and Responsibility*

How does being created in the image of God but also being a sinful, fallen person affect Lutheran teaching on genetics and the use of assisted reproductive technologies? The ELCA's social statement, *Genetics, Faith and Responsibility* identifies prenatal testing and screening, assisted reproductive technology (ART), pre-implantation genetic diagnosis (PGD) and synthetic biology as areas within genetic science that bear "both promise and peril" (2011, p. 4). The promise and peril of genetic technology pushes the ELCA to adopt a cautious and hopeful approach to new developments in genetic science,

> "The comforting information it provides for one individual may raise fears for another. The use of genetic knowledge will reshape the future of the delicate web of life, while increasingly blurring the lines between what is natural and what is artificial" (2011, p. 5).

This precaution is just that, a precaution,

> "…the ELCA does not reject the use of genetic technology such as genetically modified organisms, prenatal diagnosis or pharmacogenetics…This church believes the use of any technology should be subject to moral assessment" (2011, p. 8).

The ELCA engages in moral assessment by turning to both scripture and contemporary knowledge. For Lutherans, the Bible is the authoritative source for faith and practice, which can be made clear by modern knowledge. Such knowledge helps scripture "speak in new and needed ways in today's context" (2011, p. 9). The ELCA goes to great lengths to assert their understanding that the Bible and contemporary knowledge serve each other.

> "The ELCA holds that Christian discernment and participation in public discussions concerning genetic knowledge and its potential benefits and harms will be inaccurate if we do not learn from the research of educational institutes and scientific enterprise or from the practice of medicine…On the other hand, the meaning of genetic knowledge and

> the debates about its use will be inadequately explored and morally dangerous without attention to the wisdom of faith traditions" (2011, p. 9).

Scripture and contemporary knowledge must co-exist if humanity is going to make the best decisions regarding the use of genetic knowledge. Combining the two strengthens the understanding that God created humanity to tend to and work to steward creation's flourishing. Such tending to creation means humanity must recognize that human pride, complacency and negligence in the use of genetic technologies can lead to grave abuses and tragic consequences.

> "Present realities require difficult and complex decisions, often with uncertain and morally dissatisfying outcomes…As a community of moral deliberation, this church is called to discern an ethical framework to engender moral formation, responsible deliberation and action in response to the challenges of unprecedented power" (2011, p. 13-14).

The ELCA's ethical framework for the use of genetic knowledge is built on five interconnected principles: 1) To seek the good of the community of life, 2) Respect, 3) Promotion, 4) Wisdom and 5) Justice. We examine these principles in turn here.

The Commitment to the Good of the Community of Life (Society)

To seek the flourishing of the community of life, the ELCA says,

> "New and growing knowledge about the fundamental genetic interconnectedness and basis of life reaffirms the insights of Genesis about the continuity of the human species with the rest of creation. Scripture and science bid all people of good will to consider and positively respond to the moral implications of human participation in the intricate web of life…this value should rule against the use of genetic science that significantly injures the health of the community of life" (2011, p. 15-16).

For a couple at-risk of passing a genetic disease to their children, the commitment to the good of the community of life opens the door to use ART to prevent suffering. On the other hand, if the use of ART poses a risk of significant injury to the community of life, a constraining ethic of precaution may be invoked. A couple pursuing IVF using donor egg or sperm to avoid the genetic material that carries the mutation, also known as autologous IVF can be encouraged on the basis of the health of the community. This principle could also be used to discourage a couple from using allogenic IVF, using their own egg and sperm, with PGD because it involves the destruction of the embryos carrying the genetic mutation because one views the destruction of embryos as being harmful to the health of the community of life.

Respect

Respect is essential to Lutheran social ethics, "For Lutheran Christians, respect follows from God's regard for all life as precious, from the amoeba to the person" (2011, p. 16). The imperative to respect all life as a baseline should impact all areas of human activity with special attention to areas of human activity that requires the sacrifice of life,

> "…such as eating [of animals] or aspects of scientific research. The fecundity of the web of life calls forth awe and wonder as well as loss and mourning. Respect for life engenders both responses" (2011, p. 17).

The imperative to respect all life inevitably will cause conflicts of interests that cannot be reconciled, in these situations the church calls on its members to engage in discernment,

> "Members of this church will not always agree about what it means to respect an individual life form, a species or the biotic community. An ethic of responsibility requires this church to be in dialogue about how the directive of respect governs the many different domains of genetic science and its applications…This church believes all technologies deserve moral scrutiny because they bear on individual and corporate practices and the matter of respect for others. It rejects ideological positions that portray scientific breakthroughs and new technologies as inherently valuable, progressive, inevitable and irreversible" (2011, p. 18).

The ELCA's hope for a better future for humanity is balanced with its commitment to reducing potentially tragic consequences. This balancing act is evident in their position on human reproductive cloning,

> "This church will continue to reject human reproductive cloning as a matter of respect even if it becomes safe and economically feasible. A person should not be treated as a means to another person's end. Cloning for the sake of repeating another individual's

> genotype violates this standard. Aims other than the replication of identity may be possible, but they are not compelling today. If individuals are cloned despite societal and ELCA rejection, this church will respect their God-given dignity and will welcome them to the baptismal font, like any other child of God" (2011, p. 19).

In the above statement respect for a person, natural-born or cloned is rooted in Immanuel Kant's humanity formulation of the categorical imperative. (Timmons, 2013, p. 211). The same can be said for a life created using ART, they are a child of God and will be welcomed to the baptismal font.

Promotion

The ELCA recognizes that God's creative action has bestowed upon humanity multiple gifts and we are to promote the flourishing of creation using those gifts, with appropriate acknowledgment of our human failings. "Human beings cannot create as God does, but they are to be imaginative, inventive and responsible caretakers" (2011, p. 19). The acknowledgment of human failings leads the ELCA to give respect priority over promotion, therefore not every possible genetic innovation is worthy of pursuit. Promotion must not violate the directive to respect all life,

> "…the ELCA encourages human imagination and innovation in the use of genetic knowledge to address physical and mental conditions, relieve human suffering and improve the human situation…This church rejects striving after some imagined perfection or idealized state of human life" (2011, p. 20).

The use of genetic and reproductive technologies by a person with HD to have a child or treat their disease process is acceptable, but the ELCA stands in opposition to the use of genetic technologies in the pursuit of enhanced capabilities or the gain an unfair advantage over others.

Wisdom

The ELCA believes in making sound moral judgments one must seek and use the best information available, in that vein the ELCA encourages

> "…those who possess special or expert knowledge relevant to decision-making have a moral duty to share what they know with those engaged in the process of moral discernment and policy adoption" (2011, p. 26).

This call to share one's expertise is tempered by humility, Luther stressed the cultivation of humility as a retraining force against the sin of pride. Issues within the scope of genetics are complex, full of unknowns, conflicts and moral challenges. In this contentious environment, personal and communal humility bring to the conversation something facts and data cannot. Humility also upholds the ELCA's promotion of research within limits. Precaution should guide decisions about the use of genetic knowledge and research when unforeseen consequences pose risks, that may be rare, but are scientifically plausible. This said, the ELCA does not promote precaution that stifles innovation or technology that can promote the flourishing of the community of life.

Justice

Lutherans believe God's intention for all relationships is justice defined as, "honoring the integrity of creation, and striving for fairness within the human family" (2011, p. 20). Lutherans value working for justice as an integral part of the civil government, business organizations, professional societies and ordinary citizens. Justice is further delineated into four guiding principles: sufficiency, sustainability, solidarity and participation. The principle of sufficiency requires humans to care for the basic needs of other humans and other forms of life. For the use of genetic knowledge, the ELCA believes,

> "This church defines the public good in terms of sufficiency and contends that genetic research, medicine, commerce and biotechnology should advance the common good rather than the economic gain of some" (2011, p. 21).

The principle of sustainability wrestles with the hope of leaving something for future generations and how these genetic advances will be accessible to all.

> "Regulation must be justified by specific concerns for the potential harm of a genetic application and its delivery or by the necessity towards equal access and use." (2011, p. 22).

Along with sustainability, solidarity calls all humans to consider not only their own interest but the interests of others when making decisions and evaluating a course of action in genetics.

> "The principle of solidarity grounds the moral duty of human beings to stand together in interdependence to act locally and globally on behalf of individuals and cultures. It provides a check on the tendency of human endeavors to benefit those who hold power or privilege at the expense of those who have little or no power" (2011, p. 23).

The principle of participation calls for members of the ELCA to be involved in endeavors that impact the community of life. The responsibility ethics of the ELCA is put into action through "advocacy—speaking alongside and for those who are marginalized" (2011, p. 25). Because of the potential for positive and negative impacts of genetic research, public accountability and oversight are essential.

> "This church encourages its members and all people of good will to be aware of, seek sound knowledge of and actively participate in debates concerning public policies related to the application of genetic knowledge" (2011, p. 26).

These principles work together to form a coherent structure that can guide moral decision-making. These principles are not without their weaknesses and blind spots. Promoting the use and expansion of genetic research without a careful eye on issues of justice and wisdom can lead to the exploitation of marginalized groups. Caring for the Community can be a worthy goal, but communities of faith are rarely homogeneous bodies that all share the same political, moral or social convictions. A community of faith that encourages and supports a couple with HD to make use of genetic innovation in reproduction or gene therapy may ostracize another group with the community who believes the life begins at conception and to engage reproductive technologies is morally unacceptable.

ELCA Social Ethics: Genetic Disease, Sexuality and Reproduction

The Lutheran church takes seriously the struggle of those living with genetic disease and the impact the disease can have on their lives,

> "Genetic factors play a significant role in chronic physical conditions, mental illnesses and cognitive limitations. Certain genetic mutations contribute positively to healing or aging while others are associated with disabilities, chronic medical problems and shortened life spans" (2011, p. 31).

With this acknowledgment,

> "The ELCA calls upon individuals, agencies, organizations, corporations and governments to pursue goals, set policies or establish practices that:
>
> - advocate for genetic research and discovery that advance the good of the present generation and those to come;
> - affirm the good of genetic technologies and economic enterprises that enable the community of life to flourish;
> - encourage varieties of research aimed at improving human health and well-being; give priority to global health issues and needs, particularly those which may benefit by genetic research, even when the economic return is small…" (2011, p. 27).

Though held sacred, marriage is not considered a sacrament in Lutheran churches. The Introduction to the Liturgy for Marriage in Evangelical Lutheran Worship (ELW) begins,

> "Marriage is a gift of God, intended for the joy and mutual strength of those who enter in and for the well-being of the whole human family. God created us male and female and blessed humankind with the gifts of compassion, the capacity to love, and the care and nurturing of children. Jesus affirmed the covenant of marriage and revealed God's own self-giving love on the cross, The Holy Spirit helps those who are united in marriage to be living signs of God's grace, love, and faithfulness" (ELW, 2003, p. 286).

The belief that marriage is a gift of God and that sexual intimacy is best expressed within the bounds of marriage is emphasized in the ELCA social statement, *Human Sexuality: Gift and Trust.*

> "Couples, whether teenage, young adult, mature, or senior, move from a first acquaintance into a journey of increasing knowledge, appreciation, and trust in each

> other. This journey involves spiritual, emotional, intellectual, and physical dimensions of self-understanding…For this reason, this church teaches that degrees of physical intimacy should be carefully matched to degrees of growing affection and commitment. This also suggests a way to understand why this church teaches that the greatest sexual intimacies, such as coitus, should be matched with and sheltered both by the highest level of binding commitment and by social and legal protection, such as is found in marriage. Here, promises of fidelity and public accountability provide the foundational basis and support for trust, intimacy, and safety, especially for the most vulnerable" (2009, p. 31).

Should that sacred union produce children, they are gifts of God.

Guided by responsibility through careful deliberation, a couple determines what they believe to be the best outcome in family planning. The couple at-risk for passing to their children a genetic disease may decide to love any child whom they produce. A couple with HD, with a goal of preventing the spread of the mutation to their children, must take the responsible steps to prevent a pregnancy that has a 50-50 chance of producing a child with HD. The ELCA social statement on human sexuality sends a clear message regarding contraception.

> "All sexually active people have the responsibility to protect their sexual partner from both emotional and physical harm as well as to protect themselves and their partners from sexually transmitted diseases and the possibility of an unwanted pregnancy…This church supports the development and use of medical products, birth control, and initiatives that support fulfilling and responsible sexuality. This church also recognizes the important role that the availability of birth control has played in allowing women and men to make responsible decisions about the bearing and rearing of children" (2009, p. 32 and 35).

It is, of course, assumed that prevention of genetic disease is included in the call to responsibility. In summation, Lutheran ethics offers couples living with the risk of HD or other genetic diseases multiple options to address their reproductive needs. Couples have the freedom to deliberate with genetic and reproductive specialists to determine the course of action that best fits their situation. This blessing of genetic knowledge is offered with the understanding that life is uncertain and the decision to pursue ART should not be taken lightly,

> "It must be remembered that not all possibilities are equally acceptable and that choosing wisely now is crucial for the integrity of the community of life of which human beings

> are a part, upon which we depend and for which we are accountable. The nature of responsibility in this age of unparalleled human power calls for wisdom, humility and courage in deliberation, decision-making and action" (2011, p. 35).

ELCA social ethics emphasis of person responsibility and deliberation may speak to my progressive sensibilities but must remember that I do not represent all people. There are people who find an ethic that seeks to speak to each person's individual experience as being too haphazard, lacking real moral conviction to say that something is always wrong regardless of the situation.

The Case Study Revisited

As mentioned previously, the application of Roman Catholic and Lutheran (ELCA) religious teachings take on clarity and urgency when applied to a family. To illustrate, I return to the fictitious "Jones" family, patriarch Andrew (55) in the last stages of HD, his adult daughter Carol (30) who has received confirmation that she carries the gene for HD and her two children, Amanda (5) and Nathan (10), who are unaware of their HD status. Andrew's adult son Gary (25) who is claiming his right not to know his HD status and his fiancé Teresa (22). This family wrestles not only with the challenges of HD, but they also are trying to make sense out of their religious backgrounds. To gain clarity about the teachings of their religious traditions they seek advice from clergy and counselor alike in the following potential scenarios:

Gary and Teresa meet with a Marriage and Family Therapist for premarital work:

> **Therapist:** The last time we met you two were discussing your different positions regarding predictive genetic testing for Huntington's disease.
>
> **Teresa:** I would like to know his status. (Turning to look at Gary) I need to know your status. Without knowing, I have no choice; I must move forward as if you are a Huntington's carrier, which means I cannot in good conscience have children with you.
>
> **Gary:** How many times do I need to say it? I do not want to know. If the test shows that I have HD, I do not want to live every day for the rest of my life looking over my shoulder waiting for it.

Teresa: I do not agree. Suppose the test shows you are not a carrier. Would that not be a huge relief? Then we could move forward with our plans to start our family.

Gary: This is settled. I do not want to know. Once you know something, you cannot unknow it. I do not want to know.

Therapist: Your positions are both valid. Teresa, you want to know for the sake of yourself and your future children. Gary, you are claiming your right not to know, which is a valid position, but it poses a problem as you look towards building a future with Teresa. I cannot tell you what to do, but you must choose a path that you can both agree upon.

Carol meets with Rev. Sally Gerhardt, Pastor of Trinity Lutheran Church (ELCA):

Rev. Gerhardt: Tell me, how are things going? The last time we talked you had just received the results of your tests. How are you doing?

Carol: (There is a short pause as Carol gathers her thoughts). I am doing okay. I have been doing a lot of reading about HD and I know what to look for. There is some promising research with gene therapy, so I am hopeful that my kids might live to see a cure. My main concern is my brother, Gary. Remember I told you he is getting married and is refusing to learn his status. I have been trying to convince him that he has an obligation to be tested, especially knowing how much Teresa, his fiancé, wants to have children.

Rev. Gerhardt: The news about potential treatments sounds hopeful. We can pray for wisdom for the researchers. I can help you with your feelings about your brother's decision, but I cannot fix their relationship through you.

Carol: I am so angry with Gary. I do not want him to make the same mistakes I made. I did not know enough about HD before I had my kids and now, knowing that I am a carrier, I worry about them. What did I do to them?

Rev. Gerhardt: Your anger is understandable. You have a perspective that Gary does not. You know what it is like to live with the unknown of having children who might have inherited HD from you. You carry a weight that he cannot understand and, much like a parent, you want to shield him from following in your footsteps. But, you cannot control what Gary does.

Carol: (Looking up from the floor) Is there anything I can say to him that might change his mind?

Rev. Gerhardt: As I said before, I cannot counsel your brother through you. Do you think Gary and Teresa would be willing to meet with me?

Teresa meets with Father Robert O'Malley, Priest at St. Christopher's Catholic Church:

Teresa's family have been members of St. Christopher's for many years. Fr. O'Malley has recently been assigned to this parish and does not know Teresa personally.

> **Fr. O'Malley:** Teresa, so good to meet you. Your parents are so proud of you. What can I do for you today?
>
> **Teresa:** As you know, I am engaged to Gary. I love him so much, but he may have a genetic disease that can be passed to any children we have. He is unwilling to get genetic testing to show whether he carries the gene. I know the church is opposed to contraception, but what does the church say about taking actions to prevent the spread of a genetic disease?
>
> **Fr. O'Malley:** The church's position is clear. Catholics cannot make use of any artificial technologies that interrupt or replace the procreative aspects of sexual intercourse. Assisted reproductive technologies are considered immoral. I know these rules sound harsh, but they are there to protect us from choices that have eternal significance. The teachings of the church are there to guide us, so that we do not stray too far away from the path God has for us.

Gary and Teresa meet with Rev. Gerhardt:

This conversation takes place during their third session. The first session was introductory. Gary and Teresa each talked about their respective positions on predictive genetic testing. The second session they discussed the various options moving forward and Terresa stressed her decision to move forward as if Gary were a carrier of HD. After each session, Rev. Gerhardt had more questions than answers, so she reviewed the teachings of the Catholic Church as well as familiarizing herself with the ELCA's social statements.

> **Rev. Gerhardt:** Since we met last week I have done some research and believe there are some serious choices you two must make moving forward. Gary, are you still adamant that you do not want to know your status?
>
> **Gary:** More so than ever.
>
> **Teresa:** (Looking over at Gary with a mixture of anger and sadness). I cannot have children with you if that is your decision.
>
> **Rev. Gerhardt:** There are options available that can provide for you with children without the risk of passing the gene to them. Adoption?
>
> **Gary:** No thanks!
>
> **Rev. Gerhardt:** Would you be willing to use assisted reproductive therapies?

Teresa: You know, I was raised Catholic and the priest repeated the Church's position. But, I am willing to consider assisted reproductive options, if it means we can avoid giving HD to our kids. If you were in my shoes, what would you do?

Rev. Gerhardt: I cannot tell you what to do, but if you are asking my opinion, I believe to cause harm deliberately is immoral. The Catholic Church says you must not use genetic technologies, but as a Lutheran, I believe we are given a charge by God to care for our neighbor, to look out for and protect the weak and the powerless. You can do something to prevent passing HD to your children. Again, the choice is yours.

Chapter 4: Theological Ethics and Its Role in Public and Private Life

Both Roman Catholic and Lutheran ethics are built on the theological foundation of the Bible and the writings of their traditions. Natural Law Theory and the *imago dei* play important roles in the structuring of their respective ethical systems. Both moral systems borrow from philosophical ethics like deontology, utilitarianism and consequentialism. Roman Catholic ethics as presented by Sgreccia and May, is a reaction against utilitarian and consequentialist thinking while Lutheran ethics with its commitment to responsible deliberation is less a reaction against philosophical ethics but as an attempt to add theological language to the pool of ethical knowledge. Edmund Pellegrino gives voice to the distinctions inherent in philosophical and theological ethics.

> "To begin with, a right relationship between faith and reason in ethical discourse requires a recognition of the epistemological distinction between the two realms…Both use reason, and therefore, both must follow the usual rules of logical discourse. Philosophical ethics, however, depends solely on the unaided use of human reason. Theological ethics uses the same rules of reason, but they enrich it with revelation…In theological ethics reason is not abandoned, nor are faith and reason in contradiction. Rather they complement and supplement each other" (2011, p. 24).

I agree theological ethics and philosophical ethics are complementary to one another, not seen as exclusive alternatives. The moral teachings of the Roman Catholic Church and the Lutheran Church (ELCA) are powerful tools in assisting people of faith in the process of moral deliberation. Philosophical ethics represented by Kant's version of deontology or Mill's version of consequentialism, when used in coordination with theological ethics has the potential of speaking not only to a person's reason, but also to their faith. Mark Timmons asserts that the validity of any moral theory is based on how the theory fulfills a two-fold mission.

> "Since a moral theory has the practical aim of *providing a decision procedure* for making correct moral judgements as well as the theoretical aim of *providing moral criteria that*

> *explain the underlying nature of morality*, it makes sense to evaluate a moral theory according to how well it satisfies these two aims" (2013, p. 12).

Catholic moral teaching and Lutheran social ethics provide a framework for making moral decisions and explain the underlying morality of the action chosen.

Theological ethics may be able to guide a person of faith through the difficulties of moral decision-making in a way philosophical ethics cannot. Theological ethics is akin to practical theology which is defined as the **application of theological truth to all of life**. More than an attempt to understand God's action, theological ethics **involves participation** with God in the work of fostering wholeness. Conversely, philosophical ethics can speak to and for those who claim no affiliation with faith and the language of faith. A clinical bioethicist working in a modern tertiary medical environment must have a working knowledge of <u>both</u> theological and philosophical ethics to be most effective. My life and career have been stirred by my passion for science and theology enriching one another. Patients and their families, healthcare professionals and support staff bring their faith, assumptions and biases into ethical discussions. The clinical bioethicist enters these complex and, at times, emotional situations to bring clarity and foster continued conversation. I acknowledge the sometimes-intractable disagreements about the ethics of a proposed treatment option are common-place and many times, agreement is elusive. Nevertheless, the work is not abandoned because it is difficult. Timmons envisions normative and applied ethics as useful tools in making controversial treatment decisions,

> "Normative ethics investigates moral questions, and it is common to distinguish between questions of theory and questions of application. Normative moral theory (ethics)…attempts to answer general moral questions about what to do and how to be. Applied moral theory investigates the morality of specific actions and practices, particularly those that are controversial" (2013, p. 16-17).

The work of a clinical bioethicist is to bring knowledge of ethical theories and principles coupled with awareness and insight into the complexity of human experience.

Philosophical and theological ethics must not be relegated to the lecture halls and classrooms of academia, they must be carried into the laboratories and treatment areas of modern healthcare and into the kitchens and living rooms of people wrestling with the difficult choices inherent to healthcare and disease. Stephen Greggo and Lucas Tillett issue a challenge to those who teach seminarians to include what he refers to as kingdom ethics in the training of ministers and pastoral counselors.

> "Infertility treatment, eugenics, end of life determinations, human enhancement, and extensive application of psychotropic medications are not broad political or social issues. These are routine matters related to patient choice in contemporary healthcare. Pastoral counselors may be equipped to expound on professional ethics related to principles of autonomy, beneficence, nonmaleficence, and justice. Will they advance kingdom ethics by aiding Christ-followers to discern moral right and wrong within the dazzling density of contemporary healthcare that lies beyond bioethics 101" (2010, p. 349).

Greggo and Tillett use the term "kingdom ethics", Pellegrino calls it "theological ethics", Childress refers to it as "Christian ethics"; whatever the label, the goal is the same…assisting people of faith as they make morally sound decisions.

Theological Ethics and Healthcare Professionals: Private Faith and Public Vocation

Recall John Langdon's (1990) description of the Catholic Church as always looking in two directions with its moral teaching, looking inward to the faithful and outward to the community and culture. The outward looking mission of the Catholic Church is carried out by the faithful. The Lutheran Church (ELCA) also calls its members to engage outwardly in society, "The Gospel does not take the Church out of the world but instead calls it to affirm and to enter more deeply into the world" (1991, p. 2). Making faith and the moral teachings of the church applicable in daily life is a constant challenge. This is especially true for Christians who have their vocations within or in support of healthcare. Medical professionals, doctors, nurses, pharmacists, technicians, researchers and many others engage the human struggle with disease and face increasingly complex and ethically challenging situations. Living out one's faith and morals is difficult in a diverse society that is divided along, religious, political and social lines. The call for people of faith to live their faith publicly is essential when civil discussion and consensus building seem like distant memories from a bygone era. In his article, *The Catholic Physician in an Era of Secular Bioethics,* Edmund Pellegrino offers an insightful call for Catholic physicians to live out their faith through the vocation of medicine. I believe his advice and charge to Catholic physicians is applicable to healthcare professionals of any faith. Pellegrino begins by naming a few obstacles,

> "First, there is the obvious historical evidence of conflict even among Christian denominations on some of the most fundamental ethical issues… Second, and equally problematic, are the variations in the way Scripture is used in ethical discourse… Worst of all, such conflicts cast doubt on the idea that Christianity is a religion based on love of God and man" (2011, p. 15).

While these obstacles exist, Pellegrino insists that pushing through these challenges benefits society, "One reason to include religious commitment is that religious belief is still an undeniable reality in the lives of most Americans" (2011, p. 15). To address the conflicts over church authority and scriptural interpretation Pellegrino offers this advice, which I believe is good advice in most situations,

> "Clearly, both the physician and the patient are responsible moral agents entitled to respect. Neither can impose his or her moral values on the other. It is important to underscore this point" (2011, p. 16).

When people respect each other's status as moral agents and listen to the other's position without succumbing to the need to impose their own morals on the other, true moral deliberation is possible. The ELCA's social statement on healthcare, *Caring for Health: Our Shared Endeavor,* places the responsibility on all parties within healthcare to foster respect.

> "Good care also requires health care professionals and patients to deliberate together on the facts and values in each option for care. Doctors and hospitals should give full

> information on measures that might be taken. All care using either standard or complementary approaches should serve the patient's best interest, recognizing the patient's increased vulnerability during times of illness and respecting ethnic and religious differences" (2003, p. 14-15).

What recourse is there when the moral choices of the patient conflict with the morals of healthcare professionals?

> "Even when the health professional is intellectually and emotionally opposed to the patient's beliefs, there is still an obligation to recognize the patient's religious values. The physician (or other healthcare professional) who cannot, in good conscience, agree with the patient's beliefs in this way should withdraw from his (or her) care. This must always be done respectfully and without vindictiveness or rancor" (Pellegrino, 2011. p. 17).

Healthcare professionals have an obligation to recognize a patient's religious or moral beliefs, but recognition does not equate agreement with or acceptance of the other's faith or practices. When intractable conflicts over moral choices place the healthcare professional in a position to be unable to provide standard patient care, there must be a policy that allows the care provider to withdraw from the patient's care with the understanding that another member of the care team will serve as their replacement. This type of "opt-out" policy is only possible in large healthcare systems that have additional clinical staff who can step up and provide the necessary care. Unfortunately, many rural areas of the United States face a healthcare provider shortage, which renders "opt-out" policies difficult to implement. Healthcare professionals have a moral duty and a professional obligation to ensure that the patient receives the appropriate standard of care, the shortage of healthcare providers in rural areas of the country further complicates the issue of healthcare professionals and contentious moral objection.

Pellegrino closes his call for Catholic physicians to live out their faith and morals within their vocation by pointing to the potential negative impact of the faithful abdicating their voice in the conversation and highlighting the positive impact faith can have on science and reason.

> "When theology abandons or weakens its commitment to revelation, ecclesiastical authority, or tradition, it becomes another philosophy among many others competing for rational acceptance. When philosophy discovers principles and concepts that extend and fulfill the higher expectations of the human spirit, it leads to theology" (2011, p. 26).

Greggo extends Pellegrino's call to include those engaged in pastoral ministry,

> "Pastoral care in the area of bioethics is not a method to police believer behavior by asserting assumptions about the letter of the law…counseling in this area is entering communal dialogue regarding life in our physical bodies" (2010, p. 352).

Patients facing life-altering decisions caused by disease must be treated as a whole person, not just a person suffering from a disease. It is the obligation of modern healthcare to take a patient's morals and values, be they based in faith or philosophy, into consideration. Faith is an essential part of life for many people and thus to expect them to make healthcare decisions in the absence of their faith is short-sighted and ethically questionable. Couples living with HD, facing the prospect of creating new life need to wrestle with the medical reality of HD, but also with the spiritual aspects of HD. What does HD say about who I am as a child of God? How does a person with HD understand their reproductive choices when those choices potentially have eternal significance? There is a need for an assortment of theologically based moral systems to speak to people, who intentionally or by osmosis approach life's questions from the perspective of faith.

Theological Ethics and the Making of Public Policy

Citizens of the United States enjoy freedoms that at times come into conflict. The freedom of religion, the freedom of speech, the freedom of assembly and the freedom to petition the government are protected by the 1st Amendment to the U.S. Constitution.

> Congress shall make no law respecting an establishment of religion, or prohibiting the free exercise thereof; or abridging the freedom of speech, or of the press; or the right of the people peaceably to assemble, and to petition the government for a redress of grievances.

The freedom to practice one’s religion does not give that individual the freedom to impose their religious belief on their neighbor. The Establishment Clause,

> “…prohibits the government from making any law “respecting an establishment of religion.” This clause not only forbids the government from establishing an official religion, but also prohibits government actions that unduly favor one religion over another. It also prohibits the government from unduly preferring religion over non-religion, or non-religion over religion” (www.law.cornell.edu).

A legislative body, state or federal, is prohibited from establishing one religion over another or favoring one religion over another or over non-religion. Giving different religious voices equal time and respect in the making of civil law has been and may always be a thorny issue. Executive orders, state and federal legislation and judicial rulings that promote one theologically-based moral system over another can have devastating impact on the lives of those living with genetic disease. Embryonic stem cell research by the National Institutes of Health (NIH) was restricted to existing stem cell lines by President Bush in 2001, this executive order was reversed in 2009 by President Obama in 2009. (CNN.com, 2009).

The Contrasting Religious Traditions on Church-State Relations

The ELCA approach to political advocacy recognizes the historical separation of church and state delineated in First Amendment to the U.S. Constitution, but encourages a collaborative approach as described in chapter 4 of the ELCA Churchwide constitution;

- Study social issues and trends, work to discover the causes of oppression and injustice, and develop programs of ministry and advocacy to further human dignity, freedom, justice, and peace in the world.
- Work with civil authorities in areas of mutual endeavor, maintaining institutions separation of church and state in a relation of functional interactions.
- Provide structures and decision-making processes for this church that foster mutuality and interdependence and that involve people in making decisions that affect them (ELCA, 1987, Section 4.03.).

Lutheran congregations at the beginning of the twentieth century adhered to a "separationist" understanding of church-state relations, recognizing that there was a strict line of separation between the realm of the church and the realm of the state (Stumme, 2003, p. 52). This understanding of a "wall of separation" is still popular within many churches and for many people of faith. The cherished conviction is the state has no right to infringe on the practice of a religion and in the same way no church or theological framework has the right to dictate how civil laws are written. Such a strong separationists approach to church-state relations results in Christians abandoning their voice as Christian citizens within the public square. A more cooperative approach is now advocated.

> "Those who are both citizens and baptized belong to overlapping communities. Church and government are actors in the same society, have responsibility for each other, and share a commitment to the common good. In speaking of functional interaction, Lutherans acknowledge that there are areas in which both are legitimately engaged and affirm that they may and should cooperate without undercutting their institutional separation" (Stumme, 2003, p. 61).

The defining difference between Lutheran and Catholic and other conservative Christian understandings of church-state relations can be seen in their goals. Lutherans seek to work with governmental bodies to further common goals of peace, justice and freedom and human dignity. Catholic and other conservative Christian groups seek to use governmental bodies to bend civil laws and civil society into compliance with their theological understanding. Part III of *Donum Vitae*, **Moral and Civil Law** moves away from the setting of moral norms and church doctrine to a call for legislative intervention. Pellegrino summarizes the goal of Part III,

> "It rejects reliance on the conscience of scientific investigators to safeguard the dignity of the embryo, of marriage and the family, and the unity of the procreative act. It calls for legislation that will regulate reproductive technologies in conformity with the teachings of the Catholic Church" (1990, p. 151).

Pellegrino recognizes that this call for legislative action raises unresolved and potentially unresolvable issues for Catholics and other people of faith who live in morally diverse, democratic societies, like the United States.

Part III of *Donum Vitae* and the ELCA's commitment to advocacy encourage the inclusion of Christian values in legislation, but who's version of Christian values? Members of the ELCA are encouraged to become involved with movements and programs that endeavor to produce public policies that respect the rights of others, protect the powerless and work for the good of all, not just the few. While the teachings of the Catholic Church are authoritative for Catholics and speak for many around reproductive morality, this authority is limited when it is applied to the making of public policy in the United States. This may be true, but that has not stopped people from seeking to fulfill the call in Part III of *Donum Vitae* and enact legislation regarding reproductive technologies and abortion that conforms to the teachings of the Catholic Church.

One attempt to bring civil law into conformity with the moral teachings of the Catholic Church are personhood amendments. Personhood amendments have been placed on the ballot or brought before the legislative bodies in many states. The online news site, *Rewire*, a daily online news site with a decidedly progressive agenda tracks the progress of personhood amendments and legislation. *Rewire*'s Legislative Tracker page states,

> "Personhood laws seek to classify fertilized eggs, zygotes, embryos, and fetuses as "persons," and to grant them full legal protection under the U.S. Constitution, including the right to life from the moment of conception…In 2017, seventeen states have introduced personhood measures, according to internal calculations. Those seventeen states are Alabama, Alaska, Arkansas, Indiana, Iowa, Kansas, Missouri, Montana, North Carolina, Oklahoma, Rhode Island, South Carolina, Tennessee, Texas, Virginia, Washington, and West Virginia. All measures have failed, except for Alabama and Alaska" (www.rewire.com).

The failure to get personhood measures passed has not deterred those who seek to define a person as beginning at the moment of conception, which is the belief of the Catholic Church and many other religious groups. This movement's legislative mission is articulated clearly by T. J. Scott,

> "The idea is that by passing state constitutional amendments that define the word "person" as including the unborn, the Supreme Court will eventually be forced to review its holding in Roe. When it does, it will look at this premise-that the unborn are not included in the word "person"-and based on agreement among the states that the word "person" should include the unborn, will come to the opposite conclusion. Along with the premise changing, the conclusion will also change. The unborn would have a protectable right to life under the Fourteenth Amendment-a right that the Court would need to weigh against the privacy right of the mother. Because the right to life is the most basic and fundamental of all rights, the Court would hold that the unborn's right to life trumps the mother's right to privacy and therefore ban abortion" (2011, p. 230).

A more troubling aspect of the personhood agenda that is evident in Part III of *Donum Vitae* is the call for legislation that would criminalize any action that brings harm to a human embryo.

> "As a consequence of the respect and protection which must be ensured for the unborn child from the moment of his conception, the law must provide appropriate penal sanctions for every deliberate violation of the child's rights. The law cannot tolerate - indeed it must expressly forbid - that human beings, even at the embryonic stage, should be treated as objects of experimentation, be mutilated or destroyed with the excuse that they are superfluous or incapable of developing normally" (1987).

The call for "penal sanctions" on those who violate a human embryo's right to life not only impacts the legal standing of abortion but would make IVF and PGD criminal activities akin to homicide. The assignment of personhood to embryos, through legislation, could be used to justify restrictions on ART like IVF and PGD, which could negatively impact those living with HD. While, the personhood movement may represent an extreme interpretation of the call to bring civil laws into conformity with Catholic moral teaching, Edmund Pellegrino seeks to provide a more nuanced path for Catholics to follow,

> "The obvious practical political difficulties of implementing Part III of the Instruction do not provide a justifiable excuse for accommodation to the prevailing mores. However

> difficult, Catholic citizens must try to find the balance between their obligations as citizens of both the city of God and the city of men" (1990, p. 157).

Pellegrino acknowledges that the personhood movement and other pro-life groups put Catholics in a difficult position,

> "Catholics all too often are seen, not as fellow citizens, working for what they believe within the constraints of a democratic process, but as abusers of religious freedom, using that freedom to coerce others into conformity with the teachings of Roman authority" (1990, p. 169).

Religious freedom has both protective and restraining forces inherent to its application. I have the freedom to practice the tenets of my religious faith, but I do not have the freedom to impose the tenets of my religious faith on someone else.

The tension between protecting and restraining is foremost in the recent public debate around Religious Freedom Restoration Acts (RFRA) that have been moving through state legislative bodies over the last several years. According to the National Conference of State Legislatures (NCSL), as of 2016,

> "Twenty-one states have enacted Religious Freedom Restoration Acts since 1993. Currently, ten states are considering legislation on the topic this year. Virginia amended their state RFRA, but otherwise no states have passed their legislation" (www.ncsl.org).

The language of the amendment to the Virginia RFRA statute is very interesting,

> "The General Assembly does hereby declare again that the rights asserted in *§57-1* are the natural and unalienable rights of mankind and this declaration is the policy of the Commonwealth of Virginia" (https://legiscan.com/VA/text/HB791/id/1318612).

In Georgia, HB 757, known as "The Free Exercise Protection Act" passed both the GA House of Representatives (104-65) and the GA Senate (37-18) on March 16, 2016. On March 28, 2016 the GA House of Representatives sent the bill to the office of Gov. Nathan Deal for his signature. In a stunning move Gov. Deal vetoed the bill noting his concern over some of the language in the bill being used to defend discrimination as a religious right. Gov. Deal's concerns with HB 757 centered around the lack of protections for the LGBTQ community in Georgia and the lack of language that specifically addressed this in the areas of employment and public accommodations.

Religious freedom legislation and judicial rulings can impact people living with genetic disease. A recent example of the push to extend the reach of religious freedom is the creation of the Conscience and Religious Freedom Division within the Office of Civil Rights of the U.S. Department of Health and Human Services. This new division of the HHS is tasked with enforcing the protection of the religious or moral objections of healthcare professions. Healthcare professions who view abortion, use of contraception, use of ART's and stem cell research as immoral actions prohibited by their religious convictions or conscience. (Grimaldi and Pieklo, 2018). Religious freedom is worth protecting but placing one set of religious convictions above the religious convictions of others is precisely what the First Amendment of the U.S Constitution sought to prevent.

Another example of a judicial ruling on religion in the public square centers around health insurance and coverage for contraception. A woman has a job working for a company owned by a faithful Roman Catholic family. The company is required to provide health-insurance for their employees, but the company's owners are claiming a religious exemption to be able to deny coverage for contraception in their company insurance plan. The female employee files a lawsuit against her employer for denying her insurance coverage for contraception, even though she is married and carries the gene for HD. This couple is using contraception to prevent producing a child that might carry the HD gene. Does her request for insurance coverage for contraception pose an undue burden for her employer?

The Supreme Court of The United States (SCOTUS) 2016 ruling in *Burwell v. Hobby Lobby Stores, Inc.* used the Federal RFRA act of 1993 to decide that for-profit companies with closely held religious beliefs could claim a religious exemption from the United States Department of Health and Human Services' (HHS) demand that they provide health-insurance coverage for contraception. Justice Samuel Alito, wrote in the majority opinion,

> "In holding that the HHS mandate is unlawful, we reject HHS's argument that the owners of the companies forfeited all RFRA protection when they decided to organize their businesses as corporations rather than sole proprietorships or general partnerships. The plain terms of RFRA make it perfectly clear that Congress did not discriminate in this way against men and women who wish to run their businesses as for-profit corporations in the manner required by their religious beliefs" (https://www.supremecourt.gov/opinions/13pdf/13-354_olp1.pdf).

The SCOTUS ruling in *Burwell v. Hobby Lobby Stores, Inc*. says unequivocally that an employer who is Roman Catholic, can claim their closely held religious beliefs as justification for not offering insurance that covers contraception or ART.

My Practicum experience with the Georgia Legislature in 2017 presented me with two very different religious voices in public policy debates. One group spoke for those who seek to bring civil law into conformity with a conservative version of religious morality. These voices spoke *from* their religious perspective with militant fervor and passionate conviction to like-minded legislators, lobbyists and voters. The chosen issues during the session were religious freedom, traditional family values, protection of those accused of sexual assault, and gun rights. However, other voices spoke from their religious perspective to a pluralistic society with quiet confidence and respectful tones on issues of the equality of all persons regardless of their race, religion or sexual orientation, justice for those on the fringes of society, and freedom of choice.

During the 2017 GA Legislative session, I struggled with the label of Christian being claimed exclusively by the former group. I listened to elected officials, pastors and ordinary citizens refer to the United States as a Christian nation, founded on Christian morals; but their definition of Christian morals does not reflect my Christian morals. Impassioned speeches supposedly based on Christian morals called for the suppression of rights for people whose race, religion, country of origin or sexual orientation differed from theirs. These so-called Christian morals equated being gay with pedophilia; the call for sensible gun control legislation was described as the dissolving of all personal liberty that inevitably leads to anarchy. The religious voices that speak the loudest in the halls of government call for society to be divided into the righteous and the unrighteous. It appears these legislators and lobbyists seek a society that protects those who agree with them and labels those with a difference of opinion as subversive and dangerous to the social order. A recent example of the impact of the Catholic and conservative Christian theology belief that life begins at conception is the passage of a 15-week abortion ban in Mississippi, an update to the law in a state that already banned abortions 20-weeks after a woman's last menstrual cycle. (NBCNews.com, 2018). Christian morality defined by one set of voices, ignores Christian voices that call for justice, mercy and compassion.

Pellegrino provides a moderating voice for Catholics and other Christians seeking to fulfill the charge issued by Part III of *Donum Vitae,*

> "We must also behave in accordance with the spirit of the Gospel to act charitably, mercifully and lovingly with those who do not believe as we do and even with those whose actions are in our eyes morally hurtful…We must be able to distinguish legitimate research which does not violate moral principles from experimentation that does—between genetic manipulation, for example, that can correct inherited genetic disease and manipulation aimed at eugenic improvement of the human species…" (1990, p. 172-173).

Catholic moral teaching and Lutheran social ethics have a place in the development and crafting of civil laws, but people of faith must be reminded from time to time to heed the advice of Archbishop John R. Quinn,

> "…ethics and public policy discussions take place within a religiously pluralistic society. The church in the United States must pursue all legislative goals within the requirements of pluralistic dialogue. The religious voice has much freedom to speak and be heard, but the measure of its success is the ability to speak *from* a defined religious perspective *to* a

> pluralistic constituency which can be persuaded by moral argument, but because of its pluralist make-up will not be commanded by religious authority" (1999, 188).

When religious voices speak on matters of science and healthcare, they must speak in a manner that invites them into future conversation, not in a manner that abruptly ends the conversation. Claiming that religious doctrine, not scientific evidence, should be the guiding force in healthcare research and treatment is disrespectful to science and medicine and pushes all religious voices to the fringes of the conversation.

> "Civil law cannot grant approval of techniques of artificial procreation which, for the benefit of third parties (doctors, biologists, economic or governmental powers), take away what is a right inherent in the relationship between spouses; and therefore civil law cannot legalize the donation of gametes between persons who are not legitimately united in marriage. Legislation must also prohibit, by virtue of the support which is due to the family, embryo banks, *post mortem* insemination and "surrogate motherhood" (*Donum Vitae*, 1987. P.III).

Religious voices that enter the conversation with openness and humility have a better chance of remaining part of the conversation and being invited to actively participate in the development of policies and regulations.

> "Public dialogue and moral deliberation on questions of genetic research and its applications would be greatly enhanced if more people were included and empowered to participate. Broader public involvement is appropriate, especially because many genetic applications, like other technologies, have long-term social, economic and political ramifications. Reasonable people may disagree about what levels of risk are appropriate and whether an outcome is beneficial. Institutional review boards, peer review panels and other mechanisms of scientific oversight have been established to protect the rights of individuals and to enhance the common good" (*Genetics, Faith and Responsibility*, 2011, p. 7).

For those living with genetic disease, theological ethics and religious convictions can ostracize or embrace. Similarly, with the scientific and medical research communities, religious convictions can shut off conversation or invite dialogue. Religious voices can speak eloquently and passionately about the need for caution and deliberation about the dangers of genetic technology or they can speak loudly and clumsily about the destruction of life, or at least life as they define and value it.

Catholic ethicists and those who believe in its teachings about the origins of life, the dignity of procreation and the natural laws that govern human activity seek to paint the debate over genetic technology and research as a war between good and evil. A couple using ART to avoid passing a genetic disease to their future child is accused of committing a crime against humanity. A researcher looking to develop a cure for disease using embryonic stem cells is viewed as nothing more than a cold-blooded killer with zero regard for innocent life.

Some voices of in the debate about the relationship of theological and science speak in a manner that produces an adversarial, us-vs.-them proposition in which only one side of the debate can prevail. Theology is not the enemy of science, even though this may be the perception given by the on-going debates over abortion, stem-cell and gene-therapy research and climate change. Theology and science are human endeavors that are best when they are used in conjunction to address a human struggle. Genetic disease is a human struggle that science, philosophy, theology and ethics can address if not intentionally or inadvertently restrained through legislation or executive order. Voices calling for the ending of genetic research and innovation on grounds that it violates the religious convictions of a group at the expense of those who are not members of that religious group or who do not share their religious convictions is an abuse of the cherished right to religious freedom. Imposing a single theological position onto the whole of society is not possible. This can only occur if like-minded members of the society are willing to shut themselves off from other voices and perspectives.

Chapter 5: Faith, Ethics and Genetics: Companions not Competitors

Protective Ethics and Proleptic Ethics

Traditional morals must be given a place in the church, society and public conversation, but their voice can no longer be the only voice speaking for or about God and religion. Catholic moral teaching and Lutheran social ethics represent two of the many approaches to theologically grounded moral reasoning. Both systems speak to and for faithful Christians, but neither one is without weakness. Catholic moral teaching regarding genetics and procreation is committed to protecting human life from the moment of conception, promoting the dignity of marriage and procreation and preventing the faithful from committing immoral acts. Lutheran social ethics on genetics and reproduction is committed to responsible deliberation about pressing issues and encouraging actions that promote the flourishing of individuals and communities. What emerged in my study of Catholic moral teaching is its emphasis on protection. The teachings of the church are there to protect the faithful, to give them guidance as they make procreative decisions. Lutheran ethicist, Ted Peters (2008) refers to this style of restrictive ethics as “stop sign” ethics, inferring that Catholic and other like-minded ethicists only know how to say “stop” when ethical questions about contraception, reproduction and genetic research are brought forward. While, I may agree with Peters’ assessment, I believe a less argumentative approach is warranted. Instead of painting Catholic and other ethicists in a negative light, I prefer the term “protective ethics” over “stop sign ethics”. Protective ethics is a more fitting assessment because Catholic moral teaching seeks to protect and preserve traditional gender roles, family values and sexual morals in a world that has adapted to new understandings of gender, sexuality and family.

Lutheran social ethics, with its commitment to responsible deliberation and promotion of human flourishing, is open to progress and new ideas. However, the weakness of “responsible deliberation” is the absence of clear and precise judgments and dictates for the faithful to follow.

To the simple question, “What do Lutherans say about genetic testing?” the answer requires more than a for or against response. The questioner may become frustrated with the lack of clarity required for the various nuances of thinking and repeat the question asking, “Are you in favor or not!?” Yet, Lutheran social ethics, as presented by Peters, offers a fitting way of responding to complex ethical questions surrounding reproduction, genetic disease and the advancement of genetic technology. Instead of immediately putting up a stop sign and prohibiting anyone from moving forward, Peters calls for ethics and ethicists to take a future-oriented moral approach. Peters says,

> “I would like to contrast stop sign ethics with an alternative: proleptic ethics. And I would like to propose that a foundation for bioethics be constructed on a vision of a healthier future for the human race. That vision of a healthier future begins with the apocalyptic vision of St. John:"[God] will wipe every tear from their eyes. Death will be no more; mourning and crying and pain will be no more, for the first things have passed away." (Revelation 21:4)” (2008, para. 4).

Peters calls on theological ethics to live in the tension between the here and now and the not yet realized,

> “This tension between the future good and the present which hopes for it is reflected in the structure of Christian eschatology and the life of beatitude. Biblical symbols such as the Kingdom of God, the New Jerusalem, the new creation, elicit within us a vision of a tomorrow that will be the transformation of today, the fulfillment of our hopes for what is better. Today's church anticipates tomorrow's kingdom. Prolepsis is the term for this anticipatory embodiment of hope” (2008, para. 11).

Catholic moral teaching is firmly grounded in its history and traditions and speaks to people who do not view the future with hopeful expectation, who long for a refuge from the storm of social, scientific and technological change. The structure and decisiveness of Catholic moral teaching provides comfort and clarity for those who feel unmoored in a world of constant change. Unlike, Peters, I do not need to paint Catholic ethicists or those who follow the moral commands from the Vatican in a negative or condescending light. Catholic moral teaching on sex, gender, procreation and genetics does not speak for me, but it does speak to people around the world, therefore I argue that theological ethicists have an obligation to listen to and respect ethical positions they may find illogical and outdated.

Lutheran social ethics values compassion for the suffering, empathy with the neighbor and responsible discernment in moral decision-making. Lutheran social ethics is grounded in the spirit of the Reformation, looking forward into the future with a realized eschatology. In Jurgen Moltmann's understanding,

> "The important thing in our present context is, that on the basis of a theological view of the 'expectation of the creature' and its anticipation he demands a new kind of thinking about the world, an expectation-thinking that corresponds to the Christian hope. Hence in the light of the prospects for the whole creation that are promised in the raising Christ, theology will have to attain to its own, new way of reflecting on the history of man and things. In the field of the world, of history and of reality as a whole, Christian eschatology cannot renounce the *intellectus fidei et spei*. Creative action springing from faith is impossible without new thinking and planning that springs from hope" (1967, p.35).

Lutheran social ethics sees the changing world and does not recoil in fear, but instead engages with eyes firmly fixed on the promise that God is already present with whatever future dawns with the coming of the new day.

The "Jones" Family moves forward into the future:

Throughout this project I reference the fictional "Jones" family, particularly Teresa, a 22-year-old woman engaged to Gary. Gary's father, Andrew is dying from complications associated with HD and his older sister, Carol confirmed through genetic testing that she also carries the gene for HD. Faith is an important part of the lives of the "Jones" family, Carol is a member of the Lutheran Church (ELCA) and Teresa was raised Roman Catholic but struggles with Catholic moral teaching on contraception and genetics, in light of the presence of the mutation that causes HD in Gary's family.

What role does religion have in the realm of applied ethics? While some may argue that religious beliefs are irrelevant when making ethical determinations in genetic science and reproductive medicine, the subjective nature of faith does not negate the significance. I find a parallel in the field of theology; our subjective experiences are important, Don S. Browning calls these experiences, “practical reason”,

> “…we interpret our human tendencies and needs first by inherited narrative traditions. Yet brute reality and the ongoing experience of human nature do at times intrude and teach us nuances about ourselves that our cultural-linguistic traditions lead us to overlook or obscure. Radical empiricism’s view of experience does not contradict the narrative view. It makes it less rigid, is shows how experience, as well as narrative, informs both our principles of obligation and our perception of human needs and tendencies. It helps us see how, on some occasions, the wisdom of narrative and experience can inform and sometimes confirm one another” (1991, p. 180).

Life is a story viewed through the filters of experience, faith and reason. Religious faith can have a profound impact on how we live our lives, understand disease and make health and reproductive choices. That said, I return to the fictitious “Jones” family in their context, with their belief systems and preferences.

Teresa must decide how to proceed; will she marry Gary, despite his unwillingness to confirm his HD status? If Teresa remains with Gary she is committed to moving into their future assuming he carries the HD gene. Teresa has clarity on one issue, she does not want to risk having children who might carry the genetic mutation for HD. The hope of having children who do not carry the HD mutation brings contraception, genetic technology and assisted reproductive options into her reality. Reflecting on her conversations with Fr. O’Malley and Rev. Gerhardt, Teresa turns to the internet and finds a YouTube video from a conference on religion and genetic innovation. The panel featured theologians and scholars from Judaism, Islam and Christianity. She listened as the panelist discussed and debated topics ranging from abortion to gene therapy.

Two of the panelist were of interest to her, one speaking from the Catholic tradition and the other representing the Lutheran church.

A Conversation between John Haas (Catholic) and Ted Peters (Lutheran):[1]

John M. Haas, Ph.D. is President of the National Catholic Bioethics Center and a former Professor of Theology at the Pontifical College Josephinum in Columbus, Ohio. Dr. Haas received his Ph.D. in Moral Theology from The Catholic University in America. Dr. Peters is Professor Emeritus in Systematic Theology and Ethics at Pacific Lutheran Theological Seminary and the Center for Theology and the Natural Sciences at the Graduate Theological Union in Berkeley, California. Dr. Peters received his Ph.D. from The University of Chicago Divinity School.

Moderator: How would you define the vision and purpose of your faith's ethical teachings?

> **Dr. Haas:** We Catholics believe that the church has a particular competence to teach in the area of morals as well as faith so that Christians can know not only what they ought to believe but also how they ought to behave to be pleasing to God. One of the beliefs distinctive to us as Catholics is the conviction that faith and reason are not incompatible, grace builds upon nature, it does not destroy it; Catholic moral teaching can, perhaps with some difficulty, be understood and appreciated in the light of natural reason.
>
> **Dr. Peters:** The task of the proleptic (Lutheran) ethicists, it seems to me, is to lift up and make visible the possibilities of a healthy human future—a just sustainable, and healthy society—and to encourage pursuit of transformation in light of a vision. Because we Christians operate out of a divine promise that the future will be better than the past or present we should exude faith and enthusiasm for transformation. Our ethics should be oriented for growth and betterment.

Moderator: What do you see as the best attribute of your faith's ethical teaching?

> **Dr. Haas:** The Catholic for the most part makes moral decisions throughout his life without reference to magisterial teaching. Yet Christians do have the benefit of such teachings to assist them on their journey towards eternal beatitude. And when the

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[1] Dr. Hass's responses are taken from his chapter, *The Natural and the Human in Procreation* found in Gift of Life: Catholic Scholars respond to the Vatican Instruction and Dr. Peters responses are taken from his article, "Proleptic Ethics vs. Stop Sign Ethics: Theology and the Future of Genetics" published in the *Journal of Lutheran Ethics.* Their responses have been edited for smoothness, but otherwise I endeavor to allow them to speak in their own words.

magisterium goes out of its way to address a moral issue, the presumption of truth will rest with its teaching so that one can follow it and always have moral certitude that he will not act in a way displeasing to God.

Dr. Peters: Our response should be an ethic of transformation that avoids absolutizing past or present in order to determine what is right. By the power of the Holy Spirit we can experience moments of liberation for our self-orientation; and we can orient ourselves in loving service to others. Furthur, because our relationship with God is held secure by faith, we are free to make mistakes. We are free to make faulty judgements, even to screw up morally, in our attempt to give expression to this loving disposition.

Moderator: How do you respond to critics of your faith's ethical stance?

Dr. Haas: In all fairness to the authors of the document *(Donum Vitae)* it must be said that their sincere concern and solicitude for the human person in modern technological societies are obvious. There is no reason to think that the Instruction was issued for any other reason than in response to requests for clarification and guidance and out of the love which the church owes to man and a desire to advance only the respect, defense and promotion of man. The approach of the Instruction is one of a reasoned exposition of basic human goods and values to be safeguarded and promoted.

Dr. Peters: To fix one's ethics on retrieval of the past or on maintaining present reality is like building a house on sand where the foundation will soon be eroded away. What Christian theology adds to common daily observation is the promise of transformation. It is the vision of a better future, based on the eschatological promise of God, that provides the foundation for the ethical vision out of which today's church should live and move and have its being.

Moderator: What is the primary goal of your faith's ethical teaching?

Dr. Haas: Through the Instruction the magisterium desires to protect and promote two basic human goods: the life of the human being called into existence and the special nature of the transmission of human life in marriage. The Instruction articulates a moral teaching corresponding to the dignity of the human person and seeks to safeguard the dignity of procreation. The dignity of procreation is seen in the acts appropriate to it being shared exclusively with only one other person, the spouse.

Dr. Peters: Proleptic (Lutheran) ethics begins with a teleology that orients present values towards a vision of God's promised future. This moves towards formulation of middle axioms as principles to guide decision making in a liberal society where free people are confronted by choices. The kind of middle axioms I have in mind prompt a broad appreciation for loving relationships oriented towards human dignity; and they encourage creative impulses for new ways to realize them.

Moderator: Could you speak to your faith's opinion of those who use assisted reproductive technologies.

> **Dr. Haas:** Human procreation is placed in the transcendent realm of human freedom and cocreation with God. The physicality of our sex is entirely informed by and imbued with our spiritual nature. In an age which has witnessed the dreadful consequences of the objectification and subsequent abuse of the human person, the magisterium will speak out against any threat to the dignity of the individual person. This principle is so comprehensive that it will insist that even spouses who have married to create a family do not have a true and proper right to a child, so that they could use whatever means they choose to have a child.
>
> **Dr. Peters:** We need to say that some actions are intrinsically evil, and the ethicist needs to condemn them. We must never construct an ethics that makes it impossible for us to both condemn (when appropriate) and to comfort (when appropriate) the consciences of those for whom we are responsible. Lutheran ethics needs to deal with two types of freedom. The first is Christian freedom, we are held securely by faith in God's grace and are free to express ourselves and give of ourselves solely for the welfare of the neighbor. The second form of freedom is of choice and what is undeniable is that the fast-moving frontier of biotechnology is increasing the range of options that lie before us. If Christian bioethicists want to be helpful, they should acknowledge this situation of growing choice and provide guidance in decision making.

Moderator: Would you clarify your faith's stance on the use of assisted reproductive technologies in light of genetic disease.

> **Dr. Haas:** I argued earlier that the totality of the marriage act, its physical as well as its emotional and spiritual dimensions, the totality of the marriage act is constitutive of its dignity. This ultimately points to the dignity of the persons, known as spouses, who engage in coitus. They are, in their perfection, rational bodies which are unavoidably sexed. The only way in which they come to know reality and even God himself is in and through their bodies. The way in which they express their love for one another, forge an indissoluble bond between one another, and realize a new embodiment of their love in a child, is in and through their bodies. Conception can take place without coitus—but it is a diminished act. Such a mode of conception is deprived of its human perfection. By using artificial means of conception, it is the physician who is manufacturing the child, and this intrusion deprives procreation of its dignity. These acts of control, domination and manipulation associated with reproductive technologies are fraught with danger for the child and the adults involved.
>
> **Dr. Peters:** What Vatican and like-minded theologians should have done is to identify ensoulment with the dignity of the human person and not with the genome or the sexual act. Genomic knowledge will provide the pathway to better health, pre-implantation genetic diagnosis (PGD), already routine, will likely be used extensively on IVF embryos to determine which are healthy enough to be placed in a mother's uterus and brought to term. Should we alter the genome of the germ line, so that we influence future generations in perpetuity? If science eventually makes it possible to select out genes

> predisposing us to disease or even engineer superior genomes, might this provide an opportunity for the ethicists to embrace, at least to embrace with caution? Bioethicists can be most helpful when they lift up a vision of a just, sustainable and healthy future for both individuals and our community.

Moderator: Thank you for your thoughtful insights about ethics and the future of genetics. Any final comments?

> **Dr. Haas:** We are truly free and fully human only when we act on behalf of goods, in this case, human life and the dignity of procreation, and do nothing to assault or diminish these goods which provide the intelligibility of our sexual actions and make them possible.
>
> **Dr. Peters:** The next generation of people within our churches and within our wider society will be confronted by an increased array of choices regarding their genetic and biological futures. Proleptic (Lutheran) ethics pursues creative transformation in the confidence that God promises newness and salvation.

Teresa replays the video a couple more times as she ponders her future; she has hope for the future but is not convinced her future includes Gary. Teresa shuts off her laptop computer, turns off the bedside lamp and prays.

DNA, the *Imago Dei* and the future of genetic technology

The belief that humanity is made in the image of God is a core tenet of Christianity, this belief impacts how Christians, of every theological and denominational perspective, approach the issue of reproduction, contraception and genetic disease. Every person must work out for themselves how they understand that they are made in the image of God with the reality of their bodily existence. A person of faith who believes they are created in the image of God must come to terms with the fact that they also carry the mutated gene for HD. This struggle is real for many people of faith who suffer illness and disability. Am I the person I am solely because of my DNA? What does my genome really say about me? As a human being am I not more than the 23 sets of chromosomes that I inherited from my parents? My DNA does not define who I am in totality, it is part of who I am, but I am more than my genetic code. I am a human being with a genetic code, but my humanity is not reducible to my DNA. My DNA may assist me in making healthcare decisions, but my DNA does not predict my future. Those who choose to learn their genetic information face challenges and choices in how they understand and use their genetic information. People of faith who learn their genetic information must determine how this information informs their vision of themselves as a child of God. People of faith and the institutional church must adapt to the increasing availability of genetic information.

> "Christianity has adapted to the scientific understanding that the earth revolves around the sun. Christianity has adapted to the theory of evolution. Even if God does not change, the paradigms mortals use to partially describe and comprehend God do change and evolve. In this age, with the human genome sequenced, animals cloned, and stem cell technology expanding, Christianity must reconcile its concept of an incarnate God with the realization that our humanity is not tied to our DNA or to the sacks of protoplasm that surround it" (Powell, 2001, para. 6).

We are more than our DNA, we are embodied souls made in the image of God, gifted with reason and curiosity, we are emotional beings driven by our passions and guided by religious and moral convictions. One person can choose to access their genetic information and use that information to guide their decision-making, while another person can choose not to know, willing to live open to whatever their DNA and life produces. Still others may choose to access their genetic information and live a life that is influenced by but not beholden to this information. Returning to the fictitious "Jones" family, Carol and Gary, may make different choices regarding learning their HD status and their reproductive decisions, but each one is guided by their own convictions and morals. The freedom of choice we enjoy as human beings allows us to approach our genetic information as we do any information, we can choose to know, not to know or to know and ignore.

For people living with HD and other genetic diseases the future is now, research is moving forward to find treatments and hopefully a cure. A breakthrough in genomic research that offers hope for the future is the development of therapeutic gene editing, CRISPR-Cas9,

> "Future research directions to improve the technology will include engineering or identifying smaller Cas9 variants with distinct specificity that may be more amenable to delivery in human cells. Understanding the homology-directed repair mechanisms that follow Cas9-mediated DNA cleavage will enhance insertion of new or corrected sequences into genomes. The development of specific methods for efficient and safe delivery of Cas9 and its guide RNAs to cells and tissues will also be critical for applications of the technology in human gene therapy" (Doudna and Charpentier, 2014, p. 1177).

CRISPR-Cas9 and other emerging technologies offer hope to people living with genetic disease, but these technologies also raise concerns about abuse and fear of unforeseen consequences on future generations. Henry T. Greely expresses the hope and expectation and the caution that must be present as science moves ever closer to effective therapeutic gene editing.

> "I'm in favor of any well-conducted research with CRISPR-Cas9 (or similar systems) that does not use it to change living people or human cells that are intended to become living people (gametes, embryos, or fetuses). I'm in favor of well-conducted and regulated research to use these techniques to modify the somatic cells of people to treat disease, as well as clinical use if and when proven safe and effective. I think we need to talk more as societies about possible uses in living people not to treat disease but for "enhancement," bearing in mind that we don't have a clue how to make superbabies or how to do even minor enhancements. I am against using it to make inherited changes unless or until that technique is proven, by high standards, to be both safe and effective, at which point my reaction is similar to my reaction to somatic cell uses in existing people" (Church et.al., 2016, p. 1307-1308).

Debate rages over the appropriateness of gene editing, The Catholic Church deems gene therapy to be morally permissible if it is somatic in nature, meaning it does not infringe on the germ-line and only for therapeutic reasons. The Catholic Church deems gene therapy that proposes to make changes in DNA that can be passed from one generation to the next as morally impermissible. An alternative position is expressed by Keven Powell, M.D.,

> “All churches need their traditions and orthodoxy, but as a church of the Reformation, Lutherans must continuously challenge dogma. Rather than clinging to orthodoxy, anxiety can be overcome by more clearly affirming what Christians do value about human life” (2001, para. 7).

The ELCA encourages the advancement of genetic research that seeks to alleviate the specter of genetic disease. Catholic moral teaching and Lutheran social ethics take very different positions in their approach to genetics and reproduction. I agree with the position taken by the ELCA, but that does not mean that I believe Catholic moral teaching is invalid as an ethical framework. There needs to be room for divergent ethical positions on genetics and the use of genetic technologies, because one theological and ethical position cannot meet the needs of a religiously diverse society. There are those who are passionate that life begins at conception and to allow the use of genetic technologies, even to prevent the spread of a genetic disease is immoral. I do not agree with their position, their justifications or their arguments, but I cannot claim that their position does not speak to and for many people of faith. I argue in favor of using genetic technologies to prevent the spread of a genetic disease, like HD. I believe life is sacred and worth protecting, but I also believe we are to do what we can to prevent unnecessary suffering.

The ethical issues around genetic testing and reproductive choices for a person at-risk of developing HD do not have lend themselves to universally applicable answers. The openness provided by ELCA social ethics stands in stark contrast to the strict structure of Catholic moral teaching. Each person at-risk for HD must decide for themselves how they feel about genetic testing, whether they believe they have a duty to be tested and to use that information to guide their healthcare and reproductive decisions or that they have a right not to know their genetic information. The ELCA offers openness and space for responsible deliberation, but it lacks clear guidance given by Catholic moral teaching, it is this type of guidance that many people of faith seek. For some people being given the freedom to make up one’s own mind leaves them feeling like a ship without a rudder, subject to being tossed about by the winds of change and storms of life.

Conclusion

Theological ethics offers at least 2 frameworks that can speak to people seeking the comfort and certainty of the past and to those who look to the promise of the future. I am one who looks expectantly into the future with a guarded optimism that things will be better, but I am not so naïve as to believe the future will be filled with nothing but success. Humanity has a history of making mistakes; such propensity is not going to change. The freedom to choose is a human ability that is worth defending. The influence of personal beliefs, those of my society and community of faith shape my ethical decision-making. As I noted in my review of ethics and public policy, I cannot, nor should I, seek to establish civil laws that exclusively support my positions, particularly in the areas of genetics, reproduction and medical research.

A balanced appreciation for the potential good and acknowledgement of potential unforeseen consequences is needed in the era of constant change, especially when we are discussing changes in our abilities to reproduce and how we “design” our offspring. Honest assessment of the reasons for and against must be made with regard for those who are most affected. Change can pose a threat to those who enjoy a privileged existence in the status quo. Those living on the edges of health, wealth and status are most vulnerable. Whether you fear change or see change as your salvation, disappointment is inevitable. The future may not be as dreadful as some fear or as delightful as some hope. Some choose to move into the future by clinging to the comfort and certainty of the past, while others dive headlong into the future with hopeful expectation of what lies ahead.

The cure for HD may very well be in the not so distant future, but for now people living with the possibility that they carry the mutation that causes the expansion of the CAG trinucleotide repeat in the IT-15 gene on the short arm of chromosome 4 must grapple with how, when and if they will have children. Those who already have children must decide whether to know or not know their genetic status and how to assist their children. Our choices are guided by our experiences, our faith, our families and society.

The clinical ethicist is shortsighted if they rely on only philosophical ethics. To adequately assist in moral decision-making the entire context and belief systems of individuals cannot be ignored. Religious ethical principles are appropriate for those who hold them. Religious ethics are more than narrow restraints. By striving to be multi-lingual, speaking the language of science, medicine, philosophical and theological ethics, an ethicist can be more effective as a guide for those engaged in moral decision-making. My own bias is the more multi-lingual, the more satisfying the work.

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